

The Seropositive Ball

All people with AIDS are innocent

An
impression
of the
69-hour
seropositive
ball held
at
Amsterdam's
Paradiso
in June
1990



THE SEROPOSITIVE

BALL
A R T
ICATA

ON LINE FOR AIDS
90

The SEROPOSITIVE BALL was presented by PARADISO Amsterdam in a continuous program of 69 hours between June 21 17.00 hrs and June 24 14.00 hrs, in cooperation with TIME BASED ARTS, Center for Innovation and Co-operative Technology, University of Amsterdam, ACT UP, Amsterdam, New York, San Francisco, HIV Vereniging NL, Schorerstichting, Buddy League, NCAB, AIDS Info, ANTENNA, Mozeshuis, STEIM, Stichting Perdu, Filmtheatre Desmet, Bookshop Vrolijk, Academisch Medisch Centrum Amsterdam, New York Hospital, Simon Watson Project Space, Gay Men's Health Crisis, ACT NOW, 69 HOURS, 6th International Conference on AIDS. With the kind cooperation of Apple Computers BV, AIDS fonds and Ministerie van WVC.

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FOREWORD

Spring 1990: Andre Bongers and Eric Hamwijk start ACT UP Amsterdam. The conference of grass roots organisations of people with HIV and AIDS, initially to be convened in Amsterdam, takes place in Madrid. The World Health Organisation announces that it will boycott the 6th International Conference on AIDS to be held in San Francisco in June because of the discriminatory immigration laws of the United States which prevent people with HIV and AIDS to attend the conference. The United States Government reacts by granting waivers to people with AIDS and HIV giving them the right to enter the country for ten days. Within governments, professional bodies and grass roots organisations around the World, discussions arise whether to join the boycott or not. In the Netherlands, the HIV union supports the boycott, while the professionals in the medical field and the para-governmental National Commission on AIDS decide to go. They say they will support the good cause by wearing and distributing buttons with the text "No to entry restrictions"...

Early that Spring a small group of people were thinking about the possibility of organising the event that eventually would become The SEROPOSITIVE BALL. Their aim was to break the silence around HIV and AIDS in the Dutch public opinion at large. It was decided to make it a 69 hour event under the motto: "gaining time by losing time". And to make it happen on the same dates as the 6th International Conference on AIDS. Because the ball would go on around the clock real time connections with San Francisco and Rio de Janeiro (where many activities connected with the boycott were taking place too) would be called for. Anyone involved or interested in the boycott in the Netherlands would thus have a meeting-place, a platform where grassroots organisations, self-support groups and individuals could gather and exchange information, information of a kind not usually processed by the established media. Paradiso decided to host the ball with the idea of creating a forum under the banner of "HOW AIDS CHANGES OUR WORLD".

In the Programme book we wrote:

" Too many people have died far too early, friends and lovers leaving but their traces. There are neither solutions nor explanations that can satisfy: we are dazed by life's capriciousness. So we are employing our art and knowledge to honour the ones we love, and have lost, and to inspire our imagination to challenge a possibly horrifying future not to come true.

The fact that health is a blessing doesn't mean that those who are ill are cursed. People who are HIV-infected have to face all the classical forms of discrimination and are being isolated in a variety of ways. HIV/AIDS concerns us all, because it deeply affects the way we can afford to think about questions concerning life and death.

Threatened with an epidemic that spreads, in the first place through sexual contact (which is hard to control), the foundations of our societies are put at risk. Many fundamental principles, which seek to guarantee that it is not only the strongest and richest who will survive, are called into question. On the other hand many self-organizing structures have been created to cope with the effects of both AIDS and HIV-infection and to safeguard the quality of life of those who are affected.

AIDS functions as a catalyst for social change because it goes beyond the sum of all the personal tragedies. It has powerful political implications which need to be discussed in public debates"

LIVING WITH HIV/AIDS became our main guide-line. Although health-care in Holland is well organized, it is so profoundly structured that illness and death have become "smooth", not disturbing any public areas. The gap between personal experience of living with HIV/AIDS and the routine that rules our world, makes one realize how little natural care is left in an urban environment. Not that the need is not felt. Social and religious traditions, which provided many forms of caring

behaviour, have lost their credibility and are too suffocating for our 'Free Choice' societies. In the lost rituals and codes of behaviour individual crisis were part of collective histories, moments of reflection were alternated with moments of creative expression, enduring pain was also heroic and by times given a context of celebration. With the SEROPOSITIVE BALL we wanted to create an environment that would contain these elements but at the same time would be empty enough for people to act up themselves and express their anger and concern in both a personal and political way.

We intentionally invited people from very different social and political backgrounds in the hope to open up and put under public debate the dilemmas that are crucial for people who have to live with HIV and AIDS. The group of people that works in the AIDS-field (whether salaried or not) is rather small in the Netherlands and they know each other well. We valued their participation very much, although we realized that we took the risk of creating a false forum due to the fact that self-censorship is, with all due respect, a side-effect of this professionalism. However, these same people are often painfully confronted with the way established media present the AIDS crisis. There is very little coverage on AIDS as a social issue, and more than anyone else, they realize how necessary a comprehensive approach is, not only for people who live with HIV and AIDS but also for prevention purposes. So, although every organization or individual had their own reason to participate, for many people it seemed a good idea to join forces in the SEROPOSITIVE BALL. The idea was to create as much bandwidth as possible.

Within the Paradiso, being our first medium, we organised many moments of different character. There were the debates, lectures and workshops connected with ICATA 90 (the International Conference on Alternative use of Technology concerning AIDS): it occupies most of the space in these proceedings. But there was also a massive input from the visual arts presenting an impressive collection of photographs, posters, film and video. Wil van der Meer put together a spectacle galore in which over two hundred performing artists filled the air with their poetry, music, theatre and dance. A new play by Martien Krouwel, "Mister Sero", whitenessed its premiere, and a choreography, "Eloi, Eloi", by Conny Janssen and the dancers from DJAZZEX was specially commissioned for the occasion (both had a successful stage career since).

The building (a former protestant church consisting of a big hall with two balconies, a smaller hall and a cellar) was in itself quite an adventure to walk through. After passing through the portico under Gran Fury's banner "ALL PEOPLE WITH AIDS ARE INNOCENT" one would enter a hallway in which hung the video-chandelier by Jaap de Jonge. The main hall, decorated by Floris Vos in plush velvety colours, was divided into two distinct spaces which could be closed off from one another by means of a stage curtain. This gave the debates the intimacy needed to encourage public participation. On the balconies overlooking the main hall, 12 beds had been installed, for those wishing to take some rest. On the very highest balcony an exhibition of photographs by Frits de Ridder could be seen. nearby the dressing-rooms and a workshop-space, one could pay a visit to Nan Hoover's installation "Walking in Any Direction". And in the cellar, stories from Sheherazade's 1001 Nights were read aloud by writers and public figures taking continuous turns.

The 0+network, designed by Rolf Pixley was an experimental computer network that featured both existing sources of information as well as reports that were made especially for the Seropositive Ball. It even contained an art gallery, developed by David Garcia, Peter Mertens, and Joel Ryan. Michael Tidmus's AIDS stack, a highly accessible and interactive data base of AIDS-related information written on Hypercard, drew particular attention. The network was designed in such a way that people who were not familiar with computers were able to participate right away. The images on the screen guided the users through different areas of the network. Anyone could add their own comments on what was going on or on what had been written already. During the whole 69 hours the 15 computers at the Paradiso were in continuous use. Computers linked to the network were placed in a number of locations in Amsterdam. Among these were the AIDS wards of the two main hospitals in town (AMC and Slotervaart), two High Street bookshops (Vrolijk and

Atheneum), and the home of a person with AIDS who wanted to participate in the event but was to ill to leave his house. Many locations outside Amsterdam and San Francisco were on line at some time or other, including for instance, the ABIA offices in Rio de Janeiro, the Gay Men's Health Crisis Centre, and Simon Watson's project Space in New York.

Most of the people involved in the fight against AIDS in the United States went to San Francisco those days in June (though quite a few came to Amsterdam). Some went in order to attend the 6th International Conference on AIDS, and others to join publicly in the boycott against it. We realised that the people whom we had asked to report back to us would be very stressed for time, if they able to take the trouble at all! So we set up RADIO PARADISO SAN FRANCISCO, rented a suite in the Marriot Hotel, the venue of the 6th International Conference, and organised a telephone link with the ACT NOW offices. Jo van der Spek and Paul Verstraeten went to San Francisco as our special Paradiso reporters. Geert Lovink was the Dutch anchor man. Besides broadcasting features, such as rounds of interviews with participants to the conference and activists outside, there were regular telephone hook-ups so that people present in the Paradiso could ask questions and make comments on what they heard.

Now half a year has elapsed since the ball. When we remember those days we tend to have the image of an empty party. And yet over two thousand people visited the Ball during its 69 hours, and the atmosphere in the building was often extremely dense. Like little jewels or beads on a string, events formed a continuous round of surprises (then a workshop, now a concert, followed by a theatre play or may be a film....). And in the meantime the public went in and out in the large hall like the tide.

Thanks to the the resources, patient support and encouragement of the Centre for Innovation and Cooperative Technology, (especially the director Prof. Dr. Gerard de Zeeuw) University of Amsterdam; David Garcia and Heleen Riper, who took the trouble of creating these proceedings, an impression of what happened those days in June 1990 follows.

Caroline Nevejan
Patrice Riemens
(Paradiso, Amsterdam, December 21 1990)

CONTENTS

Foreword by Caroline Nevejan and Patrice Riemens	5
Editor's Introduction by David Garica and Heleen Riper	11
Individuele en Collectieve Strategieën in de strijd tegen AIDS door Heleen Riper	13
Individual and Collective Strategies in the fight Against AIDS by Heleen Riper	19
 Chapter 1 Politics	
Wiens HIV is het eigenlijk ? (debate)	27
Openingsspeech by Hedy d'Ancona & Peter Zuidevliet	31
HIV: Testcase for Democracy (debate)	35
Feeling hot by Jo van der Spek	41
New York AIDS "Rap"	44
Activists from San Fransisco (radio report)	45
Drugs Have the Future (debate)	47
 Chapter 2 Networking	
Various E-mail contributions (network)	54
HIV Network (debate)	55
Bundel je kwaadheid! ACT UP (network)	60
All Lines Open by Bert Baker	61
Pella Vida Brazil (network)	63
The Network by Rolf Pixley	65
 Chapter 3 Women	
Are Women the Real Losers?	69
Women in the Front Line (radio report)	71
ACT UP Women and the AIDS Handbook	75
 Chapter 4 The Media	
To Write or not to Write (debate)	79
Policing Desire by Simon Watney	87
Youth and AIDS (workshop)	93
AIDS, Art and the Media (radio report)	95



Chapter 5 AIDS, Arts and the media

Visual Arts Introduction by David Garcia	101
Gran Fury Presentation	105
Art and AIDS (debate)	107
Eloï, Eloï by Conny Janssen	113

Chapter 6 Living with HIV, Living with AIDS

Personal Reflection by Martien Krouwel	116
Art, AIDS Activism by Marlon Riggs	117
New Dimension in the Realm of Death and Dying	119
Quilts at Paradiso	121
Personal Reflection by Michael Tidmus	123
Fate or Destiny? (workshop)	125

Chapter 7 Health Care

AIDS Info Special (radio report)	129
Amsterdam Buddy 'Charter'	133
PISD Caucus	135
AIDS Info Special (radio report)	137

Chapter 8 Sexuality

Porno Story 1 by Adam Rolston	144
Porno '90 by Wieland Speck	145
Vrouwen en Sexualiteit by Michele Malik	147
Winst door Verlies? (debate)	149
Mannen en Sexualiteit (workshop)	157
Porno Story 2 by Adam Rolston	158
Psycho-Social Implications of HIV Revalation by Phil Zwickler and David Wojnarowicz	159
Porno Story 3 by Adam Rolston	160

Chapter 9 HIV World Wide

HIV World Wide (debate)	163
Response Simulation Game on AIDS in Africa	171
Interview with Arletta Pinel (radio report)	173
Interview with Nicaraguan AIDS activist	175

Credits	177
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Adresses

EDITOR'S INTRODUCTION

These proceedings intend to give you an impression of the Seropositive Ball that was held at the Paradiso, Amsterdam, in June 1990.

As editors and organisers we are concerned with AIDS in both a personal and professional way. Our question was and has always remained, how to transform this concern into a more active stance.

We shaped the ball as an event in which we invited people with and without HIV to speak for themselves. Our experience in the Netherlands is that it is necessary to look at it from a variety of perspectives and not simply from the medical point of view. Our principal aim, of allowing people to speak for themselves, also guided us in assembling these proceedings. This is why we draw so heavily on the archives of the debates, interviews and presentations which were recorded on audio tape and on the computer network during the event. Like the event itself, these proceedings are in both Dutch and English (we hope that at a later stage full translations in both languages will be possible). We also decided against following the Ball chronologically, instead ordering the material into nine chapters. Each covering a general topic. These are: Politics, Networking, Women, the Media, Art, Living With HIV & AIDS. Health-care, HIV World-wide and sexuality.

As well as fighting the myths, the ignorance and above all the complacency which surrounds HIV and AIDS in the Netherlands, we also wanted to increase awareness of the many positive developments occurring both in the Netherlands and other countries. We believe that this kind of local and global knowledge, when it is exchanged between communities, not only provides contact, support and inspiration, but can perhaps actually accelerate the fight against AIDS.

From these proceedings you will see that we set out to look for the conditions in which these kind of exchanges can take place, where a variety of voices can be heard and where information can be made available to everyone, outside of the usual hierarchies of information and power. We tried to use state of the art technology to support these principles. One instance of this is provided by the computer networks devoted to this issue, which continue to connect Amsterdam, San Fransisco, New York and Brazil. These links are helping to close the time gap between the emergence of new information and its availability to those individuals who have the most at stake.

There are limitations in organising a multidisciplinary event like this. Information, communication and knowledge are in themselves not enough. The crucial question remains what we do with this knowledge. The ball, the proceedings and the other work which is currently underway will hopefully give a boost to the Dutch discussion and provide sources of information, ideas and strategies not only for their own sake but as tools for future action.

Heleen Riper, David Garcia

We hope our readers will understand that because our medium here is text, the performing arts and entertainment, the dimension of the event (without which there would never have been a ball) will be of necessity under represented.



THE SEROPOSITIVE BALL

on the exchange between individual and collective strategies
in the fight against AIDS

HIV and AIDS ... terms referring to an epidemic still going on. It is hard to express what the consequences of HIV and AIDS mean for society on an individual and collective level. Time has shown that the shape of the epidemic changes. Problems and strategies evolve according to the experiences of people with HIV and AIDS and others involved.

During the ball two statements functioned as a guide line: "How AIDS Changes Our World" and "AIDS Concerns Us All". Although there is virus in common, it is experienced in different ways by different people. In Tanzania it has the status of one of the many infectious diseases which are fatal. In the Netherlands it is the most life-threatening infection on this moment. Nevertheless, in both countries people live with and die from AIDS. The different approaches to AIDS emerge from different political and cultural contexts.

The debates and workshops were organized under the umbrella of ICATA (International Conference on the Alternative Use of Technology for AIDS). These proceedings will give you an impression of these debates and workshops and in this introduction you will find an overview of the nine chapters.

Chapter one focuses on the different and similar aims of people involved in the AIDS field. Attention, is not only paid to the well known domain of general politics but also to those practices in which politics are less visible, such as medical science and the media.

A central question in this chapter is what kind of strategies people with HIV and AIDS can develop in order to influence policy making. The debate "Whose HIV is it anyway?" opens this discussion with a reflection on the different positions of the American and Dutch gay movement as participants in AIDS policy-making. These positions are related to strategies such as attempts to influence public perceptions, the search for alliances, activism, civil disobedience and the creation of networks.

The debate "HIV and AIDS, Testcase for Democracy" shows that HIV and AIDS function as a catalyst for social and political problems which already exist. This is illustrated by the current problems within the health care systems. The principal that health care ought to be a basic right for everyone was concluded to be a main issue in the fight against AIDS.

The tension between individual versus collective liberty and responsibility becomes visible in the discussion about general immigration laws for people with HIV in the United States, which was one of the reasons behind the international boycott of the Sixth International Conference on AIDS in San Francisco. This subject was also discussed in the debate "Drugs have the Future". In Holland there is a growing consensus in favour of a "medical" and "normalization" approach to the drug problem. It is believed that such an approach improves the situation of the drug users as well as the community in which they live. America follows another policy. The 'War on Drugs' implies, above all a 'War on Drug users'. These different approaches have

consequences for the education of and the spread of the virus among, drug users. In comparison with other countries Holland has a relatively low number of infected drug users, which can be related to the general drug policy in the Netherlands.

AIDS related information covers a variety of topics, changes rapidly and has a high degree of complexity. Information concerning medical treatment tends to be ambiguous and uncertain. At the moment the information sources on AIDS are also quite localized, (geographically and within specific groups). At the same time the number of participants - professionals and lay people- in need of information is increasing while the information sources are not always accessible. *Chapter two* questions specifically how computer networks can support accessibility and spread of information resources. The networks which were created for the Ball are used as starting point in the discussions. One of them, HIVNET, is still being used in an experimental stage.

Computer networks are capable of rapidly adapting information and allowing individuals, grass-roots organizations and professional groups access in a cheap and fast way. Computer networks create the possibility for a decrease in the time gap between the creation and spread of information. This allows for the possibility of a free exchange of experience and knowledge, along with new forms of cooperation.

In the form of news groups participants can create their own information sources, alongside existing sources such as experts, libraries, the media and information meetings. In addition a network can support those who are 'house bound' or in hospitals as an additional connection to the outside world.

The use of computer networks is not yet widespread. For a lot of people it is still a new medium of support. Many things are possible but we still face a lot of limitations.

Also explored in the discussions are network design problems in general and, specifically, those pertinent to AIDS. The design has consequences for the possibilities available to users. Design analogous to a library, newspaper, club, market place or an everyday conversation, each creates a different possibility. Validation of information, network management, the user's interaction and the responsibility for information dissemination are some of the problems mentioned. Computer technology creates the possibility of local and global exchanges of information. The question remains, how is this being used? A central problem is that the variety of information can also lead to fragmentation of knowledge, experience and action, when people cannot experience it in relation to their own situation. The creation of research strategies is mentioned as one of the conditions needed.

There is a silence around Women and HIV in the Netherlands while the same time the number of women infected is increasing. *Chapter three* looks at the reasons behind that silence and shows that women in the Netherlands are on the point of breaking this silence. Women with HIV are facing a war on two fronts. Firstly, in general women are not threatened equally to men. Many women are economically and socially dependent on men, who in the area of sexual relationships are still dominant. Secondly, policy makers and medical scientists are only beginning to recognize the particular problems of women and HIV. Thus, women are discriminated against because they are women and because they have the virus.

A number of problems are itemized. The psychological pressure in the Netherlands for one's testing during pregnancy, and pressure to elect to abort in case of a positive test result, is discussed.

Also mentioned are the failure of specific health care systems and limitations in medical research for women with HIV, and the 'safe sex' campaign which is not geared to the experiences of heterosexual and lesbian women. Self-education, women's networking and "Women and HIV" on the political agenda are cited as strategies for action.

The exchange between American and Dutch women that took place during the Ball was for many Dutch women a starting point for organizing themselves. During the Ball Dutch women organized to ensure that "Women and HIV" would also be the main topic of World AIDS Day in the Netherlands, something unintended by the "Day's" organisers. And these women succeeded!

The role of the media concerning the representation of AIDS is discussed in **chapter four**. What kind of influence does it have? What ought to be its main task, information or education?

The ambiguous relationship between scientists and journalists is looked at in the context of the Dutch "Buck affair". Medical scientist profit from media attention because it increases the possibilities for funds. Journalists, at the same time, are digging for "hot news". It is easy to forget the people who have the most at stake, those with HIV and those who care for them. To minimize such effects, the possibilities of codes of behaviour for scientists and journalists are being explored. Well organized American activists highlight the importance of media attention as a fundamental tool for influencing public opinion and policy making. In advance of any demonstration, they inform the media with 'press kits'.

Despite differences of approach in the American, British and Dutch media one can see similarities, e.g. the careless use of the words HIV and AIDS, too little attention to political dimensions and a strong emphasis on medical research.

Central question in **chapter five** is the role of the arts in the fight against AIDS. The Netherlands are still tackling the question of whether art and activism is a dangerous liaison or not. In America artists, specifically those who are involved in ACT UP have gone far beyond that question. Art and activism are bound together in one of the most powerful strategies in the fight against AIDS. Art is being used to organise and to inform specific communities from the inside and is simultaneously used to influence the world outside. In particular the visual arts are used to make difficult and complex information accessible for a wide range of audiences. The slogan "Silence=Death", refers to the cultural and political silence which has surrounded the AIDS epidemic for a long time. It is also a call for action to break through this silence. This slogan has become an international symbol in the fight against AIDS.

