HIV AND AIDS
a brief history

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Frank Rice
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ONE
Rumours

On Friday 5th June 1981, the US Centers For Disease Control at Atlanta, Georgia, published in its *Morbidity and Mortality Weekly Report* a brief technical reference to five cases of pneumocystis carinii pneumonia (PCP) in Los Angeles. The publication, which monitors the American nation's