The American artists who participated at the debate "AIDS and the Arts" posed some critical points at the organisation of the ball. These remarks referred specifically to the use of technology during the Ball. Criticisms thought to be characteristic of the standpoint of the organisers. The Ball, a utopian effort to unify or universalise the problem definitions and solutions in the fight against AIDS, with the risk of neglecting the different interests of local communities? Or the Ball, as an effort to make international links between different communities and participants involved in the AIDS domains which allows for the exchange of knowledge and information in such a way that local strategies can be improved? One strategy needed next to many others strategies in the fight against AIDS?

In **chapter six** people explain in very personal ways what it means to live with HIV and AIDS. The overriding public perception of HIV and AIDS links them to death and dying meanwhile people have to live with the virus. Though now under altered circumstances, they want to live their life like anybody else. But most of the time they are seen as persons with certain features: "criminals", "victims" or "innocents". Daily practices show that HIV and AIDS give raise to many forms of discrimination, stigmatization on the level of sexual practices, gender, class and nationality. The different contributions show how important it is to develop individual and collective strategies for breaking through this prejudices.

At the same time we cannot deny that a lot of people have died because of AIDS. The subject of death and dying is becoming a crucial issue in the AIDS practice. New dimensions of death and dying are becoming visible. People are searching for personal ways to think about their own death and for means to express their feelings of loss and bereavement. Living with HIV is the continuous balance between the will to live and the expecting to die, beautiful expressed in Martien Krouwel's contribution.

Chapter seven explores the relationship between HIV and the developments in medical science and health care systems. The task of medical science includes research into means of preventing the virus's spread and improvement of care for those already infected. A main question concerned the power of the medical establishment and whether their policy can be followed by other people, specifically by people with HIV and AIDS.

An important point of discussion was around the difference in treatment between the U.S. and the Netherlands. In the U.S. there is a general preference for testing and treatment of HIV in a very early stage, even when there are no visible symptoms. In Holland the tendency is not to promote testing, and early treatment is still a controversial issue. American AIDS activists state that people with HIV and AIDS live longer in America than in Europe because of early treatment. Questioned is how people with HIV and AIDS deal with such ambiguous information and on what bases are decisions to be made?

The pressure exerted by people's self-help organisations on medical science and the pharmaceutical industries are explored in the discussions concerning the introduction of new drugs and testing policies. More and more placebo trials cannot be ethically justified for people with HIV and AIDS who have no time to lose. So new methods of testing are being requested, like the "parallel track". International co-ordination of medical research was advocated.

During a decade of AIDS safer sex has become quite literally a matter of life and death. Posed in **chapter eight** are fundamental questions about the ways people explore their sexuality and how sexual practices can conform to safer sex attitudes. Does safer sex work against erotic excitement or can it even stimulate it? What are the reasons for the fact that, even when people know the dangers of unsafe sex, they sometimes can't overcome the temptations? What is the reason for the relative success of safer sex practices in gay communities in America and the Netherlands? One reason given is that gay people have learned to speak about sexuality and to see safer sex as erotic, while also devising "outreach policies". What can other groups learn from them?

The effects of the safer sex campaign are discussed too. After what was thought to be a relative measure of success, there is concern about a decrease in safer sex practices within the gay community. A reason for this could be that the safer sex campaign has lost some of its appeal. It could be that the safer sex campaign in the Netherlands needs to pay greater attention to those aspects of sexuality that fall outside a rationalistic approach. The effectiveness of safer sex campaigns for young people, whether heterosexual or gay, require further research. In the workshop "Youth and AIDS", school kids stress the importance for them of learning about condoms and speaking frankly about their sexuality.

AIDS as a global issues is the *ninth*, and last chapter's topic. It begins with the debate "HIV World Wide: One Problem, Different Means, Diverse Solutions?" Be they political, social or other, HIV in fact knows no borders; still, the spread of the virus suggests different patterns. The epidemic's development illustrates that HIV becomes progressively the problem of dependent and stigmatised groups in both North and South. The current spread of the virus has many connections with the social and economic positions of individuals. All over the world wealth and social position determine one's access to medical care and chances of survival. The complex structures of inequality and dependency are gone into. If a global approach of the AIDS

epidemic is mandatory, how should it be organized? How does one encourage international solidarity and responsibility? How can one foster the mutual exchange of experiences, yet not fall in the trap of Northern, colonialist attitudes toward AIDS care?

These proceedings deal with central questions around living, dying and survival. With the ball we tried to deal with this triad, not by solving or denying it, but by placing it in a context in which it could come alive.

The benefits of the ball are made clear by the quality of these proceedings. The texts reflect the broad scope of living with HIV and AIDS. The experiences of the participants ranged from individual meetings to initiatives for collective action, from having a good time to the "coming out" of people who are seropositive and from the gathering of information to discovering a bit more about what it means to live with HIV and AIDS. The ball wasn't intended to be an end in itself. It created an environment for diverse kinds of meetings to provide an exchange of various strategies in the fight against AIDS. We hope that these proceedings inspire further efforts.

Heleen Riper
Amsterdam, december 1990

* *With special thanks to Gregory Given and David Garcia who helped me with the translation of this text.*

HIV: Human Immunodeficiency Virus. HIV breaks down the human immune system. If the immune system doesn't function properly, one becomes vulnerable to a variety of infections, which would normally have been rendered harmless by the immune system.

AIDS: Acquired Immune Deficiency Syndrome. AIDS refers to the combination of complaints which are caused by the failure of the immune system. The immune system doesn't function properly, because it is infected by HIV. People with AIDS become vulnerable to a variety of opportunistic infections, which would normally be rendered harmless by the immune system. At the same time, one becomes vulnerable to specific forms of cancer of which Kaposi Sarcoma is the best known.

OPENING SPEECH

Minister d'Ancona

It was with interest that we both heard about this manifestation at Paradiso, some time ago. The idea to organise a manifestation here in our country, at the very moment at which the major international Aids conference is being held in San Francisco, has been a daring one. Although the range of Paradiso itself may be smaller, the range of topics will be wider. This was what appealed to us, and it was for this reason, that we are delighted to open this manifestation.

Joint opening speech on the occasion of the Seropositives Ball, given by the Dutch Minister of Welfare, Health and Cultural Affairs, Mrs. d'Ancona, and a Mr Peter Zuidervliet, representative of the HIV Society in the Netherlands at Paradiso, on June 21st, 1990.

Mr. Zuidervliet

At the international conference in Madrid for people with HIV/AIDS, in May, the painfulness of the AIDS situation in Africa, the continent with the highest known spreading of the virus, came out once more. Millions of people have been infected and large numbers of them have already fallen ill. There are no means to do anything. There just is not any money to buy clean hypodermic needles and to take proper precautions. In the area of health care not much can be done either. Even if certain drugs are available, they are too expensive. It is a good thing, that these days something is being done on prevention and information.

On the other hand, the use of condoms horrifies many African men. They force their wives to make love without condoms. The men have got the power, whereas the women carry the heavy burden of doing the work, cooking and looking after the children. The women are the ones who keep family life going and who are oppressed. And when it comes to a divorce, the man often takes all their belongings with him. And yet AIDS frightens African men. So now they mostly turn to young women, motivated by the idea that the virus has not yet touched these women. If there were to be a truly constructive approach towards the African Aids problem, this approach should first and foremost focus on women. For them to be made stronger and more self-conscious, but also to receive information on AIDS, is vital. A number of projects have been started and look promising. We, the HIV Society in the Netherlands, strongly wish to argue in

favour of putting more Dutch development funds into these projects for women.

Minister d'Ancona

The African Aids situation is indeed extremely alarming. From figures presented by the World Health Organization I have learned that the African continent contains more than half of all seropositive people on earth. In some areas more than 20 per cent of the women between 20 and 35 have been infected by the virus. The consequence of this will be that an important central section in the age structure of the population will be decimated. There is no other continent where Aids will cause a more serious disruption of society, both socially and economically, than Africa. With Peter Zuidervliet, I too am concerned about the position of women.

Fortunately, a great deal of international attention is being devoted to matter of women and Aids. Quite recently an international conference on this issue was held in Paris. I hope that these initiatives will stimulate the governments of African nations to acknowledge the problem and to take special measures, if only in the field of public information.

I am rather concerned about the future, when other, and hopefully better methods of treating Aids will present themselves. Only too often, these methods will be highly expensive. This could not mean that an entire continent will be left without medical care, could it? The Dutch Government has, at an early stage, taken the matter of Aids in developing countries to heart and has been contributing to



support programmes. We are among the major donor countries offering help to developing countries through the World Health Organization. Minister Pronk is exploring possibilities to increase this help. State Secretary Simons and I have told him that experts financed by our ministry can also be made available for concrete projects, especially where it concerns counselling and advisory assistance on these projects in developing countries. Although our commitment will also slightly affect the budget for the national campaign to combat Aids, I take it that all concerned will agree.

Mr. Zuidervliet

Discrimination against people with HIV/AIDS in the Netherlands and in the rest of the world is still very common. Here in the Netherlands there are of course the insurance companies, who have been requiring HIV tests in some cases. The medical test in the application procedure has now and then turned out to give rise to discrimination. There have been people who were forced out of their jobs, after they had told their employers that they were seropositive. In many instances this is based on fallacies. Sometimes it is said even openly. The supermarket manager: "If people know you've got Aids, I won't have a customer left."

Abroad the situation is far more serious. We all know the pictures and the stories from those early days of Aids in the United States. Burned down homes of children with Aids, people losing their jobs and their homes. Another matter in the United States is the discriminatory policy on foreign entry. HIV carriers are not allowed in. Our chairman, Hans Verhoef, found out himself in April 1989: The result was 5 days in prison. At the Madrid Aids conference we met a man from Nairobi. He told us that he did have a medical insurance, but that he could not claim any cost of drugs related to AIDS. If he did so, he would run the risk of having his medical insurance withdrawn. Discrimination of women has gone up again. For instance, concerning the right of HIV-positive women to have children. More than once it has happened that women were tested for HIV, without their consent, before an operation and, when actually found to be seropositive, that after the operation they were casually informed that the doctor had also sterilized them. All these types of discrimination may be fought with legal means. Public information on

AIDS and being seropositive must increase. In this manner it may be possible to get rid of prejudice.

Minister d'Ancona

Discrimination is a horrible thing. Discrimination is a monstrosity that feeds and grows on lack of information, prejudice and fear. Aids could therefore be expected to be accompanied by more and stronger discrimination. The lack of correct knowledge of how the virus spreads, prejudice against, for instance, the way in which gay people live their lives and the fear of being infected are real factors that may cause Aids-related discrimination. Going by the incredible examples Peter Zuidervliet gave just now, I can conclude, fortunately, that discrimination could be worse in this country. But if this were to be my only conclusion, I would be making things too easy for myself. I believe that we can distinguish between structural and more incidental discrimination.

For the victim there will not be much difference of which type he has been

made a victim, for policy makers there is. For me structural discrimination means the acts or the negligence of institutions, including government institutions, which consistently result in harm to individuals and groups in society. In incidental discrimination there is no such consistency. Here civilians rather than institutions are involved in discriminatory acts, such as the personnel manager, who decides to keep seropositive people out, or the member of a family, keeping the door closed for a seropositive brother or sister. In a manner of speaking structural discrimination can be combatted more effectively than its incidental counterpart. It can be traced down sooner and for that reason work better if one wants to raise the issue. And if discussion leads to nothing, government can take stronger measures, such as special legislation that can be enforced. Incidental discrimination often taken place out of the open, and is, therefore, much harder to fight. I believe that Aids-related discrimination in our country belongs to the second category. However, the conclusion that this type of discrimination is the hardest type to fight should not lead to dejection and passivity on the part of the government. On the contrary, I think that public information is an important instrument in our struggle against this type of discrimination. Many of the efforts made in the area of informing the public aimed at improving our social climate. In this area we will have to continue our efforts, or even increase them. Seropositive people and people with Aids have an important indicatory role. I am glad that they have by now organized themselves to such an extent, that they can no longer be overlooked as partners in policy making. The cooperation project of COC and the HIV Society in the Netherlands on protection of individual interests, a project supported by us, has already given support to many people with individual problems.

Mr. Zuidervliet

Sometimes I wonder what it would be like to have AIDS and to live in a provincial district. It must take a lot of travelling time to get medical treatment or tests. Discussion groups of HIV-positive people acknowledge this problem. And then one does not even mention the possible attitude of one's environment or social workers. Good care, close to home, is available for the majority of those with HIV/AIDS. But even then things may go wrong.

"Seropositive people and people with Aids have an important indicatory role. I am glad that they have by now organized themselves to such an extent, that they can no longer be overlooked as partners in policy making"

CHAIR: Thursday, June 21, 20.00 PM

Joop van Londen (Joint Secretary, Ministry of Welfare, Public Health, and Culture, The Hague)

HIV: TESTCASE FOR DEMOCRACY

GUESTS:

Dr. Abbas Kakembo (Public Health Service, Kampala-Uganda)

Peter de Klerk (medical specialist, Dutch Consumer Ass., The Hague)

Dr. Robert Newman (President, Beth Israel Medical Center, New York)

Ernst Roscam Abbing (Chairperson of the NCAB - Dutch National Commission on AIDS & Director Public Health Service Rotterdam)

Simon Watney (Writer and Chairperson of the Terrence Higgins Foundation London)

Johan Westenberg (jurist, Chairperson of the Dutch HIV Ass, Amsterdam)

With comments from New York Cornell Hospital by: Dr David Rogers (U.S.A. Presidential Commission on Aids)

& from San Francisco at the VIth International conference:

Dr. James Allen (Director, Nat. AIDS program Office, U.S.A. Dept. of Health)

In many ways AIDS is threatening the tenets of democracy and welfare state. At the centre of this debate is the inherent tension between individual liberty and responsibility and collective liberty and responsibility. Issues pertaining to public health policy, insurance coverage, prevention, tolerance towards differing lifestyles, the situation in the South and international immigration laws will then come under periew.

Chair

AIDS or HIV as a test case for democracy. Does AIDS change the world? Are we talking about more discrimination after AIDS has come into the world? And what is behind that discrimination? Is it perhaps the tension between public health and individual interests? Democracy has to look after public interests and after individual interests as well. Is there a tension between the two or not? This question has implications for topics from access to insurance, to labour, to military service, to health-care, to education, social security and perhaps even to jail.

Dr. Newman

I am Robert Newman, president of Beth Israel Medical Centre in New York City.

My hospital treats more addicts than any other institution in the world. It is one of the largest providers of services to patients with AIDS in New York City. My basic premise is, that there is no conflict, no conflict, between the needs and the interests of the individual and the needs and the interests of society. If there are going to be policies and practices that are going to be disadvantageous to individual people who have or are at risk of getting AIDS, then the same policies and practices will be harmful to the entire society and the corollary is also true if one reaches out and is responsive to the needs and interests of those who have or are at risk of getting AIDS one will benefit every single person in that society.

Simon Watney

I chair the health education group of the main non-government organisation in Britain, the Terrence Higgins Trust. I also work compiling a 1000-page manual which updates every 90 days on all aspects of the UK epidemic.

It's clear that the American government is in contravention of World Health Organisation directives and also of the charter of London of January 1988, of which it was a signatory. So on the immigration issue it seems perfectly clear and in each of our countries, we can see infringements of civil liberties. As they effect prisoners, people seeking insurance, in particular single men, and on down the list of housing, social benefits and so forth.

It is hardly surprising that the UK is no exception to this pattern of discrimination, against people known or perceived to be living with HIV. I think in the European Community (although we have to think about collective policy issues here and how we can best use the institutions of the European community on our behalf). I'm also very concerned, at the way in which the European community has tended to assume, across the board, that medical research, certainly for people living with AIDS, will be done in America. It is perfectly clear that the fiasco of the AIDS clinical trial group in America means that nobody in Europe is going to benefit in any way at all from the bulk of research being



done in the United States. We have to understand that in Europe research is overwhelmingly dedicated to the finding of a vaccine. This is a discriminatory research, if it means that that goal is set to the exclusion of the health needs of people living with HIV infection throughout the European community. This seems to me to be a fundamental issue of discrimination which is endlessly overlooked. Our experience has, overwhelmingly, been with asymptomatic HIV infection in Europe, rather than with AIDS. As we move into the 90's sadly the situation is likely to change and we have to get real to the needs of bio-medical research as a genuine European community.

Chair

We have the honour to have Dr Kakembo here from Kampala Uganda.

Dr. Kakembo

I am the senior medical officer with the capital City Department of Public Health. I have been working on the AIDS epidemic since 1986 and I am involved on the School Aids Awareness Campaign. Currently we have covered all the schools, why schools? You may ask. In my country the age distribution of AIDS is 0 to 5 years in about 10% of cases 15 to 45 in about 85% of cases. However, between 5 and 15. There are practically no cases. We thought this is a group

which needs information so that they can adjust their behaviour.

My particular interest at this conference are, the immigration limitations to students from Africa going to study abroad. Some of them have been subjected to HIV testing and denied the chance to study. Others have been expelled. This is the result of panic. What is needed is international cooperation on prevention, cure and research. United we stand, divided we fall.

Johan Westenberg

I represent the Dutch HIV association. As to the National Commission of AIDS control our policies will be to the Dutch quite clear.

This discussion about discrimination is a very important one. Looking at AIDS and at all the developments within the whole AIDS circuit, should change general ideas about health care, about society. We should not isolate AIDS as a separate tragic disease. Which it is, but we should look further. We should learn from AIDS.

Peter de Klerk

I am from the Dutch General Consumers Organisation and we are approaching HIV and AIDS from the consumer's angle. This involves patient's rights. We are also looking to the issue of access of health care and access to insurance.

We are considering the issue of being obliged to be tested. One of the most

important issues is that the pressure to be tested for HIV could be a try-out for other practices. For instance, hereditary diseases which could be tested, by the developments in genetics which would allow for testing. So we want to warn about the precedents which these forms of obligatory testing might set.

Ernst Abbing

I am chairman of the Dutch National Commission on AIDS Control. This committee has the task of advising the government. It also coordinates different prevention activities. My main task is to combine different interests, to advocate a climate of understanding and tolerance and a public attitude, not of indifference, but of commitment to those who already effected or at risk.

Chair

We start this debate with a call from New York. We have the opportunity to speak with Dr Rogers.

Dr. Rogers

Regarding the situation surrounding AIDS in the United States right now, I would say we have wide differences of opinion, both medical and political on how the issues should be handled. It varies widely from one locality to another. The areas hardest hit, which are New York and California, have quite enlightened policies in terms of funding care for patients with AIDS,



also of research, of increasingly good protection of confidentiality. Finally, some late but at least encouraging, federal response, in terms of better recognition of the problem. They are, compared with you in Amsterdam, educationally because we've got quite entangled, in matters of taste and morality, that have prevented us putting a really explicit, effective education program that's culturally appropriate into the many groups that are hardest hit by AIDS.

Chair

Have you any opinion of our policy in the United States?

Dr Rogers

One of my questions would be, how you have fared with your needle exchange? Do you have any evidence that you have reduced your levels of HIV infection by being more permissive in terms of the distribution of sterile works to drug addicts.

Ernst Abbing

Of course we are a bit proud to have those projects. But I must confess that our reputation abroad is much better than the reality. Very often it's the case that if you have something that's progressive compared to the rest of the world, its reputation is exaggerated. But at least we try to continue in this direction. Mutual understanding at an international level is very important.

Audience

Hello, I'm from New York could you give me an example of one enlightened policy in the United States?

Dr. Rogers

Oh I would use New York State as the example of very liberal funding for treatment of people with AIDS. Supplying drugs to people with AIDS, who can not pay for them. The development of AIDS care centres in 23 different units within the state, mostly within New York City. All of those I view as moves in a positive direction. There are many gaps. A scandalous lack of nursing home beds, residential units, of housing, continued discrimination in jobs, in insurance and also lack of effective educational programs. So the news is both good and bad. But with a number of areas we can point to where things are moving in the right direction.

Greg Bordowitz (from the audience)
I feel like I'm caught in the middle of a TV show!

"In Europe research is overwhelmingly dedicated to the finding of a vaccine. This is a discriminatory research, if it means that that goal is set to the exclusion of the health needs of people living with HIV infection."

Just by way of criticism, I am on the ADAPT program, I am HIV positive, I do get drugs from the state, but I'm also out on the streets and do needle exchange and do AIDS education for Gay Men's Health Crisis. No one knows about it. It is not true that the ADAPT program gets drugs to more than half the people who actually need it. Its by no way enlightened. There are no enlightened policies in the United States as far as I'm concerned.

Simon Watney

I'd like to ask, you mentioned culturally sensitive or culturally appropriate education materials. From a European perspective, it often looks as if the notion of what is culturally appropriate is a euphemism for denying any kind of appropriate information to gay youth in America, lesbian youth, to black youth, Asian women, and so on. Would you agree with this generalisation?

Dr. Rogers

I would categorically agree with that generalisation. We have failed very badly to get sensitively into the cul-

tures you mentioned and develop material that is readily understood, and are at least reasonably effective in having people consider behavioural change to deal with HIV infection.

Dr. Newman

I think the fundamental problem that exists in the States is that there are many people in America who view individuals with AIDS or at risk of getting AIDS, because of behaviour, as somehow the enemy. As evil people and they feel that there should be policies and practices to punish them and to hurt them and certainly not to help them.

As a cynic, I would not appeal to the humanitarianism of such individuals, but I would try to appeal to their self-interest. So whatever they, through fear or ignorance would like to do to "those people". I think pure self interest should compel them to reach out and offer help. And I just wonder here if in the Netherlands and in the rest of Europe, whether there is this polarisation. What has been referred to as a false dichotomy. And I believe it is a false dichotomy. Of the public welfare versus the individual welfare. Or whether there is a greater degree of enlightenment that recognises that indeed there is a commonality of interests whether we like it or not.

Ernst Abbing

I would like to respond, because tolerance, which Holland is famous for, is a very superficial thing. People are much less tolerant than they appear to be. That has also become noticeable in the HIV crisis. Not from the point of view, that people will directly tell you to go away and look after yourself. It is more as though it doesn't affect people, there is always the attitude of you are the ones who are going to get it and we are not. They just feel pity for you.

Dr. Kakembo

From a Ugandan point of view, and generally on the African continent. Because of the extended family, there is a lot of sympathy for patients with AIDS. The families care for these people until their death. Is this true in Europe and America?

Dr. Newman

It sounds like its the antithesis, What was just said about the Netherlands and I think this applies in the U.S. It is viewed as somebody else's problem

and there is absolutely no compassion and no desire to reach out and to help.

De Klerk

On the issue of a false dichotomy. In the Netherlands, it is a mixture of real compassion and on the other hand, an understandable self interest. There is a desire to reach, for example, the drug addicts, not just cynically but I think also with some compassion.

Dr. Newman

With regard to drug addiction, that is one of the greatest areas of difference between the Netherlands and the US. Here drug addicts can have access to treatment almost upon demand. Throughout the US there is a waiting period of anything from 4 months to 6 months or longer. Someone who comes in and says, "I am sticking needles in my arm three or four times a day, I want help" are told maybe in three months or six months you'll get treatment. That is such an insanity, not only from a humanitarian standpoint but because these individuals

are going to get sick. They are going to spread the disease and the cost is going to be borne by everybody. In that respect I think you are far better off in the Netherlands.

Dr. Kakembo

I would like to comment about treatment generally. The main form of treatment is supportive. Most of the agents that are used are very expensive. I wonder whether the international community will extend further support and cooperation on this? Because the African patient, in the majority of cases, will not be able to acquire these drugs, because they are very expensive.

Simon Watney

I think the situation of drug users in Europe draws attention to very interesting areas of conflict of policy both between Europe and America and within the US and also within Europe. If we look for example at Spain or Italy we see epidemics which are overwhelming amongst injecting drug users and their sexual partners, unlike for examples the Netherlands and the United Kingdom.

In Britain social policy, interestingly, for drug users has not been concerned primarily with getting people off drugs. It's been quite literally with needle exchanges. And there has been (one of the earliest in Europe) programs, with, I think, more than 50 different bases around the UK providing different kinds of needle exchanges on the basis of different kinds of policy. It certainly hasn't been the case in Britain that you had to say no, before you got help. Capping that, I think there is another issue. Which is, in Europe thank God we have the benefits of socialised medicine, but the benefits of socialised medicine come with costs, and the cost is complacency. The fact that throughout Europe, most of us, women or men, tend to take for granted the assumption that the medical profession is doing everything it can for us. Which of course is a nonsense. This makes organisations like ACT UP or any interest in the politics of drug care very difficult to develop and sustain, anywhere in Europe.

Audience

I'd like to ask doctor Newman what his reactions might be to knowing that we have a policy of complete discouragement against anonymous or otherwise testing,

and/or early treatment, and/or early access to any medical care what so ever. Aside from the needle exchange program, which affected the broad heterosexual public and was put into place in the most amazing amount of time. Condoms for homos cost over three guilders a piece. What does he think of a medical care system that doesn't even provide that?

Dr. Newman

I think even the most ardent admirer of Dutch policies and practice would not be so naive as to believe that there aren't some areas here as well which need improvement and which are open to criticism. The grass is always greener but I would leave it to my Dutch co-panelists to comment on dutch policies.

Audience

I would like your comments on the fact that people are discouraged from testing of their HIV status.

Dr. Newman

I think a hallmark of what a society should provide is anonymous testing rapidly at no cost, or at an absolutely minimal cost if that is not available here. Then that is one area where, like the US, there is a big problem. If condoms cost three guilders, that must be the last best buy in America, because they're a hell of a lot cheaper there.

De Klerk

I want to react on the comparison between the United States and the situation in Holland. Lets not exaggerate the situation here. We also have problems. I don't think there are major conflicts between public health and individual rights. But where there are financial interests involved, then we do have those problems. We have had a general discussion about testing, whether obligatory or otherwise. And also when financial issues are involved, there is a danger of isolating some groups of patients, consumers, where this isolation has never existed in the past.

Dr. Newman

There are also different degrees of evil. Not having anonymous testing readily available is obviously a big problem. Having state legislatures throughout the US that are on the brink of or in some cases have passed laws regarding compulsory testing under certain circumstances having a

"As Douglas Crimp pointed out, seldom have societies so savaged communities at the worst hour of crisis in their history, as in relation to the HIV epidemic. That is the sight of discrimination as I experience it"

very vociferous and unfortunately quite effective lobby saying that there must be mandatory testing at the time of entry into certain type of job. The medical societies throughout the US are calling for mandatory testing of every single person that is admitted to a hospital. I think that on the scale of what is horrible, that move towards mandatory testing and the threat to confidentiality is probably one of the most horrible aspects I can think of

Audience 1

I should like to dwell upon the issue of the Dutch testing policy. There is also in the Netherlands the possibility of being tested anonymously. Someone talked about testing being discouraged in the Netherlands. We prefer to emphasise the concept of informed consent. By informed, we mean that you know all the advantages, but also all the disadvantages of knowing your Sero status. We take this issue very seriously in the Netherlands. Its connected to the policy of making prevention an overall activity not only for those who are already infected.

Audience 2

But you are not properly informed! There is no indication of the advantages of early treatment, early diagnosis, learning about your base levels, your T cells or anything, so that you can take appropriate steps at the right stage of the disease. Its not true that you say all of the positive things. There is not one positive thing, apart from a possible negative outcome, that is put in the list and there are something like fifteen negative consequences, all of a psycho-sociological nature.

Simon Watney

I think this business of testing is important to see from a European perspective. Each country has its own coherent policy on testing. Interestingly, in the extremely conservative UK, there is no question of confusing HIV antibody testing with preventative medicine. The only mandatory pressure comes from commercial companies. Phillips, interestingly, is exporting that policy into the UK. It's not so much homosexual or heterosexual, it's homo-economicus who is at the heart of mandatory testing in Britain. This is quite different from the situation here or in France or in West Germany. These debates have to be internationalised within the European community and we have to see that sometimes countries which have ostensibly less

progressive politics on the surface have better policies around antibody testing. And there is a clearer perception that testing is of course primarily, a means of access to potential treatment.

Audience 2

We do have the opportunity for relatively inexpensive testing but at every stage of the game, counselling, pre counselling, co counselling, it is discouraged. There is a complete neglect of the positive aspects of that knowledge.

Audience 1

I don't think this is true. The intention of the policy is to give a broad spectrum of the advantages and drawbacks of knowing. Included also, is the uncertain perspective of early intervention. At the moment two advisory boards are preparing a recommendation on the advantages of early intervention. Maybe it will change the attitude to testing. This advice will come through in July.

Audience 3

I'm from the COC (the Dutch gay movement) and very much involved in the testing policy. We haven't got many disagreements with the testing policy. The policy is in the direction of encouraging people to make their own choice. Up to now it seems there are many disadvantages to being tested, for example concerning work and insurance problems. People are very disappointed if they are tested and then afterwards decide if they want to be insured or apply for a job. You have to be careful to decide what you want, but it is your own decision. Informed consent is the central issue and our point of disagreement with the authorities is that informed consent is not provided with enough care. People are often not informed about consequences relating to jobs, insurance. That's the real problem. On the subject of early intervention, we have to be very careful, because up to now the investigations don't prove the advantages of that.

Chair

After all these Dutch nuances I would like to ask Dr Kakembo how he feels about this whole subject.

Dr. Kakembo

I, as somebody from Africa, feel left out. Because the issues in Africa are, firstly, the main mode of transmission, accounting for over 90% of cases is

heterosexual sex. The other minor modes of transmission are infected blood, needles, and from the infected mother to the unborn child.

When we discuss the availability of safe needles exchange programs, I feel left out. What I would like to hear discussed are the approaches to the purely social welfare crisis, created by the AIDS epidemic, for the normal heterosexual practice in Africa. The other issue, is the care of the AIDS patient. We have the support from the family, but not the drugs for the patients, issues like insurance policies are far removed from my situation. I would like to discuss issues like what kind of support and health care is available for example in the community. I got involved in the evaluation in the National Red Cross AIDS Control Program. One of the recommendations was the development of a simple drug kit that can be used by village health workers in their communities to support AIDS patients.

Simon Watney

I can't comment on the situation in Kampala beyond what we read in Europe and through communications with health-care workers there. What seems to be shared however round the world is this completely fatalistic assumption, more in Europe than either America or Uganda that HIV will inevitably in all cases lead to AIDS and that every one with AIDS must die.

Now it seems to me that as soon as you are diagnosed with HIV, a huge army of homeopaths, aromatherapists, clinicians, councillors, and therapists rush at you from all directions to hasten you towards your "good death" it seems, sometimes preferably as soon as possible. What it's very difficult to do here is to make it plain across the divisions of class, of gender, above all, I think, in Europe, still, of sexuality that a terrible crisis is in our midst. As Douglas Crisp pointed out, seldom have societies so savaged communities, at the worst hour of crisis in their history, as in relation to the HIV epidemic. That is the site of discrimination as I experience it most acutely both throughout the European community and it should be added in the US, Africa, and still further afield. We can learn as much from Australia where they have a very good national plan drawing very early on from affected communities as much as from the US at this moment. The federal nature of Australia can make it more relevant to us

than some aspects of American social policy.

Dr. Newman.

I think the prospect of Western countries reaching out and responding positively to the almost unthinkable dimensions of the problem in a country like Uganda would not be that great. On the other hand from the standpoint of some senators from the Southern part of the United States who view drug addicts as evil, disgusting individuals and gay people as deviants who bring their problems on themselves. Perhaps the Ugandan who got AIDS in the good old-fashioned American, heterosexual way might be a good target to generate support from certain members of the American congress. But I wouldn't bet on it.

Simon Watney

Surely, health care provision should be above party politics and its arbitrary whims. Health care provision and research should be above any kind of legal discrimination. Unless health-care provision is written at a level of constitutional requirement, with an ethical understanding of the democratic principals involved, none of our nation states can properly consider themselves democracies. This is one of the many dimensions in which few countries in Europe, if any still, can consider themselves fully fledged democracies. It ill behoves us, as many of our foreign ministers did the other week, to go so far, as to criticise African countries and say we would actually not aid them any further, unless they subscribed to predominant models of Western democratic party politics. This, I think, is frankly shocking and is medical imperialism, as well as cultural imperialism of the worst kind.

Dr. Newman

The issues of immigration policies and anonymous testing are, for hundreds of thousands of American drug users absolutely irrelevant. Because there is no way that they could even think about getting treatment for HIV problems, when they are denied treatment for their immediate three, four, five time a day heroin habit.

We have in New York City an estimated two hundred thousand heroin addicts who are on the streets, half of whom, at least, are known to be seropositive and for whom there is no treatment capacity whatsoever. A hundred thousand seropositive heroin addicts and there is no point in testing, educating, or doing anything with

them. If they see the light and say "yes I want to stop using heroin and I want treatment" we say "Terrific, if you can survive six more months you can get treatment". In the mean time we can't tell them about bleach because someone tells you that's condoning drug addiction. That's our situation, maybe it's no consolation to European countries facing their own problems. There is a story about the meanest guy in the world who dies and no one knows what to say about him. Finally somebody gets up and says "His brother was worse". So if you take consolation from knowing there are worse situations elsewhere that's ok, but it's little consolation to me. ■■■

Saturday, June 23, 10.00 AM

The HIV Network

CHAIR:

Marjo Meijer (*General practitioner, Amsterdam*)

GUESTS:

Aristos Bouius
(*Amsterdam*)

Jozette Donnisson
(*Computer Center of the AMC - Amsterdam*),

Michael Polman
(*Antenna/Interdoc, Nijmegen*),

Rolf Pixley & Prof. Gerard
de Zeeuw (*CICT - Centre for Innovation & Co-operative Technology - University of Amsterdam*),

Michael Tidmus (*Artists Against AIDS, Los Angeles*)

Networking seems to be the key to effective, non-bureaucratic information exchange and solidarity. Personal computers have heralded breakthroughs in fast, reliable and cheap communication for individuals and grass-roots organisations. They hold a great potential for social networks, provided the link between 'human' and 'electronic' activities runs smoothly. As one of the aims of the Seropositive Ball is to demonstrate this method of interaction, both computer-experts and social networkers from AIDS care organisations will discuss the issues, choices and opportunities presented by these two forms of networking.

Michael P

The word "networking" has come to mean a unique new form of cooperation between organisations and individuals, who on a horizontal basis are willing to cooperate and exchange information.

Networking has also become a word for exchange via computers, because computers have shown their capacity for linking information, ideas, opinions, and views on a global basis. In fact, in terms of general networking between people and organisations, the introduction of new technologies, like computer networks, to issue orientated movements, such as the AIDS movement, provokes a kind of chicken and egg situation. We have found that in other situations like, say, labour and human rights, where if you introduce this kind of technology it creates in itself possibilities to network, to cooperate, to exchange information.

Often there are enormous gaps between people in terms of expertise and knowledge. Access to information sources of this kind can produce a kind of horizontal form of information exchange creating new possibilities of working together. But getting back to the chicken and egg situation. You need to have people and the organisations there, willing to network, and not only a computer network.

Michael T

To me networking is a way of dreaming. It's a way of imagining what you

could possibly do and sharing the information with other people. It's a way of finding out what other people are capable of and finding out what you're capable of. Then putting the two together and putting the information out for people. Our biggest difficulty is that we have to deal with a technophobia. A reluctance of people to accept that the information can come in some electronic form. That the information can filter down from large computer to small computer to individual, and then be distributed via Fax or Xerox machine, and lower and lower forms of technology until it's just written on a subway wall.

Rolf

My fallback for designing the communications for this conference was that it was enough that Michael Tidmus's stack would be available on computers around the world. Whether those computers were connected or not. The actual sending of a disc of information, itself a very dense media, together with Micheal's regular updates of the information. In a sense, this becomes a network by itself.

As far as the communications go, at present, networking on the technical level tends to fit in with a technological culture. So my question became, "In what way could it be presented so that there didn't have to be specific support for the technology and yet it still worked". This is a very important design point at this moment for electronic communications. For example,



the FAX machine works because you press a button and I think that all of the communications systems that we have will have to get to the point where it works because you press a button. In terms of the design, it was important that people did not have to have some sort of position in order to have access to the system. I wanted the network itself to define the inclusion and exclusion of individuals. In other words, as the conversation reached a level where it was, shall we say, literate, people would be involved or not involved according to their interests. As oppose to their ability to prove they were responsible or some other criteria. I think the access to technology is usually very elitist.

Gerard

There are many different aspects to networking and support. I would like to say that I was shocked by the information that Michael gave in his programs. And the way some of the groups in the United States and other countries behaved towards the problem of AIDS.

A few days ago, I was talking to a medical couple who are extremely open, but still defended their position as one in which they could decide whether or not to provide information to patients. And my statement would be that this type of network that we are dealing with is just the kind of thing we need to undermine people like that.

Jozette

My problem with having dealt with the network going on at the moment is that however much you can make it socially horizontal, it is still a very elitist thing to have a computer at home, connected to a network.

Networking as I see it will only be available through institutions. And that means there must be certain institutions that will make networking possibilities available to groups they support. For instance, if we could keep a computer like this in the hospital linked to this kind of network it would become institutionalised. This does not mean that the institution will validate everything that is on the network. Then it becomes a political problem. For instance, you give the patients the ability to communicate on the network. Whatever comes over the network will not automatically be validated by that institution.

Aristos

I use networks on a daily basis as part of my work. That's mainly because the

information can be passed on so quickly. For instance, when I have a correspondence in San Francisco for the Silicon Valley News, for my magazine, it's useful for me because he can deliver his information to me within minutes. In addition to what people have talked about here, I think it's the speed of information that is vital for people with HIV and AIDS. On medical issues, on availability, and even more in terms of exchange of personal information. Because of the elitist element we must look for ways to distribute the information more widely than simply to computer users.

Louk

I loved the program on the computer which I have just seen (Michael Tidmus's AIDS stack). In the Netherlands we need these kinds of networks. In particular, in the AIDS hospitals spread all over Holland. In order to spread the information around the country. In this way patients could correspond with one another by means of the computer. But if people are working from their computer at home, there will also be a lot of rubbish on the network.

Michael T

What's wrong with that? It's the reality of everyday communication, it happens in the subway or on the bus. This is part of communication. But there are two levels. You have the actual information you want to disseminate, and spread over the network on information available on AIDS. And you've got personal encounters, discussions and conversations going on, it would be unique to have both because both meet the needs of people.

Audience

I looked at "sci. med. AIDS", a kind of network on AIDS. What surprised me was that patients and professionals were talking on a high level on HIV and AIDS. So the patients were sometimes more informed than the professionals. The patients were themselves professionals—the boarder disappeared somewhere.

Audience

Who checks what goes on these networks?

Aristos

I don't think medical information needs to be checked right away.

Jazette

This comes back to my previous point, which is to do with validation of what goes on the network. If you institutionalise the right and the ability to use the network. If you make the origin of, say, medical information known. If it comes from such and such a ward of the Amsterdam General Hospital, you can at least expect that that doctor thinks he knows what he's talking about. Or if a patient sends out a report and you know he's in hospital, you can assume that he also knows what he's talking about because he's there. But what I like about the network so much is that, in contrast to, for example, patient groups and things like that, this network is available for people who have nothing to do with the situation. In other words, they are not ill and they are not a doctor. Through networks the information is available to a wide variety of people

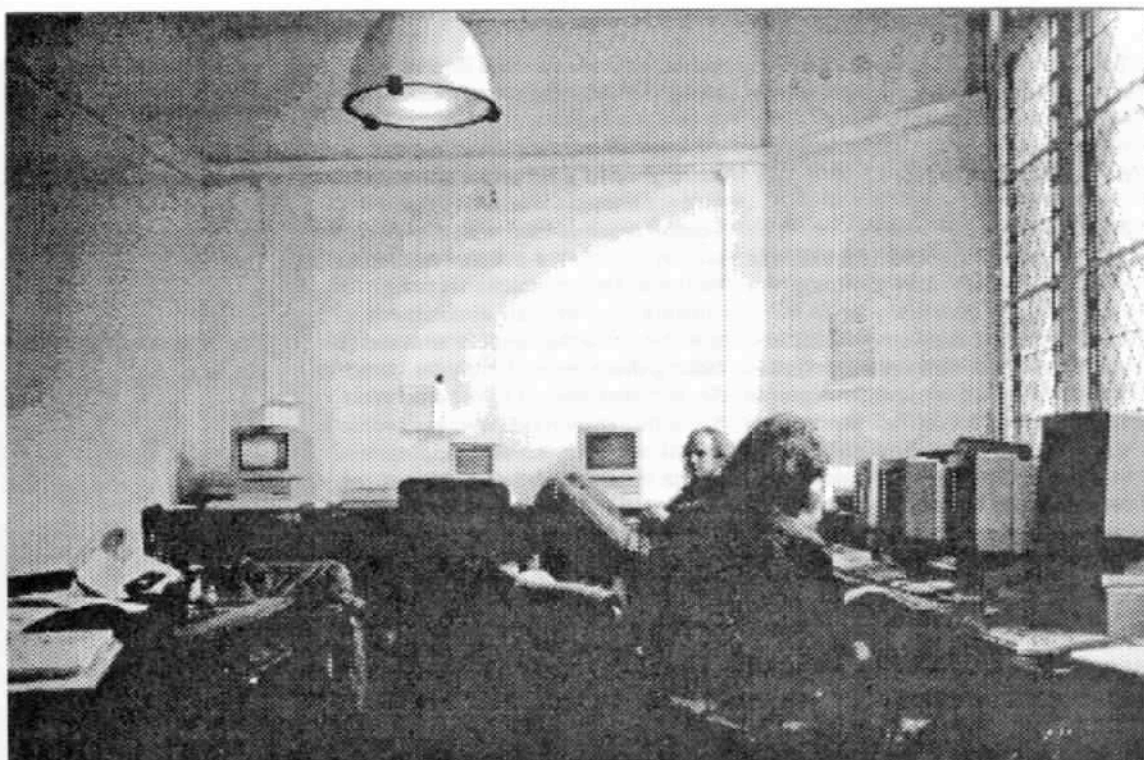
Michael T

In the U.S. there are all kinds of information which is electronically available. There is information from medical experts, there is crap that comes from fundamentalists and there is another kind of information. For example, there is a person with AIDS in New York City who has a problem with his laundry. They have come up with certain solutions for how they can get their laundry done. They tell someone about it who puts it up in the form of a story on an electronic bulletin board service in New York. And then it travels via telecommunication to Los Angeles. I download this information and either send it by post or FAX to my mother who works in Orange County with a group of AIDS patients. She disseminates this information about how you can get your laundry done in New York. You take what information you need from that and figure out how you can get your laundry done in Los Angeles.

Rolf

I want to take up the point you raised first. This is to do with the authority of information emanating from computers. How true it is. This issue is directly tied into the problem of authenticating the information that is available on the computer networks.

This network, here, is set up so that it becomes so casual, because the access is so easy. You begin to use your normal authentication processes. You look at a piece of information. You look at where it says it comes from and then you begin to check it out. You ask



friends, you make phone calls and so forth. And so the normal authentication procedures begin as soon as the access becomes as casual as the normal access routes for communication.

The problem of authentication in computer networks will never be solved unless the information sources are locked, and as soon as you lock the information sources you lose a lot of information. For example, there are a lot of alternative treatments, there are a lot of abstracts that won't be shown at the 6th International Conference. A lot of stuff that won't ever be authenticated, for example, drug trials that were not sanctioned by official agencies in the U.S. that simply can't be authenticated by being put into large data bases. A friend of mine wrote a paper about the discrimination against small presses, and small book publishing companies by the large data bases of books. This is true for all kinds of information. The two problems go together, the authentication and the accessibility of the information.

Jazette

Also there must be the willingness to put it on the network. There might be a lot of information that people do not want to broadcast. And they keep it to themselves. And that might be infor-

mation you want. How do you get that?

Michael T

At first sight this seems like a problem of elitism. That is, people being afraid of computers. If this system were in place for a longer period of time, more people would respond creatively to the situation. Over this period the information in the network would get more and more vast. You would begin to realise you could rely on this source but I can't trust this person. You begin to pick and choose between where you get your information.

Chair

Like you make your choice in news papers, which one do I like, which journalist can I trust.

Rolf

There is a process of moderation that goes on in the global networks. Essentially every global news group that we are tapping into here is either moderated or unmoderated. The moderation for example, of the "sci.med. AIDS" group is for people in various parts of the world who, any time a message is posted to their news group, receive that message before it goes onto the global network and, in a sense, authenticate it. That's not "fool-proof" because any computer network is breakable, and breaks always hap-

pen. But there are various mechanisms for dealing with that filtering and so on. It doesn't have to be a completely open system and I think that moderation is a very nice way of going about it.

Audience

Should networks be a platform for dubious political material, sexism or racism, for example, should that be moderated or not?

Rolf

Well, I don't have an answer to that. But on the basis of what happened here, when we started and people started reading, there was essentially nothing on the network. Bit by bit various people started connecting with various organisations, and began putting in substantial articles. But in the mean-time there was a flood of conversational messages. Some of it rude some of it funny and so on. The intermingling of these things has an interesting effect. It's like going to a party which you thought was going to be insane and you find a couple of people who are having a very interesting conversation in the left-hand corner.

Chair

But this is also a legal question. For example, in Holland if you write something racist you can be brought to trial.

So this is quite a big thing with computers, when you can place something there anonymously. A lot of rubbish placed on computers can pose big problems,

Michael P

Yes, we see this problem for example in Germany, we saw it during the Hackers party here last year. In fact a lot of neo nazis are using the bulletin boards and the networks to express their feelings about Jews,immigrants etc. And there is even talk about "Nazi ware" in Germany. The software is freely available, games for taking people to the gas chambers. This is happening and you have to lock it out.

Chair

How can you lock it out ?

Michael P

There is no real solution. Moderation, in the sense that everything has to be filtered previously, I think would be wrong. It would kill the discourse, the discussion, the spontaneity. The uniqueness of computer-networking lies in its immediacy. It's like picking up the phone, you have the feeling you want to respond immediately. Not like a letter which goes onto your pile and you find some easy night to answer them. You see something on line and you respond to it. If you know that response goes first to an moderator that would kill a lot of the discussion. I think it's better to have a post moderation. Somebody responsible for the bulletin or on line conference who takes out the trash, the whoops messages and hello from Amsterdam, and things which you don't want to store for the rest of the conference. Or messages which people have strong objections to. We have done this on other international boards in the South. However, although we installed and implemented the option of taking out information, it happened maybe once or twice during the last six years.

Rolf

When I was working on this project I was thinking about two terms. One is moderation which is the idea of pre-filtering. Which is the mechanism already in place. Another alternative is mediation and that is somebody who is looking at the network and essentially helping the conversation. This is like a club I'm interested in creating in which you could come read your magazines and so on and have conversations with other people. This was

based on the idea of the English elitist clubs like the Athenaeum. But I had a problem with the authentication processes involved, such as you had to have gone to a particular school and so on. I wanted there to be no authentication process for the club, yet I still wanted it to be the people I wanted to be there. And my solution is to have a conversation and an atmosphere in the club, in which people who didn't belong there would simply be bored. So with mediation it may be possible to create a conversation where people would not want to do inappropriate things because of the context of the conversation. The way that it was being mediated and so forth. I would use social structures to control the technology instead of some explicit mechanism of censorship.

Aristos

Apart from that, I think it is useful to have the pigs of your society on your network now and then. So you see what's happening in the field as you do in normal life.

Audience

I care more about the filtering of medical information about medical experiments and trials. Who decides whether this information goes on to the network ?

Michael P

The person who puts it on the network. If someone makes a discovery about AIDS, he or she is the person who will decide whether or not to disseminate the information.

Audience

Shouldn't the discussion be open on a network and not taking place behind closed doors, by professionals who decide whether information should be made publicly available? It's like an open forum in a news-paper. You have the right and the option to immediately respond, and say, for instance, this is bull-shit. Or if a story is not considered to be useful or valuable people respond to it.

Jozette

If you have a network like we have for this conference, then what you will most probably find is that patients who are involved in a trial maybe even decide to come out with the results of the trial. Telling other patients that they are trying a new drug in a trial and this takes place even before the doctors want to come out with the results. If the patients place this information

"Our biggest difficulty is that we have to deal with a technophobia. A reluctance of people to accept that the information can come in some electronic form. That the information can filter down from large computer to small computer to individual and then be distributed via fax or Xerox machine and lower and lower forms of technology until it's just written on a subway wall"

on the network, the doctors will then be forced to do something as well, to justify what they are doing. I think that would be quite a good thing.

Rolf

I think that one of the crucial things that happens here is, if you take the example of the news releases here recently.

In the computer network, the medium of the publication of the results is the same medium as the responses which, in an interesting way, brings them both to the same level. Reactions can have as much power as the initial statement. That is a very interesting effect.

Gerard

There are different types of activity involved. One is comparable to the activity of writing a scientific paper. A scientific paper is putting something in front of a community in such a way that people will act on it, in terms of checking, for example, comparing it to

what they know etc. So a scientific result is not news in the sense of news in a news paper. It is something that suggests that others check it. I think that the scientific type of procedure has developed over a very long time. It has taken centuries, and it takes some time to understand that also the networks might develop the same type of procedure where something is put in front of other people not to test their gullibility but to find out whether they are prepared to continue working on it. So there is a different type of procedure that can be developed.

Michael T

My interpretation of that is that the history of science has been a history of doubt. Through the centuries countless scientific theories have been disproven and to put the information up there and allow people to respond is to further that discourse.

Gerard

And of course for most of the time there has been no individual, no coordinator, no selector in that sense. It has developed as a habit.

Michael. T

Only time itself has performed that function.

Jozette

In spite of what Rolf says I still have a slight problem which I encountered in trying to use the network yesterday, when I was working from the ward in the AMC.

Besides the people who were trying to see what was happening, and trying to get messages to Paradiso, and see what was happening in San Francisco. Also some real medical questions about treatment came up and I immediately found it very difficult to decide which news group I had to put them in and how to describe them so that people weren't just reading them in terms of that's a nice message but trying to get the issues to the right people. So that the people who sent the messages would get the right answers.

There should be two levels, one that is more informal and a different level for medical discussion. It doesn't have to be just doctors but the content should be medical and for that I think you do need a mediator.

Rolf

I think what we've done here is a prototype, it needs to be up long enough to develop its own social

structures. That also involves different levels. You can see that on the computer network here and on the other nodes. The very first news group on the list is called "sci. med. AIDS and the very last one is called "soc. mofss". Which says Social News Group for Members of the Same Sex, which often carries information and discussion about AIDS. This is a very informal group and "sci.med. AIDS is. In this way, you see the leveling that is going on and you see where people post things. I think the network that is set up here is not well enough explained in terms of what the groups are and how they operate.

Michael P

I would like to add something based on experiences from other networks. This network just started a few days ago and I certainly hope it will continue, but I think that the response so far has proved that there is a need for such a network. The problem is the amount of information, you don't know where to find, which information. You can discuss it here in a rather artificial way in terms of what kind of news groups we should open and how to name them. You are then forced with each message to give a subject. As though you were to place a message in an envelope and then write on the envelope what the envelope contains. You must first look at the envelope before you look at the message. Because there are thousands of envelopes, it's difficult to follow the various discussions.

In the last days I've been monitoring news groups for picking up, manually, information which goes to the SARA networks because we want to have enough filtering, by which I mean personal filtering. I am making the same mistakes, but we didn't have the automatic software to be able to transport that information to the other networks in the South of the world, who are also linked with this conference.

We have a problem in Geo net, one of the systems we use, consisting of about 13 Non Governmental-Organisations. We have about fifty thousand pages per month going through the network. These are not personal messages, these are all NGOs. Small grass-roots organisations, institutions, working on a variety of issues. But this is two hundred megabytes, and most people say "but I only take about five pages of the network per month".

So I think what Michael Tidmus has shown, is possible, and what I hope will also become available on line, are these kinds of hypercard applications, so that you can, kind of, browse through information. It doesn't have to be so structured, envelopes and headings. It's like being lost in a library, where the hell should I look for the book? I want to be able to walk through the library and pick up any book I want. I want to be able press my finger on a given issue and immediately get a list on all the other messages that are referring to the same issue. I think that kind of software support will become available and its very important otherwise the network discussion ends up as a large Sahara of information.

Rolf

The original reason I got involved with computers was simply to access large data bases of information in the United States. And one of the things that I'm interested in working on, and is becoming a central issue in the avant garde in computing, is the creation of what are called agents. In one sense our moderator becomes an agent. But in a stronger sense what I'm looking at is the design of automatic agents, that can have a sense of where to find appropriate information. The issue I was looking at was, instead of an information explosion, we need an information implosion. Essentially it asks the question, how can I get what I want. Instead of getting everything related to what I want. So the question becomes how to create an agent that can have intuition about content. And make it available to the network. Finally I'd like to say that the nice thing about this discussion was that we had a network to criticise. So there was an actual physical object that had problems with it. I've listened in on lots of conferences that have talked about computer networking, but they are talking about a theoretical thing that doesn't actually exist. ■■■

THE NETWORK

The Seropositive Network provided interactive computer access to communications and information resources during the Seropositive Ball. Using the Hypercard application from Apple, running on remote and networked Macintoshes, it provided a consistent and user-friendly interface to HIV/AIDS databases, a gallery of works produced by *Art On Line For AIDS*, and NetNews/ Mail communications between our various locations in Amsterdam, New York and San Francisco.

In the attempt to by-pass the usual terminal interface and complicated command structures of Electronic Mail/News, we developed a hypercard communications program that made it possible to read messages from a global network by only clicking on buttons with a mouse.

Wide Area Network

Most of the software for this network has been developed in Amsterdam and was distributed via E-mail and courier to our locations in N.Y. and S.F. The large-scale design used Macintoshes with the latest version of our suite of Hypercard stacks connected by either modems or a local area network to a local Unix machine at each of our nodes. The Unix machines provided mail/news access to the Macintoshes and forward the relevant articles and messages to our other locations via the Usenet network. The Macintoshes were distributed among hospitals, art galleries, and activity centres. Any member of our public at these locations was able to browse the stacks of Art & Information we supply and read/write Netnews articles. During the conference any Apple Macintosh, equipped with a hard disk, modem and our software, within calling distance of our sites was able to participate in this on-line conversation.

NetNews & Mail

In the attempt to by-pass the usual terminal interface and complicated command structures of Electronic Mail/News, we developed a hypercard communications program that made it possible to read messages from a global network by only clicking on buttons with a mouse. When composing a message only the body need be typed, the subject and user's name are optional. Users were spontaneously created during the course of the conference. The modem connection to the network was made by a hypercard script and require only

one mouse click by the user. Messages between nodes were transferred within minutes and any one actively connected was notified.

We have arranged with Jan Zita Grover (jzg@well.sf.ca.us) on the Usenet network and Michael Polman (geo2: Antenna-NL geonet) on the NGO Networks [Greenet, Peacenet, Geonet,...] to be our mediators, to facilitate the discussion of issues related to the Seropositive Ball / ICATA'90 event in Amsterdam and the Int. Conf. on AIDS in S.F.. One global newsgroup and several newsgroups local to our nodes were created on the Usenet, paralleling the discussions on the NGO networks, to carry the traffic of these activities. A gateway was engineered at the University of Amsterdam to link these networks.

Databases

A remarkable AIDS database stack designed by Michael Tidmus of ARTSAVANT in L.A. was distributed. With his cooperation developing a world-wide version of this stack, providing AIDS resource information and statistics in a global context. Michael Tidmus gave an opening lecture and workshops at the ICATA'90, in Paradiso.

Art On line For AIDS

David Garcia from Time Based Arts, Joel Ryan of STEIM and Peter Mertens of the Rijksacademie are co-operated with us in assembling a gallery of art works in the Hypercard format. The works ranged from Video/ Animation-like sequences to single monochrome images collected from



around the world. For many of the artists this will be their first use of the computer medium. A proof form was distributed describing the size and format of images in hypercard for artists who preferred to produce works off-line, which we then digitized and included in the Gallery. Contributions were also made via fax. Works of fiction and poetry were also included.

LOCATIONS

Hospitals:

Arrangements were made to place Macintoshes at Academic Medical Center in Amsterdam, the New York Hospital / Cornell Medical School and the San Francisco General Hospital. These computers were placed both at the bedside of patients with AIDS and/or in public spaces.

Art Galleries:

Time Based Arts in Amsterdam, the Simon Watson Project Space in N.Y., and the Cap Street Project in S.F.

offered public access to Macintoshes in the context of multi-media events.

Conference:

At the Paradiso in Amsterdam will be approximately 20 Macintoshes for public use, editing, and artists.

Experimental

An attempt was made to integrate faxes into the Network. Using a fax-modem on a Macintosh, it is possible to capture and display faxes in real-time in Hypercard. Incoming faxes were shown on the network in Paradiso and then relayed out to a list of fax machines at remote sites.

Rolf Pixley

```
Path: ooc.uva.nl!hiv-seropos-ball
From: hiv-seropos-ball@ooc.uva.nl (Hans Bronk-
horst at AMC Hospital Amsterdam)
Newsgroups: hiv.seropos-ball
Subject: New messages
Message-ID: <10658@slice.ooc.uva.nl>
Date: 23 Jun 90 12:10:56 GMT
Sender: usenet@ooc.uva.nl
Followup-To: hiv.seropos-ball
Distribution: hiv
Organization: Seropositive Network
Lines: 7
```

Here in the AMC we are very happy with this sero+ net. A lot of valuable information and also touching messages. We are wondering now whether we are not receiving messages anymore, we haven't seen new messages for the last two hours. Thanks for all the greetings

workshop

ARE WOMEN WITH HIV THE REAL LOSERS?

Annie Wright, Amsterdam, 22 June.

After the presentation of the *Women & AIDS Handbook* and a short break, the group resumed positions in the bowels of the Paradiso for a panel discussion chaired by *Marjo Meijer*, a general practitioner from Amsterdam.

The discussion began by members of the panel introducing themselves:

Marjo told how she had become involved with the issue of women and AIDS in 1984 through the Dutch prostitutes' movement: 'they will always be the scapegoats'. As a lesbian and doctor she found that she was losing friends and patients. She has helped produce a women and AIDS information packet. This had elicited a response from the government to the effect that women were jealous, and wanted to be also able to claim this virus for themselves. She hopes to organize a Women and AIDS on 1st December (World AIDS Day). *Marjo* stated that there is little care for AIDS and HIV women in the Netherlands. The only support as to date is being provided by the Rutger Foundation (a private body set up to provide sexual education & information). However, women have to pay to attend meetings, something unheard of for the equivalent men's organizations.

Anita is body positive. She works as a volunteer for the Dutch HIV Association and attended the recent conference in Madrid. She commented that women are the fastest growing AIDS group.

Arianna van Gelderen is a midwife who has lost many friends. She considers the screening of pregnant Dutch women for AIDS "a sad development", and is very much against it. One reason is the difficulty of explaining the situation to ethnic minority

groups (eg Turkish and Moroccan) women. Also it leads to the forced abortion of healthy children (up to of whom 70% are HIV free). A blood sample is automatically taken and HIV women are given only 24 hours to consider an abortion. Still, very few midwives and obstetricians have refused to participate in this scheme.

Ria Bos is a doctor's assistant. Her pregnant daughter was diagnosed as being HIV positive and had an abortion. *Ria* brought her back to the Netherlands but no help was provided for her. There was simply no appropriate care for women. *Ria's* daughter died in December 1988.

Michelle Malik is HIV positive. She was infected by heterosexual contact. She found that existing support groups were exclusively for men. She wants to start more organizations for women.

Kate Thompson comes from England, is HIV positive and has also discovered to her shock the lack of any women-oriented support network. She helped found "Positively Women" which has received funding over the last 18 months and now employs several full-time women workers who are also HIV positive. Positively Women organizes home and hospital visits and publishes leaflets.

Alexis Danzig's father was gay. He died of AIDS three years ago.

Zoe Leonard has lost many friends. She feels that there is no excuse for



new cases of AIDS; "there should be condoms on every corner, clean needles, and dental dams in every bar."

The first item of discussion concerned women in the Third World. A woman in the audience stated that in Africa and South America there is a very high risk of infection from heterosexual sex, a level sometimes as high as 20%. Africa is frequently blamed as the source of AIDS and as a reaction it is a taboo subject in many African countries.

It was mentioned that there would be a Safe Sex for Women workshop the afternoon of the next day. A man demanded somewhat aggressively to know why it would be open to women only. The answer was that there would be an equivalent workshops for men. Zoe pointed out also that it is important to discuss with women together, in an unhibited atmosphere, ways of persuading men to use condoms.

Robert from the Dutch HIV organization asked about the symptoms of women with AIDS. Zoe repeated what she had said during the workshop: the incidence of chronic gynaecological problems, candida, vaginitis, warts, cysts and chronic obstructive pulmonary disease. She reiterated the vital importance of research for women and mentioned a woman she knew who had gone so far as to steal medical findings that were being purposely delayed and kept from public consumption to allow the scientist involved the time to organize a dramatic launch of his results. Zoe commented that women have died without ever knowing that they had AIDS. The authorities have stopped taking statistics in New York City because make them responsible for those people with HIV and AIDS.

An American man in the audience said that poor women don't have access to good treatment in the U.S.A (while women earn on average just 60 cents to each dollar earned by men). Michelle stated that defective cover by medical insurance in the Netherlands sometimes means that people have to pay their own AZT.

Zoe said that in Holland HIV testing is discouraged because causes discrimination whereas it is encouraged in the US which is good in terms of treatment however for the poor there often is no bridge into those facilities.

The discussion was concluded with a call for help in the organizing of the Dutch 'Women and AIDS' Day on 1st December 1990 (World AIDS Day).

WOMEN, AIDS & ACTIVISM

The average woman in the United States with AIDS will die within six months of diagnosis. The average man will live six *times* longer. **Women, AIDS & Activism**, produced by AIDS activists, not only reveals the context for this discrepancy—social, economic, and political patterns of racism, classism, sexism, and heterosexism—but also lays out a strategy for change. From grassroots safe sex education to issues of access to resources, to challenging the government to include women's interests, **Women, AIDS & Activism** goes beyond looking at AIDS as solely a medical crisis. The volume also contains critical and groundbreaking medical information. Nine years into the AIDS epidemic The Centers for Disease Control still maintains no specific categories of findings on the behavior of HIV in women's bodies. **Women, AIDS & Activism** looks at the research and asks the questions the medical/research establishment has ignored: for example, what is the connection between the rise in cervical cancer and HIV? Without asking the right questions, you won't get life-saving answers.

Nowhere else is all the information in **Women, AIDS & Activism** available. With informative discussion of safer sex and sexuality, HIV testing, treatment and drug trials, public policy and activism, this is the only thorough and up-to-date analysis of AIDS issues for women. Looking at issues specific to lesbians, heterosexuals, bisexuals, prostitutes, intravenous drug users, teenagers, mothers, pregnant women, and women in prisons, this book is essential reading for everyone concerned about women's health and the AIDS crisis.

EXCERPTS

Epidemiological statistics do not account for all AIDS cases. Many women are diagnosed with HIV infection only after they are dead. Since the CDC has not changed its definition for AIDS, women who die of an opportunistic infection before they are even considered eligible for an actual AIDS diagnosis are excluded from the total statistical picture — that is, they not

only won't get counted but they won't get treated: they won't qualify for health benefits, child care, rent subsidies, or other support services.

From "What the Numbers Mean" by Riso Denenberg

Lesbians are not an isolated community: there are lesbians who shoot drugs and share needles, there are lesbians who have been married, who have babies, who are in prisons, who have sex for money, who get raped. When examining the AIDS epidemic, it becomes obvious that stereotypes are useless: it's not who you are that puts you at risk, it's what you do.

From "Lesbians in the AIDS Crisis" by Zoe Leonard

About the fourth or fifth woman said, "I'm here because I have AIDS." There was an intense silence. It was the first time anyone had said that aloud in a group. By the end of the meeting, several more women had



said that they were HIV-positive. Breaking the silence, the faith that it took, and the trust it built was really how ACE started.

From "Prison Issues and HIV" by AIDS Counseling and Education at Bedford State Prison for Women, New York.

What's happening now is that the big established AIDS groups are going to the small ones under the pretext of working together and learning about "minority outreach." In practice, they end up ripping off their ideas and getting big grants based on their longer track records and their experience with the funding establishment.

From "Cultural Sensitivity In Practice" by Yannick Durrant

So I made an appointment with the Beth Israel Infectious Disease Clinic. And they sent me to the neurologist and the rheumatologist and the GYN and the Hospital of Joint Diseases, and every last one of them had a different approach to what was going on with me.... I had to apply through a social worker for welfare. Suddenly, here I am, from making \$30,000 a year, having a good job, to being totally caught up in the bureaucracy, of trying to get money for my son and myself.

From "Fighting for My Life" by Melinda Singleton

ACT UP is a true coalition. Everyone puts up with what my mother would call everyone else's mischigas—craziness. I have come to appreciate what each person can and will contribute because they share a commitment to the saving of lives.

From "AIDS and Politics: Transformation of our Movement" by Maxine Wolfe

Women, AIDS, and Activism also contains a glossary, a national resource list, and annotated video and print bibliographies.

Friday, June 22nd 1990 15:30 GMT

POLICING DESIRE

*Simon Watney's book **Policing Desire** has proved one of the most important and influential critique, of the representation of the AIDS crisis by the media. The Seropositive Ball was the setting for the official launch of the book's translation into Dutch, by the Schorer Stichting.*

As well as giving the lecture which follows, Simon Watney contributed generously to many of the debates which took place during the 69 hours, giving us the full benefit of the breadth of his involvement in and knowledge of the epidemic and its implications.

Policing Desire, written in 1986, was an attempt to look back over six years of madness, and to try and get people as angry as I felt then. As angry as I still feel today, although in the end anger just wears you out. At the end of this translation is a chapter which brings the story up to date.

Policing Desire was written before we got wise to the role of the pharmaceutical industry in this epidemic. Before we realised some of the negative consequences of living with socialised medicine in Europe. Above all before we had the example of ACT UP as an AIDS activist force.

This morning in Amsterdam I watched BBC TV AM (needless to say, being British, they ignored the San Francisco conference altogether). However, they did give us an AIDS story. We met a little girl, five years old. HIV-positive, her mother, we were told, was an injecting drug user. We were then told nothing about what happened to her unfortunate mother. Nor were told anything of the child's relationship to her mother. She's been adopted. She has according to the report the "AIDS virus". The male voiceover said "this little girl will get AIDS and then she will die". I am quoting exactly. We then cut to a scenario of injecting drug users in Edinburgh. Where it was explained that injecting drug users constitute the greater majority of people with HIV and AIDS in that city. We were then told that one in a hundred men in Edinburgh are seropositive. It is added that safer sex would be working if people stopped having casual sex. Cut to a bomb site with five people standing in the rain. This was the opening of a site for a new hospice. Finally the piece ended with the information that Edinburgh "may become the source of a heterosexual epidemic".

You could write a book just about those three minutes. Firstly there seems to me to be a refusal, even at this stage of the epidemic, to distinguish between, on the one hand, the virus, with very clearly understood

means of transmission. And on the other hand the syndrome – of twenty five or so potentially life-threatening conditions, to which people with HIV may become vulnerable. I stress the word may, because the medical evidence from Britain is still quite clearly that within ten years only 50% of people with HIV are diagnosed with AIDS. Therefore the fatalism which informed the whole of this section was entirely unnecessary.

The program required the little girl with HIV to be doomed to AIDS and doomed to death. It often seems that this picture, which I analysed in great detail in *Policing Desire*, has been very strongly resistant to modifications of any kind. Whether via medical modification or modifications in terms of the social organisations that have grown up around the world in the form of selfhelp groups and other organisations that support people with HIV and AIDS in their communities.

The inability to understand that safer sex is not incompatible with sexual pleasure again speaks from the very early days of the epidemic the same way that the site of the hospice with the implications of death and morbidity speak from the very core of the way it is convenient for our societies to think about AIDS.

The idea that Edinburgh might become the source of a heterosexual



epidemic again speaks for an extraordinarily primitive way of thinking about epidemics. Of course there already is an epidemic in Edinburgh. An epidemic among heterosexuals who also happen to be injecting drug users. They don't just happen to be injecting drug users. The reason why there were such horrific levels of HIV prevalent in Edinburgh can be explained in two words. THE POLICE. Throughout the 1970's and 80's the Scottish police literally drove injecting drug users into circumstances where they were obliged to share needles, by denying any kind of over-the-counter sales in chemist shops. A ruthless puritanical anti-drugs policy is the simple explanation for the prevalence of HIV in Edinburgh. A policy which is still in place. This meant that recently two hundred registered heroin addicts were taken off methadone overnight. So two hundred heroin addicts left Edinburgh the next day. So the epidemic travels.

There is also an epidemic among gay men throughout the United Kingdom. But of course these are not real people. They are not the sort of people who would watch TV am. Not the sort of people television makers have in mind when they're speaking into their autocues.

These are some of the problems which I tried to analyse in *Policing Desire*. How does television regard us, in relation to HIV? How does the press regard us in relation to this epidemic? And it seems to me that despite the great difference between our two societies, Britain and the Netherlands, in many respects the Dutch press is not much better than the British press. The inability to distinguish between HIV and AIDS; the refusal to address the political dimensions of this epidemic; the general collusion with extremely autocratic biomedical authority etc., are very similar throughout the European community and it's the European situation that I want to talk about in conclusion.

We know that AIDS can be sold as a human interest story but only in relation to certain humans, the little girl for example. I am yet to see on British television or in the British press one single story which even asks the question or could imagine asking the question of gay men, of what it's been like to live through the 80's and the AIDS crisis? Such a question is un-

thinkable because such people are unthinkable. Those are the important questions that we must bear in mind as we go into the 90's.

Most of us have lived through a decade in which our experience of the epidemic in Europe has overwhelmingly been that of asymptomatic HIV. However, as we know, unfortunately people are likely to become ill in the 90's and our experience is likely to become much more like that of the cities in America. Not New York not San Francisco but Denver and Dallas where the overwhelming experience is of direct AIDS symptoms. And of the problems of establishing proper continuity of care between hospitals and people's homes. Between general practitioner's clinics and up-to-date information. That continuity of care should not, I believe, "buy in" to the notion that every one with HIV has to get AIDS. Or that every one with AIDS has to die as a result.

Because we have the advantage of socialised medicine, most Europeans are extremely passive in relation to the institutions of state medicine. We tend not to appreciate the enormous significance of the fact that all our socialised medicine systems have a gun held to their head by the multinational pharmaceutical industry.

The journalistic part of my work involves me in very difficult issues. You will doubtless remember the ridiculous and totally unethical sensationalism earlier this year around Dr Buck's work here in the Netherlands.

We've seen miracle cure stories almost every month of the year for the last five years. Now of course this is totally unacceptable by any proper journalistic standards and yet it goes on all the time. However, we do have to get stories into the newspaper for the simple reason that if Burroughs Wellcome or Hoffman La Roche or another company comes up with a very promising HIV drug, then it's necessary for that drug to get publicity for the stock markets of the world to register it so that the medical team in the laboratory continues to get funded.

This is the kind of nightmare situation that none of us could have anticipated. Even two or three years ago. It is very important to internationally

update on those updates of our strategy that we could not have anticipated in advance. Almost everything we do has unexpected consequences. Who would have expected, for example, that in Margaret Thatcher's Britain the department of health would have forbidden all AIDS civil servants and policy programmers to go to San Francisco when the Dutch travel with impunity. This is the kind of paradox which we see throughout the epidemic. It would be preposterous to try and read off almost any aspect of AIDS against the traditional polarities of left and right. On the contrary, we find right wing politicians who are relatively principled in HIV policy. And we see left wing bigots.

It seems to me that we have two worlds of AIDS. The world that we here at Paradiso inhabit. Whether or not we have HIV ourselves. Whether or not we have friends who have HIV. A world in which we understand from a practical point of view the need for safer sex. A world in which we understand the need to distinguish between HIV and AIDS. And then this other world, which almost refuses to acknowledge our existence, except grudgingly, which occasionally will pull us in for consultation, but will only listen to us in so far as what we say fits in with a previously decided agenda. Here is just one example. Earlier this year in Britain, and doubtless in Holland, the new figures for the life expectancy of people living with AIDS was published in London. The figure showed conclusively that the life expectancy of women and men in Britain with AIDS had increased from an average of one year up to just above two years. In the course of just the last two years. This of course is very good news. News which relates directly to improved standards of patient care. New treatment drugs, many different factors. However, every single national newspaper in the UK except the gay press, splashed this story in banner headlines as if this were a story about HIV. As if this were a story which told us that the AIDS epidemic is ending. Usually followed by the kind of sentence which says that "gay men have listened to government warnings and have cut the numbers of their sexual partners". What is important to understand about the safer sex revolution, wherever you look, whether in San Francisco in 1983/84 or London and Amsterdam in 1984/85, is that revolution was achieved among gay men long, long before most of us had

Time has only taught me that somehow I have to hold on to my own anger. Even if I have to express it in different ways to different audiences.

any direct experience whatsoever of either HIV or AIDS and it cannot be sufficiently stressed, given the very different experience of America and Europe that most gay men in Amsterdam or London today have never knowingly met anyone with AIDS. They may increasingly be likely to know friends with HIV. But the great success of the gay and lesbian movement in Europe have come from the strength of our culture. From our press, friendship circles, from talk in bars, not from a fear of death as it's pumped out at us by the health education authorities of the world. But through our confidence in ourselves and one another. Above all through our ability to talk about sex. As my friend and esteemed colleague Douglas Crimp in New York pointed out years ago, paradoxically we are almost saved by our promiscuity. The fact that we have the confidence not to continue in relationships which are causing us pain, means that we learn to be able to be confident about our

sexuality. I say this of course with my heart in my mouth, because no one ever attains that perfect degree of confidence that they would wish. But it is the very fact that it is because we are not tied by the hypocritical idealisation of marriage. It is because we understand the need for individual and collective growth that we have been able to adapt to safer sex.

What is so frightening is the assumption throughout Europe that the rest of the European community has nothing to learn from gay men. What is this extraordinary fear, even from countries as liberal and progressive as Holland, which suggests that gay men inhabit some other planet? As if there is something called morality which the rest of the population has, whereas gay men live somewhere "extramoral". The only constituency in Europe which has behaved responsibly by and large for the sake of the whole population has been gay men.

As we move into the 90's, then, a number of issues come into play. In Europe we have to understand the terrible situation in the field of research. The governments of the western Europe, perhaps understandably, but foolishly, assumed that America would come up with a cure, and they haven't. The AIDS clinical trial group financed and run by the centres for disease control is a fiasco. As those of you who read Mark Harrington's article in *Gay Times* will be aware, the only way we're going to get adequate treatment and cures in Europe is through biomedical research in Europe. And that research is not taking place. In Britain the government has spent over forty million pounds on HIV-related research. Every single penny of that research has gone towards vaccine technology. Of course vaccine research is not entirely distinct from therapeutic research. None the less it seems an almost unbearable insult that all the research facilities go to protect the uninfected, white heterosexual and not a penny is spent on trying to save the lives of the hundreds of thousands of people at this moment living with HIV throughout the European community.

Such priorities implicate themselves at every level of the management of the epidemic. *Science Magazine*, one of the most reputable journals of popular science, in a recent editorial, stated that basically there was little justification for therapeutic research,

since the danger was that by increasing the life expectancy of people with AIDS, the epidemic would be worsened. The logic is very simple. For the scientific writer the longer you live with HIV, understood as some sort of predatory monster, the more likely you are to stalk out into the night, deliberately infecting the innocent.

One of the leading virologists in the United Kingdom, a Professor at the University of Reading, speaking for the medical research council, recently said that research for therapeutic purposes for people with HIV and AIDS raises in itself a moral dilemma on the same grounds, because it might, I quote exactly, "run the risk of prolonging the lives of people who would be infectious within the community".

When in *Policing Desire* in 1986 I argued that we were being offered in the name of health education strategies from the mainstream of social management from the early 20th century: the management of reproductive sexuality; the management of the categories and identities of sexuality; and when I argued that gay men and injecting drug users were regarded in our entirety as disposable constituencies, I was widely criticised in the United Kingdom, but not in America where that relatively simple point was widely understood. I must say it was a painful realisation for me to discover the full extent of the indifference to the lives of gay men, not only in Britain but throughout the European community.

Time has only taught me that somehow I have to hold on to my own anger. Even if I have to express it in different ways to different audiences. We are going back to the same problems that become expressed in different ways. And if we look now at the "degaying" (the removal of those who are most experienced) in the management of the epidemic we can only conclude that the situation of the 90's in Europe looks bleak indeed. And it is these circumstances that we have to think about how we might be most productively engaged as activists. Because — we should make no mistake about it — we are all going to have to become activists sooner or later in relation to this epidemic. The hospitals in this city are already all but overwhelmed. And your epidemic has hardly begun.

In England, the Department of Health recently halved their estimate of the

number of gay men in London in a city of eight million people down to one hundred thousand. On the basis of that epidemiological calculation, hospital beds have already been pulled away from AIDS wards in the North West Thames region. The worst effected part of the United Kingdom, which is to say one of the worst effected places in Europe. We are only going to get those beds back through civil disobedience. We are only going to get the drugs and clinical trials that we need, expect and have a right to, through concerted activism.

You in Holland have an example which you've given to me and to the rest of the world on what lesbian and gay men can achieve within a democratic consensus, in a pluralistic society. I'm afraid however that having achieved your rights now many gay men and many lesbians will sit back and say that this is not our issue. We cannot allow HIV and AIDS to be seen only as an issue for people with the virus; this would be a form of totally unacceptable brutality.

Wherever I go in the world, I see disputes between the tradition of gay liberation and gay politics and AIDS politics. We can learn from this totally unnecessary divorce. There is no aspect of lesbian and gay politics in the 90's which, in one way or another, will not be effected by the epidemic. That is not to say that the epidemic should exhaust all our work and all our time in relation to larger issues. But if we do not learn from America the desperate folly of imagining that we can have a lesbian and gay or a sexual politics which knows nothing and cares less about AIDS, then that sexual politics will be worthless, because it will be achieved at the expense of people with HIV today who do not necessarily have to die of AIDS. And it is in this spirit that I would encourage you in the Netherlands to think about your own strategic interventions in the years ahead.

An introduction to Simon Watney's book "Policing Desire" by Peter van Rooyen of the Schorer Stichting.

Dear Simon, in your book *Policing Desire* you give a thorough analysis of the rhetoric of AIDS. The discursive structure of AIDS commentary; its

repetitions, its slippages, its omissions, its narrative patterns. Representation, you say, is not merely a reflection of real life but an integral part of it. Representation, I think, helps to shape people's concepts of themselves. Of who and what they are. Or at least what they should or should not be. Above all, it sets boundaries between us and them. *Us*, as you show in your book, are white heterosexual, monogamous people living a family life. *Them* are the perverts, the drug abusers, a threat to the very fabric of society and of public health. The audience at large is considered to be a monolithic block and all diversity of race, sexual habits, and preferences, age and gender are ignored. As far as any moral question is raised in the British media you studied, it is based around issues of promiscuity and monogamy. No doubt AIDS raises moral questions, but they have little if anything to do with sexuality, promiscuity and monogamy, but everything to do with democracy, protection of privacy, legal protection against discrimination and above all with the representation of diversity.

Your book provides an enormous number of examples of the hysterical and derogatory ways in which the British media, not only the tabloids dealing with AIDS and homosexuality. It wouldn't be right to indulge in stories that there is no difference between the Netherlands and England. It is my impression that in this country, at an institutional level, that of government, parliament, and major parts of the press, a taboo on anti-homosexuality has emerged over the last decade, which still seems to be in force, despite the AIDS crisis. This at least prevents blatant homophobia from finding its way into news coverage. Even Christian fundamentalists have to pay lip service to their love for their homosexual neighbours. The fact that we have hardly any tabloids such as those from England may well have been of major importance in the emergence of such a taboo, yet there is little reason to become selfcongratulatory. There are numerous liberties in the Dutch press. It still seems to be difficult to make distinction between people who carry the virus and those who have full-blown AIDS.

Just two months ago a major television program broke the news that Pro-

fessor Buck had found the long-awaited cure. In five years time there would be no more AIDS, he declared. The news program showed the professor in his living room, on a walk with his wife, answering telephone calls of congratulations, accepting flowers. It was as if he had just won the Nobel Prize, which was probably what it was all meant for anyway. Later, to use a Dutch phrase, the news was blown out like a candle in the night. It was left to the people with AIDS or Seropositives, their friends, relatives and loved ones, to pay the price. More basically, I think that the structure of the discourse on homosexuality in the Netherlands does not differ significantly from this discourse elsewhere. You show in your book that this discourse is based on an absolute dichotomy of homo and heterosexuality. Homosexuals in Holland are at best a more or less respectable minority, and as such are set apart from mainstream representation. Ignored unless there is news of ugly discrimination, of which every decent Dutch man has learned to show

Discourse on homosexuality in the Netherlands does not differ significantly from this discourse elsewhere. Simon Watney shows in his book that this discourse is based on an absolute dichotomy of homo and heterosexuality.

abhorrence. But let there be no ambiguity about homosexuality. A stunning comment in a major newspaper about a recent exhibition on the history of homosexuality in Holland 6 months ago, was that the exhibition did not define homosexuality. In fact the organisers had done a wonderful job in deliberately visualising that ambiguity, and that at best the whole concept of homosexuality is arbitrary. Something similar happened last year, when a brain researcher claimed that he had found the biological origins of homosexuality. When he was attacked on the ethics of his research and his 19th-century presuppositions of sexuality, editorials questioned the fuss that was made by the gay community. Since difference did not imply deviance, implicitly they meant to say that now at least it was clear who is and who is not a homosexual, the best news being that they were not.

Dear Simon, even though your book is about England and the United States, for a variety of reasons we, the editors of the Schora Stichting, thought it important to make the book available to a wider audience in Holland. It may offer a warning of what is ahead of us if Rupert Murdoch were to gain a foothold in this society. Or what Thatcher might mean for Europe if she is still in power after 1992. No doubt she would try to continue her crusade on the continent. But most importantly, it is your way of discursive analysis which provides the tools to analyse not only this topic but also related subjects. Not only to the gay community or to gay and lesbian scholars but to professionals, journalists, and media specialists alike. As editors of the Schora Stichting, we take great pride in publishing your book. And personally I feel most happy to present you with the first copy of the Dutch translation.

Simon Watney's reply

Thank you very much. It is a tremendous honour for me to be published by really the leading institute in the world for the active support and understanding of human sexuality in its entirety, which is what lesbian and gay studies should always be about, if it's going to be worth pursuing at all.

I think that we can see that twenty years ago in Europe and America we successfully saw through and bettered the pseudo-science of the late 19th century, which tried so very hard,

and continues to try, to turn us into "homosexuals", into a subspecies of the perverse. Now I think it's time for us to take on science proper, time for us to take the gloves off. And it's not Victorian sexology we're fighting, it's ruthless homophobia, in the laboratories of virology, and immunology. If we can beat the virologists, then I think we can beat the sexologists too. Thank you.

INTRODUCTION

(JUNE 21-JUNE 24, 1990)

THE VISUAL ARTS OF THE SERO POSITIVE BALL

*Let the record show that
there are many in the
community of art and
artists who chose not to be
silent in the 80's.
(Gran Fury)*

ART ON LINE FOR AIDS

As Douglas Crimp has frequently asserted, the art generated by the AIDS movement, however compelling, can never be thought of as a compensation. To do so would be to betray those who in sickness or in activism have their bodies on the line.

But although there can be no compensation for devastation of AIDS there may perhaps be consolations. At least the consolation of hearing the silence broken. And until recently the silence from the visual arts community in the Netherlands has been deafening.

Despite the, in many ways admirable, dutch welfare system, there exists within our community a paralysing complacency which is only just beginning to be challenged, most notably by the women's caucus within ACT UP Amsterdam. But even now one can find oneself confronted by a seemingly impregnable wall of denial and resistance. It was working within this context which lead me to give a higher priority to activist works than to an art of memorialisation, which of course should never be denigrated.

ART ON LINE FOR AIDS emphasized artists who use non traditional media such as film, video, computers, publications, and posters. In other words those media designed for public spaces and those avenues of mass communication where the dominant representations of AIDS could be explicitly challenged. The programme was divided into 4 parts:

1. ART IN PLACES [mostly installations]

2. ART ON WALLS

[Outside and Inside, posters, murals and graffiti]

3. ART ON SCREENS

[film, video, computer graphics and texts]

4. ART IN NETWORKS

[mail, electronic mail, fax & phone]

Visiting Artists

GRAN FURY were formed in 1988 and are a collective of AIDS activists who use their expertise as visual artists to oppose government and social institutions that make people with AIDS invisible. Two members (Robert Vasquez and Mark Simpson) of GRAN FURY attended and gave a lecture on the group's works and actions. They also erected a thirty-foot banner outside the paradiso.

MICHAEL TIDMUS is an artist and award winning software designer from Los Angeles and member of Artists against AIDS. In his work the computer plays a significant role both as tool and medium. His numerous programs of AIDS information are widely distributed through BBS networks. His major work at the moment is the AIDS Stack, a Hypercard application, consisting of an extensive database of information, statistics and community service listing. Michael Tidmus showed the newest development of the AIDS Stack including a world wide version which was especially made for this event.

MARLON RIGGS, celebrated director and award-winner (including an Emmy for *Ethnic Notions*) presented



his recent films *Affirmations* and *Tongues Untied*.

Marlon Riggs is also known as a prominent media activist who has testified before the U.S. Senate and spoken at the Museum of Modern Art in New York. He gave one of the opening addresses, held workshops, and attended a round-table discussion with other artists.

GREGG BORDOWITZ is the associate producer of the GAY MEN'S HEALTH CRISIS *Living with Aids* programme. A weekly TV show for Manhattan Cable. He is a member of the TESTING THE LIMITS COLLECTIVE, a group of seven producers who were established to document the birth of the AIDS activist movement and expose underlying issues of the AIDS crisis which the mainstream media have for the most part ignored. Gregg Bordowitz presented the video and TV programmes with which he has been associated and attended workshops, forums and debates.

ZOE LEONARD, an artist and activist from New York, will took time out from building her installation in a hospital near Ghent, Belgium, in order to represent the ACT UP NEW YORK WOMEN AND AIDS HANDBOOK GROUP. She introduced the Handbook project, attended discussion groups and workshops.

The GANG OF FOUR is a group of activists / artists from New York whose work place a special emphasis on direct action. A representative of the group, ADM ROLSTON, will launched a campaign of stickers and posters throughout Amsterdam which were especially designed by the Gang of Four for this event. He also placed an installation in the TIME BASED ARTS gallery.

Rosa von Praunheim

Rosa von Praunheim started as a painter, tried his hand at literature. He began filming in 1967 and his breakthrough came in 1970 with the films *Die Bettwurst* and *Nicht der Homosexuelle ist Pervers...* He has made around 30 documentaries and feature films since.

Wieland Speck

One of the strategies most likely to succeed in the promotion of safer sex, is communication material which, rather than seeking to moralise or frighten, actually manages to eroticise safe sex practices.

Wieland Speck makes Porn films of very high quality and high production values, which are sexy, explicit and safe. As well as showing the films Wieland Speck also gave a talk about the ideas and attitudes behind his work.

Art in Places

NAN HOOVER recreated her installation 'Walking in Any Direction', originally shown in the Stedelijk Museum Amsterdam. The sense of stillness which her installations create will allow this space to function as a locus for escape and quiet contemplation.

JAAP DE JONGE installed his video chandelier in Paradiso. He also developed the "package time clock" which was be installed over the entrance to the main hall of the Paradiso, and marked the passing of the 69 hours.

GRAN FURY placed a 30-foot banner over the entrance of Paradiso which read "ALL PEOPLE WITH AIDS ARE INNOCENT".

The GANG OF FOUR will have an installation in TIME BASED ARTS.

RAINER GANAHL, from Vienna, will make an intricate two-monitor installation in TIME BASED ARTS.

Art on Walls

We will include posters, stickers, stencils, slogans, photographs, images or murals from the following artists: the late Keith Haring, Group Material, Hugo Kaagman, Act Up Amsterdam, Act Up New York, Act Up San Francisco, Gran Fury, Border Arts Workshop, Lawrence Weiner, Frits de Ridder, Urban Scrawl, Gang of Four



Art on Screens Film

ROSA VON PRAUNHEIM will present his AIDS trilogy: *Schweigen ist Tot*, *Positiv* and *Feuer im Arsch*.

MARLON RIGGS will present his two recent works *Affirmations* and *Tongues Untied*

WIELAND SPECK from Berlin will present his porno films

Video

A basic element in our video programme is the "Video Against AIDS" package: "Video Against AIDS is thematically organised around nine sections which provide a creative framework for increasing awareness on the viewpoints, ideas, facts and political organising strategies related to the AIDS crisis' Video Data Bank Catalogue.

This programme includes:

PWA Power: Survival of the Delirious *Andy Fabo*, *Michael Balser*, *Work your Body Gay Men's Health Crisis*; also material from their weekly cable program "Living with AIDS."

Discrimination: The Second Epidemic *Amber Holbaugh*.

AIDS and Women: Safe Sex Slut *Carol Lee*, A Struggle for Life *Coyote*, Doctors, Liars and Women: Activists say no to Cosmo *lean Carlomusto* ~ *Maria Magenti* Resistance: The AIDSEpidemic *John Greyson*, Snow Job: The Media Hysteria of AIDS *Barbara Hammer*, We Are Not Republicans *Adam Hassuk*, *Robert Huff*, Stiff Sheets *John Goss*.

Mourning: Mildred Pearson: When You Love a Person *Yannick Durand*, The Inaugural Display of the Names Project Quilt *David Thompson*, *Danny Stashu Kybartus*

Community Education: Se Met Ko *Patricia Benoit*.

Loss: A Plague Has Swept My City *Em jay Wilson*, This Is Not an AIDS Advertisement *Isaac Julien*

Analysis: They Are Lost to Vision Altogether *Tom Kalin*, Reframing Aids *Pratiba Patmar*.

Activism: Another Man *Youth Against Monsters*, Part I of Testing the Limits, NYC.

The following tapes are not in the "Art Against AIDS" collection but will also be screened at the Seropositive Ball:

The World is Sick *John Greyson*, The Pink Pimpernel *John Greyson*, Bright Eyes *Stuart Marshall*, Sehnsucht nach Sodom *Hanno Boethe* and *Hans Hirschmuller*, Diana's Hair Ego *Ellen Spiro*, The Feeling of Power *Robert Beck*, DS NEWS: a demonstration *Bob Huff*, Video Album 5....The Thursday People *George Kuchar*, D.H.P.G. Mon Amow *Carl Michael George*, The Safe Sex Films - complete serie *Weiland Speck*, Le Rose et le Noir *Daniel Brun*, Fear of Disclosure *Phil Zwickler* and *David Woinarowicz*, Documentary tape of Jenny Holtzer Laments installation courtesy DIA Art Foundation.

Art on the Networks

MICHAEL TIDMUS, from ARTISTS AGAINST AIDs, Los Angeles, will demonstrate the exciting development of his AIDS STACK, a hypercard application which shows how much a visual artist can achieve in this field.

GROUP MATERIAL from New York, will place the DEMOCRACY WALL section from the AIDs TIMELINE on the electronic gallery within the O+/ network.

The following artists and writers put some of their work on display on the electronic gallery:

Lawrence Weiner, Act Up Amsterdam, Act Up, New York, Act Up San Francisco, Rainer Ganahl, Michael Gibbs, Gregory Given, The Ambassadors of Esthetics, Neo Faxism, Seymour Likely, Foundation for Art and Power, Arthur Kempenaar, The League of Dead Artists, Three Millennia.

David Garcia.

Saturday, June 23, 2.00 PM

ART AND AIDS

This was one of the most contentious and interesting debates which took place. Not least because the way in which the ball was organised and the principals which informed those choices, came under close critical scrutiny by some of the most articulate of the visiting participants.

CHAIR:

Sebastian Lopez
(freelance curator and critic)

chair

How do you feel about showing in established museums?

Robert (G.F.)

The only reason that we use museums is because they give us a venue for getting our message across. If the Whitney Museum gives us money to do bill boards in New York then that's what we do. If the Museum of Modern Art wants to give us money that will allow us to work in a public place, if they are willing to do that then we're very willing to work for them, or for anyone who gives us money that allows us to do the work that we need to do. Which is to communicate information about the political, economic and other subtexts that surround the AIDS crisis. Because it's more than just a medical condition.

Eric (audience)

I'm an artist living in Amsterdam. Aren't you afraid that if you use the museum structure in the United States that your work will become a yuppie commodity only affordable by the rich?

Mark (G.F.)

We think about that a lot and most of our work is like performance it's lost after it's made. Once it's been posted on the street or on a bus the object is gone. It lacks the substance of art work in that sense that it can be taken and hung on your living room wall. We try to resist being inside museums.

Adam (gang)

One of the reactions from Gran Fury implied that somehow we could only present our view here as a view of the

United States. On some level I don't know if I agree with that. My work as an AIDS activist has taught me that I need to reach out to the people I'm engaging. And I really wonder about the context here whether there isn't some level of denial.

Since I came, from my first conversations with the organisers there was a reaction of we don't have these problems here. I'd like to hear from the rest of the panel. Because my experience here is that there has been an incredible discrepancy.

There is a debate going on here about whether or not early intervention. Meaning preventative medicine, was in any way useful or helpful and I think in New York we realise that that is a very important thing. It does extend life. It concerns me that that isn't being discussed here and somehow it's descriptive of the way in which the whole thing has been organised in terms of 69 hours I don't know a person with AIDS who could handle staying up 69 hours, or sleeping in a bed upstairs that doesn't seem very helpful to me. I'd like to open the conversation to that. If we want to keep in the art context how can the artists here begin to engage the kind of work that's being done in the United States.

Daniel

As a European artist living in Holland, I don't feel we have these issues of censorship. The national health care is very well set up here. As we don't suffer that much from that kind of problem this means that activism is much slower and weaker here than in America. In America you have all



those problems. Lots of things here are taken care of. You get your medicines for free with no problems.

Adam

But what medicines !?

Daniel

Can I finish? As a matter of fact in the Dutch art scene, or at least in the video part of the art scene, there are very few artists who are concerned with that issue at all. I must be one of the one or two who has done something. So this issue has not reached our art scene because we don't have these problems of censorship to the extent that the Americans have it. We don't have problems of the national health because we have a national health. Those things are very well taken care of here in Europe, well certainly in Holland.

audience

I think that's very delusional. We live under the delusion that we have good health care. We have equal access to negligent health care. We don't have to fight homelessness. We have a welfare state in place from the 50's 60's and 70's which has led to complacency smugness and arrogance. Every time someone goes to America from the AIDS field they go and look and see how things are going on and they come back with the same things they went with. Oh! the homeless, oh this, oh that, and they return feeling even more superior. But here is no access to early treatment here. Where the diagnostic skills are abominable. Where there is not even a continuing medical educational requirement in this country. People walk around with degrees earned forty years ago and haven't opened a book since. They make believe they are professional doctors. It is not all good here. Every one equally subject to the same almost criminally negligent medicine. If you think otherwise I think you're living in a dream world.

Frits de Ridder, artist living in Amsterdam (from the audience)

Mr chairman we are drifting off, wasn't the subject of this debate the arts?

audience

We are drifting off arts maybe but people are not engaged in general because every body thinks that everything is hunky dory.

David Garcia (one of the organisers, speaking from the

audience)

I'd just like to address the issue that Adam raised which was the denial which exists here. I absolutely agree with him. And one of the main reasons for doing an event like this was to convene the discussion, on this subject. And confront those problems of denial.

From point of view as organisers, the whole event is a learning process.

We are all working on a voluntary basis, in this sense we are amateurs, but we are not ashamed of this status. So I just wanted to make that point, that I accept the denial which is present. But that one of the purposes of this event was to confront that denial.

Simon Watney (from the audience)

Can I just come back to the point that was raised over here. Some one just said that raising medical issues in an art forum was drifting away from the subject. This seems to me to be completely symptomatic of the very unfortunate divisions, which are widespread in Europe and which assume you have a culture of AIDS distinct from medical issues.

What we learn from groups like Gran Fury is that culture can play a central role in communicating issues about biomedical power. About the ways in which throughout the European community we boast about having socialised medicine. We boast about having good social services. But our social services and our healthcare provision only ends up by accepting that everyone with HIV will get AIDS. And that every one with AIDS will die. This is a terrifying situation which in some ways is much worse than anything which is happening in America.

Precisely because we've lived, overwhelmingly, with asymptomatic HIV on a small scale in Europe rather than with the horrifying scale of AIDS cases in America we do tend to be complacent here. The role that artists can play in this epidemic is not just producing fancy etchings of people with skeletal faces, and the other kind of dreary fine art work which prevails throughout the European community in the name of art. The point of cultural production in Europe should be to communicate the facts that hundreds of thousands of people will die unnecessarily. A bureaucratic death of red tape. The red tape of our national health services. It can also speak of the failure of government commitment to gay men in particular and drug users. But also

by extension to the rest of the population. This is one of the greatest challenges that any visual artist or any verbal artist can take up. And we have to challenge this notion of something over here called medicine is distinct from something over here called art. That is why the European art world is as fucked up as it is.

Gregg

Not to preempt any of that. But along the lines of criticism of the conference. In the hopes of improving such contexts. The pitfalls of some art about AIDS are reflected in some of the failings of the conference. For example there have been many instances in the conference where technology has been used merely for technologies sake. And I've often felt trapped in a technological formalism. For example where phone links were created on panels where it seemed to me that the sole purpose of having the panel was not the panel itself but the phone link. What was fascinating about the panel was that we the people from New York could speak to people in New York. This had no consideration for the actual content, of the discussion going on itself.

I've often felt, throughout this conference that I've been trapped in someone else's brilliant idea. Which leads me to ask in whose interests has the conference been organised? No conversation I've been in with very fine people has ever manifested itself with some notion of common interests based on the specificity of our experiences. Because the way in which this conference is organised, is based on a utopian notion of a free exchange of information, instituted through technology. A use of technology that is unquestioned, uncriticised, unproblematised. The notion that a universal space can be established through phone links, faxes, and modems. If there is one thing that is established through the kind of work we do is that there is no such thing there. There never has been such a thing as any universal categories, principals, or experiences. In the future I would like to see at all conferences that the interests of the people who have the most at stake be reflected and that there is some acceptance of difference that isn't evened out or erased through some notion of free exchange through some neutral means which remains unquestioned.



Paper Tiger TV New York (from the audience)

I would like to add another symptomatic thing at this conference is that there is a bizarre notion of public or audience crisis that is going on here. So maybe people on the panel could talk about their experiences in terms of building audiences. The different kinds of audiences that their work has so that we can get a little beyond the museum and the gallery and talk about how artists are actively involved in building their audiences, and how that is part of outreach for activism itself.

Gregg

For me the issue is community and the specificity of community, and I hate to keep harping on the conference. But the way that it's chopped up, like television, that it's something that an individual plugs into. To me this destroys community. There is no sense of collectivity. To me the important thing about ACT UP is I get a sense of collectivity of collective fight. I get strength for that fight. If you deny collectivity you deny any source for political action. I mean that is the way our governments work. They divide the bureaus up into a million different parts that you can never address as a whole. So for me the critical thing is community. I think the graphics work that way, in that we can put images on

ourselves that identify ourselves as part of a community, or have graphics that organise us into a community.

Heleen Riper, one of the organisers (speaking from the audience)

Can I make a remark because I am one of the organisers. I think it is always good when people express their reflections on what is going on as David said for us it is a learning experience. But I want to say that living with AIDS and living with HIV is very different in the States than it is in Holland. And what we have tried to do with our Sero Positive Ball, is to focus on living with AIDS and not only in relationship to people who are involved in the HIV community. But more broadly. And to focus on the fact that HIV is a very difficult problem which concerns all of us. In Holland you still find that the problem is only discussed in specific groups. In response this ball has tried to integrate all aspects of living with AIDS. That's why we want to integrate art with science, with theatre and so on. We as organisers are happy that you make your remarks but there is a cultural difference between the States and Holland in how people deal with HIV. You are here with eight or ten people from the states, you have a lot more experience and for a longer time. We are trying to learn from your experiences but we must also find our own way. When I was in New York and

San Francisco I really saw for the first time a fighting spirit. And with our approach we want a little of your spirit to fight but we have to do it in our own way.

Alexis Danzig, ACT UP New York (from the audience)

The good intentions of the conference organisers notwithstanding, I came here to present information about women with AIDS. This is fairly new information for us in the States, and very new information for people in Europe. I just want to say that our workshop was held in the basement with fifty people there mostly women. It was fairly difficult for one woman who is HIV positive, and on crutches to get down the stairs. I just want to reiterate what was already stressed on the panel that conferences like this must be made with the interests of the people who have the most at stake. In other words this conference should look to the people with AIDS, and learn from their experiences. Women who have AIDS in Holland have no services. No services. I think that should be stated.

audience

I am born American living here eight years and it's been beyond me to figure out what our own way is except doing it slower and less intelligently. We use a cultural leaf for our in-

competence. Every time we say "well we do it differently". Well we don't do it! What is our way? You explain it to me what is our way? Our government is —

Heleen

I am not representing the government. And may be there are faults with what we have done but what we have attempted, is to create a process originating from different kinds of perspectives, and to have a lot of variety in our program. In the way we work with people. It is so easy to say that the women's workshop was in the basement. But we have just one building! We had no idea how many women would attend. So try to make this a constructive discussion. We are glad you are here and we like to learn from you. And a little fight in life is always very good. But there are many things that we simply don't know and have to learn. We are aware of this.

Annie Wright, an artist living in Amsterdam (from the audience)

I think that something the Americans here should understand. The situation in Holland is entirely different. There is enormous apathy. I think it took tremendous courage for the organisers of this conference to make a beginning. Yes there are mistakes. Of course. Our audiences are small because most people don't want to hear about this subject. If you talk about AIDS people don't want to listen.

In fact there is censorship here. a very clever form of censorship. It works like this. If you do the "wrong thing" they just ignore it. It simply doesn't exist. That is the most effective possible form of censorship. We are just at the very beginning of trying to build something up so bear with us, help us.

Gregg

Well do what's specific to the context that's the thing. I recognise and respect the interests and intentions of the organisers. I have no interest in critiquing the size of the audiences. Frankly I think you get the most work done in small contexts where people can share information. What I want to talk about is a specific notion of community based work. And the notion of forming an audience. My specific critique forms around certain ways in which this conference has been organised, which could be better employed not informing an audience but shaping an audience.

In terms of outreach in terms of the coincidences of things, there is to

much going on, a kind of ideal of a multiplicity of events. Trying to create a kind of academic interdisciplinary notion of a totality rather than organising along interests. Or creating a situation in which interests could form themselves. I'm talking specifically about a frustration with being here right now, and not being able to form a specific dialogue. Because of the interests in a representation of everything.

Marlon

What strikes me, in listening to people talk about their experiences around the table as compared to the organisers of the conference. This is not so much a critique as an observation. Almost everyone here is in some way directly affected by HIV either they are positive themselves or they are concerned about their status. They know loved ones who are dead, or who are sick or who are positive. We are coming from a spirit very directly involved in our communities. I know that in my work I am addressing a specifically African American context. And in the work its not just to put it out there. In a museum or on television. It is in a way to encourage people to come forth and declare themselves, as black gay men. If they have HIV to, to declare themselves in that way. And to feel proud and emboldened in doing that. I want find out where people are coming from, in terms of their own community space. What struck me is that people were approaching it much more in the sense from the top down. Trying to organise a sense of art and AIDS rather than people being intrinsically intimately involved in the community, and intimately involved in HIV. I am not saying that there is anything wrong with that, but I think that it creates the kinds of problems that we've seen here. I haven't seen the kind of multicultural audiences that I would be especially interested in dialogue with. I know that this is an international community in Amsterdam. I know that there are people who are effected by HIV and AIDS who represent the international diversity of the community here in Amsterdam. And yet I have not seen those kind of people here.

I think that in part reflects, as it often has reflected in the United States as well. The kind of people who are running the organisation, who are creating the forums for discussion. This is not something that can be learned from us as if we are doing it perfectly. Because I see the same kind of dy-

Because the way in which this conference is organised, is based on a utopian notion of a free exchange of information, instituted through technology, a use of technology that is unquestioned, uncriticised, unproblematised

namic occurring in the United States which is why people of colour often don't participate in ACT UP. Are not part of the gay men's health collectives, rant part of the organisations and services. Our forum is directed supposedly to the community. Because the community has not been properly defined in a way that acknowledges the diversity within it. And I see that again in what's happened with the organisation of this conference. This has lead to the level of frustration that we are having here.

Simon Watney

If we are going to develop strategies as cultural producers around HIV and AIDS, we can't afford to start from talking about the epidemic. Obviously HIV and AIDS are as different from Amsterdam to Arnhem as they are from London to New York. There are many overlapping epidemics moving at different speeds, according to different modes of transmission. The situation in Europe is in some ways

simple. There are fifteen million people in Holland. There are less than two thousand diagnosed cases of AIDS. There are over sixty million people in the United Kingdom and just three thousand cases of AIDS. So there is no way that Europeans perceive this epidemic in any remotely similar way to most people from the large cities in America. The difference between New York and Alberkerky is much less than that between New York and any where in Europe, in terms of the experience of the epidemic. For example we all talk about the national health services in Europe, which nation? We talk about public health but which public? These are the kind of deconstructive strategies that are as applicable in Europe as they are in the United States.

Interestingly very few cultural workers in Europe have taken AIDS as their focus for that kind of deconstructive aesthetic. Also of course many artists won't be interested in this kind of deconstructive aesthetic. Because of their own particular investment in state subsidised art production, existing throughout the European community. Which hardly exists in America. The National Endowment for the arts in America has only a sixteenth of the available money even in Margret Thatcher's Britain. Institutionally, epidemiologically, discursively, the differences are gigantic.

Where I think we can have genuine dialogue is to try and respect those differences and how we can work from here on to try and raise levels of awareness, about HIV and AIDS in the context of all the other divisions, of class and race in Europe. Even the phrase "people of colour" I can't talk about people of colour in London. I'd be locked up. The whole conceptual framework for thinking about these issues is so radically different. Quite seriously, people who talk about "people of colour" are racist in Britain. No black person or white person involved seriously in ethnic and racial issues can use that language. We have to find our own ways of communicating the grotesque inequalities of health care provision within and between different communities, as they are highlighted in relation to AIDS. In Europe as has been pointed out repeatedly treatment care is woefully behind that of people who are fortunate enough to be diagnosed in America. Why is the life expectancy of gay men with AIDS in New York approximately twice that of gay men with

AIDS in the European community? This is a disaster in Europe a complete disaster. We have wonderful counselling and therapy, we have wonderful hospices. We have everything laid on for people who are about to die. But we have absolutely no acknowledgment whatever about the way socialised medicine is overall barrel with a gun of the pharmaceutical industry at its head.

These are issues which artists can deal with. These are issues which I think artists should be dealing with. What we see in AIDS activist aesthetics is the most remarkable political art, given the difficulties of that phrase, since the work of the thirties. Of course the Russian revolutionary art leading up into the twenties. It seems to me that it is on that analogy that we should be looking at Gran Fury's work. How do complex ideas get made accessible to large complex societies? Gran Fury offers Europeans amazingly sophisticated but at the same time accessible strategies for pointing out the murderous hypocrisy practised in the name of the national health services of the European community, not only in relation to AIDS. There is a great task here for cultural workers. But we won't understand where and how we can work strategically if we imagine that our situation is the same as that in America.

Heleen

I have a question for Marlon, I don't know if I have interpreted him in the right way but you told us that the people who are here from the States now are all involved from their own community, and from the loss of their own friends. That story is the same for us all. To have HIV or to have friends who have HIV is not a possession. There is something called HIV its an individual, its a social, its a cultural problem. It concerns all people. You cant say that its my problem alone or its your problem alone. Did I interpret you correctly?

Marlon

I agree with that, I wholly agree with that. but what I see is that the people on the panel are so directly involved in community organising and involved in community organising because they feel themselves immediately threatened. As oppose to sensing a general threat because these people are part of humanity. Because this virus directly threatens them it moves them to create work which addresses the

community in a way in which they know they will be able to catch the community's attention and to draw them in. What I've been frustrated by is that without the number of Americans here I would really have no one to talk to. For me that is a frustration in a double sense because I wanted to talk to more than Americans, in coming to Amsterdam. I wanted to talk to other people, working if not in the arts then in relation to HIV and working around HIV issues and that by in large hasn't happened.

David

As Marlon addressed me directly earlier I feel I should respond, on a more personal level. To tell you my story of how I got involved with this event. Just under a year ago I was at a funeral of a close friend of mine who had died of AIDS. I went home feeling very depressed, frustrated, and impotent. Once home, I just turned on the TV and by coincidence there was a program from the BBC's late show in which Simon Watney had visited New York and shown a cultural community which wasn't silent about this subject. And I was immediately struck how in comparison we in Holland were completely silent. There was simply nothing. I had no idea what to do with that awareness but later I met Caroline Nevejan, a programmer for this building, (she is the head of our team, a woman of whom we are all very proud). She told of her desire to organise an event that would convene some sort of discussion.

Michael T.

Can I also come in on a number of things regarding the organisers. I've been involved in this conference from basically an anti aesthetic point of view. In that I've been involved with the technology, the setting up of the links and providing information and providing software programs. Frankly as a person with AIDS I don't give a fuck about what your motivation is for getting involved I'm just happy that you are involved and doing something. That's the first thing. Secondly, the structure of the technology here is such that its been interfaced down to a level of pushing buttons. So people can put up information anonymously if they decide to do so, or with their name on it. They can get information that's coming from activists in San Fransisco, they can get information from Simon Watson's space in New York. I'm all for this exchange of information.

The fact that the structure of the proceedings is a little strange is just a cultural difference. And I chalk it up to being parallel with cabaret Voltaire, I don't understand everything that's going on and yes as a person with HIV infection and asthma and a number of other difficulties I have problems going up four flights of stairs to get to my room. These differences in architecture and culture are just differences and you have to accept them for what they are. And thirdly on the technology note what will come out of this conference eventually is that new sources of information are being established in Europe and in America. New links between Europe, America, Asia, South America are being established. We can exchange and share information and that I think is reason enough to support the organisers of this conference.

Gregg

If these links are being forged which I hope they are, I think that's fine. But there has to be some kind of questioning of this notion of free exchange of information, without any interest or agenda behind it. Although I've had an enormous amount of pleasure in sending information back to San Francisco I haven't been involved in a way in which it can be put to use in any way.

I always question technology in terms of its use and recognise that its not developed by people who function in my interest. Therefore its very difficult to figure out how to use it in our interest even though we should.

Usually it serves the interest of technocrats etc, computer hackers breaking in to government computers and stealing things I'm all for that. Breaking into networks or guerrilla satellite ventures I'm all for that. But the question before us is not so much how can Gran Fury be established in Holland but what can Holland do in learning from the experience. What can Holland do in the interest of those who live in Holland. What's interesting about presenting this work in a lot of places. It doesn't work for instance when someone wants to say establish a Living With AIDS program (a weekly program for Manhattan cable TV) specifically some where else if its not benefiting or not working in the interest of the community for which its developed. The only reason Living With AIDS program works for The Gay Men's Health Crisis is because we have the resources. And a community that needs access to specific information that can be provided for television. Now I'm sure that need exists here but

the set of questions are what are the interests? What are the goals? What are the needs? And perhaps then what follows is how do you do it.

Mark

One thing that I feel very strongly, as an American and living through ten years of the AIDS crisis is that looking the Dutch and saying we were in this place, in America a number of years ago. And thousands of people have died. So part of what we are saying as activists is that you don't have the time to have discussions about this. You have to start doing work immediately. Cultural workers have to start doing work immediately. People have to start to take control of the situation. If not people are going to die needlessly. This is the point that everyone can work on. This can be contained. But if people don't do the work. And don't address the issue and keep saying well its bad in America but its not that bad here. Well it will be bad here! Yes Americans are being hysterical. We're being hysterical for a very good reason because it can happen here unless you take control of the situation and do something.

Adam

I feel like we've picked on the organisers. I just wanted to say that I have seen really incredible things happen here. Alexis's Women and AIDS panel was a really beautiful thing. I think women are walking away from that panel and their going to do something tomorrow. If we've just four people who are going to go out and do something that's incredible.

Gregg

There are other things on this panel which would have been interesting to bring up. Memorialising work took a bashing to some extent which I don't think is necessarily fair. What I've learned in New York is the multiplicity of work the many different kinds of work that are being pursued are accumulating into a very powerful force. The only criteria I think there should be for AIDS work is that it should be made honestly that it shouldn't be removed for any reasons of objectivity, or academic reasons. It should be about what one has at stake, truly in the epidemic. If it is true, which I think it is, that every one has a stake, then the work should be formed along those lines, and those interests.

Michael T.

Just to point out the cultural differences which exist between the West and the East coast in the United States. Gran Fury is exhibited in museums in New York. On the west coast in our community art gallery in the city of Los Angeles they put on an exhibition for which, in the beginning, the sole requirement for being included in this exhibition was that you were either dead from HIV or you were diagnosed positively with HIV.

This exhibit was put on and is probably closing this weekend and contains work by five and six year old boys and girls and their experience of AIDS. This concept behind this exhibit was presented to me in December/January of this year. I immediately reacted by firstly providing them with material to read, October magazine and so on. And trying to get this curator a well intentioned straight woman to pay attention to what she was doing, which was exploiting children. I wrote letter after letter she involved more aspects of the community, yes. Including some self proclaimed AIDS activists in Los Angeles. She expanded the scope of the program to include people who were living with HIV. Or people who were just making art about HIV but it still had this focus of Los Angeles and when she couldn't get enough people she started calling people in from San Francisco and Toronto, and other areas and representing them as people from Los Angeles. Eventually what it evolved into was myself, my lover and Maurice Kite who is the chairman of the Human Rights Commission the county of Los Angeles being the only people in Los Angeles who were opposed to this exhibition, of children's art work about AIDS. Work by dead artists who had died of HIV infection who were presenting monochrome field painting, work that had absolutely nothing to do with AIDS, in the context of it being work about AIDS. ■■■

SEXISM REARS ITS UNPROTECTED HEAD



**MEN:
Use Condoms
Or Beat It.**

AIDS KILLS WOMEN

SPRING AIDS ACTION '88: Nine days of nationwide AIDS related actions & protests.

23 Jun 90 22:38 GMT

REPORT ON THE WOMEN'S SEXUALITY WORKSHOP

On the 23rd at 17:00, Alexis and me, together with another 20 women, had a workshop about women's erotic and safe sex.

Because we had a quiet room where we had the chance to talk intimately, we could discuss freely about various things like: how to put on a condom, how to make oral sex safe (with a square piece of latex e.g. dental dams), to use lubricant with nonoxical 9, how to use a dildo, which body-fluids are contagious, etc. We also talked about the fact that it is impossible to retrieve the background of your various sexual partners and so came to the conclusion that it's best to have safe sex. The fact that there were as well lesbian as heterosexual women helped us to look at the problems that occurs in both situations, e.g. in the community of lesbian women in Holland the fact that Aids can also influence them is still not acknowledged. In the heterosexual community it's maybe worse because people still don't fully believe that it will affect them if they have, so called "normal sex". Even though cases are known of heterosexual women being contaminated with HIV by so called "normal sex".

Another item was that we as women need to emancipate e.g. free choice of partner, frequency, the right to masturbate, the right to talk about your sexual needs and wishes incl. the right to say NO, the right to have safe-sex when you are HIV-infected.

All in all it was really a warm discussion and we came to the following conclusions; Women should properly educate themselves about their body-functions, there should be research done about women and HIV as well on medical as psycho-social ground, in Holland we need safe-sex education throughout the country for women,

women with HIV should stand up for their rights, there should be psycho-social workshops for women with HIV/Aids, we try to find a manufacturer to produce latex squares for oral use, there should be a meeting place for women with HIV/Aids to talk and discuss with each other, women should have contact on an international bases, we will try to convince the NCAB (national committee fighting against Aids) of the necessity to announce coming World Aids Day in the name of WOMEN (as in Holland they changed the subject of World Aids Day)

I would like to thank hereby all the women which were present at the workshop and everybody who is fighting for the rights of women with HIV/Aids. I also hope that Minister d'Ancona can help us to make our wishes come true.

With Love,

Michèle Malik.



READ MY LIPS



KISS IN

Friday, April 29:

- 9:00 pm March from Christopher & West Sts.
- 10:00 pm Rally at Sheridan Square
- 10:30 pm Kiss In at 6th Avenue & 8th St.
- 11:30 pm Tracks—ACT UP/ACT NOW Fundraiser

FIGHT HOMOPHOBIA: FIGHT AIDS

SPRING AIDS ACTION '88: Nine days of nationwide AIDS related actions & protests.

Gay Day

Friday, June 22, 1.00 PM

"HIV world-wide

CHAIR:

Maria Paalman (SOA, -
Foundation on Sexually
Transmissible Diseases -
Utrecht)

GUESTS:

Frits van der Hoeven
(Royal Tropical Institute
Medical Coordination
Secretariat, Amsterdam)
Dr Abbas Kakembo
(Public Health
Service, Kampala-Uganda)

Jurgen Kurras (Consul,
Amsterdam).

Sue Lucas (UK NGO
AIDS Consortium for the
Third World, London)

Shylama Nataraj
(publicist & social activist,
Madras)

Veriano Terto Jr. (ABIA -
Brazilian
Interdisciplinary Ass. on
AIDS, Rio de Janeiro)

With intervention from
Kigali (Rwanda) and
Bulawayo (Zimbabwe) by:
Dr Guus Tasseron
(Swedish Children Fund)
and Dr Bart Wolf (Central
Hospital, B'wayo) and
local groups.

"HIV world-wide: One Problem, Different Means, Diverse Solutions?"

HIV infection may know no borders (whether political, social, or otherwise), yet it are dependent and stigmatised groups in both North and South who appear to be hardest hit: men with homosexual contacts, drug-users, prostitutes, and ethnic minorities in the North, and those who are involved in, but also very vulnerable to, the modernising process in the South, such as migrants, refugees, people selling sex, transport workers, and military personnel. Wealth and social position determine all over the world one's access to medical care and chance of survival. Specialists from South and North will try to disentangle the complex mechanisms of inequality and dependence, ignorance and discrimination.

The following statements were submitted:

By Bart Wolf:

(1) AIDS should indeed change our world or better our culture. The AIDS virus fell on fertile ground in our world-wide culture, where everything and everyone become a commodity to be sold and consumed. As long as women (and less often men) have to sell their bodies to make a living for themselves and their families and as long as men measure their standard of living through the number of partners they have sex with, the AIDS epidemic will have a fertile breeding ground.

(2) The medical community reacts to AIDS as with other epidemics: it looks for the magic bullet. It has not learnt from the past when epidemics disappeared, not so much because of medieval interference, but because of socio-economic and cultural changes in society.

(3) People already infected with the AIDS virus need a fair social deal from society. They should engage themselves in activities to prevent the fur-

ther spread of the AIDS virus. In return, all possible medical, psychological and social assistance should be offered to them. However, this should be done on the basis that assistance can only be called 'good' if it is available for everyone and must be called 'bad', if it is available only for a few privileged members of world society. On the other hand, the path of forceful restrictions or treatment of the few, with neglect of the many, will lead to feelings of anger and revenge and ultimately encourage the further spread of the AIDS virus.

By Dr. Abbas Kakembo-Luberanga:

(1) Out of about 159.000 cases reported to the World Health Organisation (WHO) by June 1989, 25.000 cases (15.7%) were from Africa. The prevalence of HIV infection in some countries, like Uganda, Zambia and Zaire, is between 5-10%. It is estimated that up to 250.000 people could have died of AIDS world-wide by now and a figure of 750.000 globally is estimated for the year 2000. The disease is not yet stable, but continues to spread into previously non-infected areas. For instance, in West Africa it increased from next to 0% to 4.6 % between 1987 and 1989.



The main mode of transmission in Africa has been and remains heterosexual intercourse in over 90% of cases. The epidemic therefore inevitably stimulated an active review of the African traditional and cultural "sex networking". Our social values and social esteem are definitely at stake as already some countries are legislating against certain forms of marriage and/or heterosexual relationships. Thus individual and cultural freedoms are threatened. So is the well-known African sexual prowess. An estimated 85% of cases of AIDS occurs between the ages of 15 years and 45 years. This is Africa's most important socio-economic group. The average life expectancy at birth in Africa is below 60 years and about 70% of the total population are below 15 years and childbearing women between 15 and 45 years. Clearly the AIDS epidemic in Africa is striking a young population. Who then will build the future and how about the present?

(2) The commonest cause of death in Africa are communicable diseases such as malaria, tuberculosis, measles, tetanus, etc. They account for about 70% of the deaths. The AIDS epidemic affects this group of diseases by only making the situation worse. It therefore seems to me that Africa should have a well-organised regionally based AIDS programme which will be able to:

- (i) Review and make appropriate recommendations regarding the social/cultural implications of the AIDS epidemic.
- (ii) Co-ordinate the different national programmes because of the uniquely similar demographic, cultural, socio-economic and political backgrounds cutting across the African countries.
- (iii) Present the African point of view and collaborate with the rest of the world through the WHO.
- (iv) Co-ordinate research-oriented activities such as Treatment and Epidemiology.
- (v) Co-ordinate integrated activities in the management and control of HIV/AIDS and other communicable diseases.
- (vi) Handle sensitive issues such as HIV testing for purposes of travel, employment, study, etc.

We must remember that the AIDS epidemic is not only a health care crisis

but a socio-economic and welfare crisis. United we stand, divided we fall.

By Guus Tasseron:

(1) about discrimination:

Why do citizens from African countries need a medical declaration that they are not sero-positive order to visit almost all European countries? The automatic presupposition that black people from a Central or East African country might have AIDS, is a nasty experience for a lot of people visiting or studying in Europe.

(2) about help:

In politics - world-wide - there is a lot of attention into the research (& the epidemiological treatment) of AIDS and into purely medical aspects in general. Why is there no social policy for the victims and their families, which can be translated to the national level?

What is the families reaction to having AIDS and how do they react to children after their mothers dead? How do AIDS patients react on their environment, do they organise themselves, or does one seek anonymity by leaving their families and going to live in a big city?

How do AIDS patients deal with their work and work environment?

By Jurgen Kurras:

(1) In order to realize the difference in the approach of AIDS- education and -prevention between the so-called 'Western' countries and the developing nations in the Third World, we have to look into the un-outspoken taboos still existing in the developing countries:

- taboo on sexuality
- taboo on prostitution (sex tourism)
- taboo on homosexuality
- taboo on information concerning HIV infections, and
- taboo on AIDS prevention.

Only the drug problem is getting more and more open for discussions and proposals for preventions are being aired.

I feel that the above-mentioned taboos, which of course are part of the cultural heritages of people and tribes, cannot be removed in a very short period, but can be adjusted little by

little with good information and educational programs.

By Sue Lucas:

(1) Vulnerability to AIDS and HIV is closely linked to economics and resources. Developing countries with weak economies and few resources are likely to be more affected by the epidemic than richer industrialised countries.

(2) Vulnerability to AIDS and HIV is increased by inequality, both in general and within relationships. In general, powerless sections of the society - often women - are exploited by richer sections. Where this exploitation is sexual, HIV will spread. In relationships, where one partner is weaker she/he cannot insist on safer sex and is vulnerable both to infection and blame.

(3) Fragmented societies are also vulnerable. HIV itself contributes to fragmentation, creating a vicious circle of

It has been estimated that in Bombay alone that of a hundred thousand commercial sex workers, fifty thousand are infected. These are official statistics so the real figure might be much larger"

discrimination against minorities and marginalised people. People who may be vulnerable are driven to deny their vulnerability and are therefore unable to seek help - thus increasing the likely spread of HIV.

(4) Women are increasingly vulnerable when economies decline, as is happening in much of Africa. Without access to employment, strategies for survival may depend on multiple relationships.

(5) Children are particularly vulnerable because of their dependency. Those who are infected are dependent for their care on mothers who are likely to be sick themselves. Those who are not infected may be not only orphaned but also discriminated against. This will affect both mortality rates.

By Frits van der Hoeven:

(1) In response to the growing Aids epidemic especially in Sub-Sahara Africa, a growing amount of funds meant for existing health programs is re-allocated to Aids control programs, thus increasing the present health crisis.

(2) Many leading specialists believe that the 'blessing-in-disguise' of Aids is that it is a white man's disease motivating force for massive research for which an incredible amount of money seems readily available. It is, however, clear that for the Third World potential Aids-victims the blessing will remain a dream

(3) HIV-infection will continue to strike the well-to-do and professionals, but it has already become yet another disease of the poor. The spread of the virus is strongly linked with migration, and poverty is the major force sustaining a male-dominated migration. Eliminating the root causes of poverty will be a strong weapon in Aids control.

(4) No refugee, who is seropositive or does suffer from Aids, should be denied basic rights on this ground, or be excluded from re-settlement programmes.

(5) Selective testing of cross border travellers must, by definition, be discriminatory and therefore unacceptable from a human rights perspective

Chair

In the Western World we are not used to infectious diseases being fatal anymore. On the other hand in the developing world there are still many infections which lead to death. So for the developing world, the perspective is very different from our own. In this debate we want to emphasise control and care and not talk so much about education and prevention.

Veriano

In Brazil the first cases were registered in 1982 and 1983. And since then the numbers are increasing without any control. We have officially about eleven thousand five hundred cases of AIDS in the country, especially concentrated in Sao Paulo. The real numbers could be approaching thirty thousand cases, putting Brazil among the countries with the highest incidence of the disease.

In our country there is no such thing as a real nation-wide program of epidemic control. Hospitals, physicians and medicines are scarce. And PWA lack any kind of support, whilst at the same time suffering from all kinds of prejudice and discrimination. That is the overall position of the country right now. Desperate.

Jurgen

I think that the problems which we have heard about from Rwanda are identical with those in the other developing countries. I think that culture which I consider a heritage, is a very important and with Western eyes it's importance is often underestimated.

Chair

So to clarify the issues. On the one hand, Uganda is trying to stem the spread of the AIDS epidemic by using the law to forbid youngsters to have sex before they are 18. But Rwanda says that they do not believe that that is possible. They don't think it will work and they would rather stimulate the distribution of condoms.

Veriano

We have something in common with Rwanda. In Brazil it's very common among young people to have sex. For us it's not an economic but a cultural issue. We have a very sexual culture. Children begin their sexual lives at about ten or eleven years old. Our

attitude is not to condemn such practices. That won't get us anywhere.

We have a very male sexuality, bisexuality in Brazil is very common, for instance. But we are only just beginning to understand our own sexuality.

Sue

I want to focus on the difference between protecting people and controlling their behaviour. I think it's a very fine line between the two when the law is being used as an instrument. When the law is used to control behaviour, and certain actions become illegal. There is then likely to be more discrimination. And this drives the whole problem of HIV and AIDS underground. People won't come forward for help because they have been doing something illegal.

Dr Kakembo

I want to start by saying that Uganda has been one of the most open countries on issues of AIDS. Uganda has led the health and education campaign ahead of the rest of the African continent. In Uganda we are passing a law to protect youngsters from "Sugar Daddies and Sugar Mummies", that is, the enticement of young girls and young boys by elderly ladies and men for sex. This law (if it goes through) is aimed at protecting our youngsters but cultural factors are definitely considered. Health education has been at the forefront of protecting the children. In 1987 the Ministry of Education and the Ministry of Health, with the assistance of UNICEF and WHO, launched a school, awareness program which has now reached and covered almost all schools in the country.

Shylama

In India the first case of HIV was detected in 1986. Much later than many other countries. If there are no "officially" large numbers of HIV in the country, then the government, as well as private organisations, even those working with high risk groups, have not made HIV and AIDS education a priority.

In the last few months the figures have changed drastically. It has been estimated that, in Bombay alone, of a hundred thousand commercial sex workers, fifty thousand are infected. These are official statistics so the real figure might be much larger. The unfortunate part has been that these kind of figures and the scare that HIV

has generated world-wide has led to unofficial policies of detention. These policies are not sanctioned by Indian law and yet they occur time and again. For example, one year ago approximately thirty women who work as commercial sex workers were detained under law because they had been arrested under the Immoral Traffic Prevention Act. Whilst in detention they were found to be HIV positive and, though they completed their period of sentence, some as long as three years ago, they are still under detention. Two weeks ago this number had swelled to more than six hundred and fifty. Then about nine hundred women were sent to Madras which is in the south of India, where I live, from Bombay, under police escort to be sent back to their own families. When the nine hundred women were tested, about six hundred and fifty were found to be HIV positive and they now are under detention too.

Dr Kakembo said earlier about the question of law being used to protect people. This is one instance where the law has been used to harass people who ought to be protected. In India we face a situation where women are more vulnerable. Because we have a fairly inadequate medical system which allows infected blood to be transfused and allows the use of infected needles time and again. And women are more vulnerable to hospitalisation. So whenever you talk about laws you must keep in mind that there are sections of the population, especially women, who are open to even legal harassment.

Chair

It seems that the possibilities to stem the spread of the epidemic are closely related to socio-economic problems, not only in the developing world but also in the developed world.

It seems that the HIV infection is afflicting the marginal groups in all societies. People who are worse off already. Women in the developing world, homosexual men, drug users, sex workers, migrant workers, people who are already stigmatised or discriminated against already. It's often said that AIDS is a poor man's disease. And the situation in the Bronx in New York is not so very different from that of Kampala in Uganda.

Sue

Yes, HIV and the spread of HIV is strongly linked to disadvantaged people. In the developing countries it was

often said that HIV was affecting people who were more widely-travelled and better educated. This is now beginning to change and in Africa, as well, it's affecting the poorer sections of society as well as the richer sections. But in Africa it is compounded because the skills are very rare, there are not many trained people, so that if one of those people is affected by AIDS and dies it will have a much greater impact on the country as a whole, than in developed countries where there are so many more trained people.

This means that that person is not there to train other people. So on the issue of immigration and training, you find that there is a discrimination against people from Africa by governments who would have had them as students. So this is a new limitation on those developing countries that are already affected by AIDS, because they can no longer get the training support from other countries for all of their students.

On the question of costs. If you look at treatment of people with AIDS. The cost in America now is just over \$7000 a year to treat one person with AIDS. If you compare that with the money available to governments in developing countries, health ministry expenditure per person, per year, in some of the poorest countries in Africa is under one dollar. So you can see that Africa will find it extremely difficult to cope with this epidemic both from the point of view of prevention and the treatment of people without an enormous injection of resources from the North. What I think we have to do is to try and think how that can be done.

Veriano

Yes, in Brazil we have this problem but there are differences between south and north that we should take account of. For instance HIV affects marginalised groups in the U.S. for instance. But in that country you have more means to combat the disease.

Jan Visser (audience)

One of my activities is to try to facilitate networking among prostitutes throughout the world. And I would like to ask a practical as well as a political question. Dr van de Hoeven said that one of the problems is whether the developed world is willing to give money to aid the developing countries and, on the other hand, I've heard that developing countries are denying that there is an AIDS problem. So how can

we connect the people in the Western world, who are willing to raise funds, and channel that money to developing countries through those grass roots organisations who can use that kind of money effectively. For instance from what I know of the WHO they can only operate with the approval of the government of any given country so when those governments need to approve such projects I think it will be a very difficult task.

Fritz

We realised in our work that it's very difficult to find sufficient local organisations to receive our money to start effective programs. For that reason I emphasise again that the spread of the HIV virus is strongly linked to migration. And migration is strongly linked to poverty. If we support programs and organisations in their anti-poverty programs, we are indirectly combating the AIDS epidemic. It is a question of how we can identify which organisations are equipped and have the resources, the possibilities and the entrances into the community to have effective programs. It is a matter of time before the people realise what the AIDS problem is.

We know that where the instances are so high that people are losing their relatives to AIDS they are the ones who are motivated. We know that there are organisations in Uganda, in Zambia, where people who are infected themselves are very effective because they are motivated and know what the problem is. Those are the people we can support. Further, I think that it's a very important issue that we support all kinds of development projects which are aimed at alleviating poverty itself.

Chair

Sue, Direct bilateral help from one organisation, one NGO to another in the developing world. Or go through the U.N. organisation?

Sue

I think we are talking about two different levels. We are certainly talking in the first place about direct links between grassroots organisations in the developing countries and the developed countries. And the transfer of resources between the two.

I agree that we have this problem of identifying organisations in the developing countries. But I think that people do respond to this need, we've seen this happen in Uganda, we've seen it happen in Zimbabwe, and I'm sure it

"Brazil got last year about thirty four million dollars for our national AIDS program. But the NGO's and the people living with AIDS saw nothing of this money. We don't know what happened to this money"

will be happening in many other countries throughout the world. That there will be grass-roots organisations responding. We have to keep up those links. So that we know where they are when they emerge. So that we can try and identify them and get resources to them. But I think that is at a very small level because non-governmental organisations don't have enormous resources and they are spreading them very widely. So that's the beginning of it. Trying to identify organisations. Trying to get them going. Trying to get the ideas across. After that you come back to the UN agencies and the World Health Organisation. Although you're right the W.H.O. funds do have to be approved by the aid control programs. But I think that's quite right because you cannot have a lot of different strategies in one country. You've got to have coordination in something as big as the AIDS problem is.

Chair

That's right, W.H.O. is now establishing firmer links with NGOs in order to give them money to continue their work in the developing world. We have slipped into the third issue, which is the exchange of knowledge and experience between the developing and the developed world. And since there is some discussion here as to what NGOs in the developing world can do, I would like to begin by asking Dr Kakembo to tell us briefly about Tasso which is an example of NGO in Uganda?

Dr Kakembo

In Uganda a group of HIV positive individuals came together three years ago and formed an association which is a support group or task force for the support of AIDS patients. They care for each other. And coordinate activities with the central government and voluntary agencies. It is working very well and I happen to have been involved on the evaluation of some of its activities. I think it is a good example of community support through infected individuals.

Field worker from Ruwanda (phone link)

I completely agree with the need for small grass-roots organisations because they are much more effective than large organisations. They are close to the people and can cooperate with them. Pass on knowledge. Where as big organisations have rules coming from above.

Chair

Do organisations such as Tassa exist in Ruwanda?

Field worker

Ruwanda is a small country. But there are a lot of small organisations. And at the moment they are thinking very hard how to combine their efforts. For instance the churches are very active in Ruwanda. I am working with sero positive women and men who in time decided to organise themselves. This organisation is made up of poor people so one of their main problems is of course lack of funds.

Chair

So that takes us straight back to where we left off. By having money channelled bilaterally from NGOs in the developed world to NGOs in the developing world.

I want to ask our journalist from India whether she would like to tell us some-

thing about the possibility of what experience and knowledge from other countries, be it the developed world or other developing countries, would India, who seems just to be starting to control this epidemic, would like to have?

Shylama

To start with, only ten days ago the government of India put HIV and AIDS on its priority list. A ninety million dollar AIDS control program was announced sometime in the first week of June. Up till now India denied that it had a problem and therefore it also denied access to funds by existing NGOs in the country, who may have wanted to work with HIV. But the government has now gone on record to say that it realises that HIV is going to assume something of the nature of an epidemic. And the Indian government is seeking funds. So on the first count, India has officially accepted that there is a problem. And that it is willing to ask for funding by international agencies.

Secondly, in India we have a very strong NGO network. There are many NGOs in the country. Working in many fields. Particular success has been had by NGOs working in family planning and in health. Because family planning is one of the government's most serious priorities. Therefore it has also encouraged NGOs working in this area. Now it would seem natural to try to persuade these NGOs to take on programs which also talk about HIV and AIDS. To focus on it not as a sexual issue, not as a sexually transmitted disease that affects certain communities but as family and health problems, that they can fit into their own program.

The help that NGOs will need more than funding, will be education. In the fact, many people have very little idea about what HIV is. How to react to people with HIV. What are the needs of HIV positive and AIDS patients. I think one of the most valuable things NGOs can have in India today is to be able to learn from the experiences of other countries. Particularly Africa. Where I see that socio-economic patterns are very similar. So if we could have training in those sort of areas, that would be even more valuable than funding. To make sure that the funds are channelled properly.

Veriano

Another problem we have, especially in Latin America, is the corruption. Because we have the government

eager to lay its hands on the funds, for instance from Europe or the US. Brazil got last year about thirty four million dollars for our national AIDS program. But the NGOs and the people living with AIDS saw nothing of this money. We don't know what happened to this money. There is no treatment in hospitals, no preventative information. The government did nothing. The European community will no longer finance the Brazilian government. Because all the money they gave to Brazil disappeared. The same could be said for Argentina, or Peru because we have such authoritarian governments. We have this mask of democracy but in fact we have authoritarian and dictatorial roots which help to promote the corruption in the country.

Chair

Thank you for bringing that up. Obviously a very sensitive issue that is also being brought up in the WHO Global Program on AIDS Management committee that was recently held, where they divide about a hundred million dollars each year for AIDS.

The donors, exactly as you said, are very worried about how much of their money will fail to reach its final destination.

Audience

In, for example, our country we have big banks who got rich exploiting Third World countries. I think it's scandalous that countries such as ours talk about human rights but do very little for the human rights of AIDS patients in underdeveloped countries. I would like to ask how we could force our banks, our rich, to invest money in the Third World countries.

Chair

I would like to ask our consul, who is supposedly knowledgeable about politics, what we do with that question.

Consul

We have to realise that the pharmaceutical companies do not have any moral responsibilities to the issue of AIDS.

All the Western countries have a certain budget. In Holland we have two and a half percent from our budget going to the developing countries. This two and a half percent is divided between the Ministry of Development and the Ministry of Foreign Affairs. The problem is how a government can give help if they receive a request. Without a request the Dutch govern-

ment will not give help. Now governments in the developing countries, especially when asking for money, don't think firstly about medical aid. Their first thoughts are for industrial projects, and I agree with the previous speaker, we have a lot of corruption and nepotism in these countries. So governments in the Western hemisphere are very careful about granting money. But the pharmaceutical industries are a separate issue, they are based on a free enterprise system, they operate on a purely commercial basis.

Sue

I want to speak from the point of view of NGOs which are what I know most about. I think when we are talking about the differences between developing and developed countries we need bear in mind that we are actually talking against the background of economic decline in Africa. This creating more problems and greater vulnerability all the time. We also have to look at the root causes of this vulnerability and whether there is anything we can do about that.

There was discussion from Rwanda about the causes of prostitution. So often prostitutes have been blamed for spreading HIV, but they're put in a position where they have very little choice. There is very little said about the role of the partners of prostitutes. There are particular vulnerabilities of women. We have to try and help them. Because they are often in a less powerful relationship both in society as a whole and in their individual sexual relationships. They don't have the power to demand that men should wear condoms. In addition they are also the carers. So as well as being likely to be infected themselves, they are also likely to be responsible for caring other people and of course their children.

Then there is the whole problem of discrimination. Several of us on the panel are here because we are not in San Francisco. The reason we are not in San Francisco is we believe that discrimination is going to make HIV more prevalent, that we have to draw attention to it. And it's more important to draw attention than to get the information, at this moment. We know it's important to spread information but we believe that stopping discrimination is even more important in the fight against HIV and AIDS.

I think that NGOs can bring these things to the attention of the world as a whole in this case. There is a lot of

"the only persons who will be challenged under that law and excluded under the law is a person who comes in and in very clear unambiguous language states that he or she is homosexual".

attention now on the U.S. immigration laws and that is due to the movement of Non Governmental Organisations. The problem is much wider than the U.S. entry restrictions and I hope that this campaign won't stop when San Francisco finishes. We will continue to draw attention not just to the U.S. but to all the other countries which are bringing in these kind of laws. Finally I think we need to think even more about the effect on children, both on the children who are infected through their mothers infection and on the vulnerability of young adults. But also on the children who are surviving and are going to be left without help, without support. This is going to be a massive problem on already weakened economies in Africa.

Dr James Allan speaking on the phone from San Francisco is asked to comment on the present immigration policy of the US. (Director, Nat AIDS Program)

Office, U.S.A. Dept of Health)

In the United States we have had laws since 1987 that have restricted HIV infected people from travelling freely to the United States. The primary application of the law is for people who wish to move permanently, to immigrate to the US.

If a person is seeking an immigrant visa, our law does require that they be tested for HIV. and if they are found positive they may not obtain a visa. In addition the law applies to all travellers to the US in addition to immigrants, although we don't require testing, the immigration officials do have the authority, if they suspect that somebody may be infected, to require them to be tested or to undergo a medical examination. This of course has had the effect of being very discriminatory under some circumstances and has placed the US in a very difficult position in the world community.

from the audience.

I would like to ask what changes are prepared at the moment to have this law changed?

Dr Allen

What you have to realise in the US is that you have many different players that have an impact on our laws and regulations. The primary law was passed by the congress of the US. It was passed with a very large majority in favour of adding HIV to our list of

dangerous contagious diseases for which we will not allow a person to immigrate to the US.

The departments of the administration that are also involved include the Public Health Service in the department of Health and Human Services, the Immigration and Naturalisation Service and the Department of State. We are trying to get the best medical and public health judgement and then to work with the policy-makers either to amend the regulations in some way or, according to our lawyers, we will need to get the law changed in order to effect a different immigration policy. To enable people to come to the US on a short-term basis to attend conferences like the 6th International Conference, we have made some administrative changes, including allowing HIV infected people to be waived into the country for the purpose of attending a conference or to obtain a ten-day visa to allow them to attend a conference.

Audience

I would like to know if, in addition to this recent law, whether the Mclelland Act from 1952 which in part was aimed at so called sexual deviants, whether that law is also an impediment right now to certain individuals being admitted to the US, either as visitors or as immigrants.

Dr. Allen

That law is part of our total immigration and naturalisation laws. It has not been an actual impediment under the majority of circumstances, since the instructions that the immigration and naturalisation services have issued that the only persons who will be challenged under that law, and excluded under the law, is a person who comes in and in very clear, unambiguous language, states that he or she is homosexual. A person who does not say anything will not be asked about it. Nor will other evidence such as a tee-shirt or buttons or literature found in the luggage.

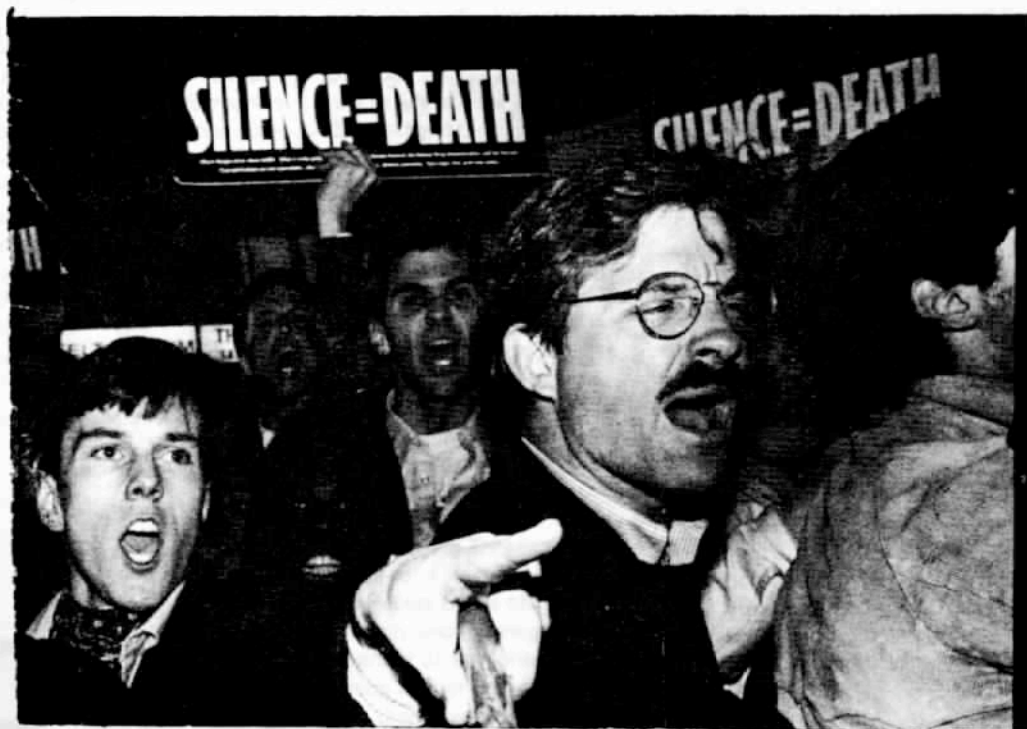
None of that information will be used as evidence against the person, it has to be an unsolicited, very clear unambiguous self-professed statement.

Audience

How do you find out if somebody is HIV? At the immigration boarder, who decides? Is it the immigration officer who decides whether someone should be tested or not?

Dr. Allen

It could happen in one of two basic ways. First, if a person needs to get a visa to travel to the United States, when they apply for the visa, they have to answer a question on the visa application form as to whether they have any dangerous, contagious diseases. Now they are not told what diseases are on the list. And then



there is a parenthesis, "such as tuberculosis."

If the person answers yes on the application, then the consular official will question them further about what diseases and make a determination as to how to handle the situation. In addition if the person does not look well, or if the consular official suspects that there may be a problem, they have the authority to request that the person undergo a medical examination.

The second part would be when the person arrives at the point of entry to the US. The immigration official also has the right, if he suspects that there is a problem, to ask the person to undergo a medical examination. But that is done only under very infrequent circumstances.

Audience

But how do you think it should be done? How would you recognise a person with HIV? I wouldn't.

Dr Allen

Well, I haven't worked at any of our points of entry, any of our airports with the immigration officials, so I really can't answer your question directly from personal experience. As I indicated, I think for the most part it is not applied, though certainly someone who comes in and either does not look well or who for some reason raises a question in the mind of the immigration official could be asked questions, but my understanding is that it's a rare circumstance unless the person initiates it in some way.

Audience

What are members of the scientific community such as yourself doing to combat this kind of discrimination?

Dr Allen

The centres for disease control in the public health service have consulted with a large number of public health and medical experts, about the risk of travellers with different infectious diseases including HIV but not limited to HIV. They have proposed a revision to our list of dangerous contagious diseases. And these experts have recommended to the public health service that on the basis of medical knowledge and public health knowledge, that infectious tuberculosis is the only medical condition for which a person should be excluded on a temporary basis until they have received sufficient treatment that they are no longer infectious.

We are working within the administration and with members of congress to make sure that they have this information and that they understand the implications. We would like to see the situation resolved.

Chair

Do you feel that the criticism and demonstrations here in Europe to the situation now in America, do you think that has any impact on the feelings of your government?

Dr Allen

Certainly many of us believe that this information has reached our government officials in a way that perhaps from inside the government, we can't manage. It's hard to say what impact that will have on policy, but it won't do any harm.

Audience

Doctor, you say you are trying to work from within the administrations. To get this law changed. What do you think is the chance of that? When George Bush refused twice to open the AIDS conference in San Francisco. Instead going to a re election campaign for the honoured senator from North Carolina (Jesse Helms)?

Dr Allen

Since I am not in the political structure, I really can't answer that question. ■■

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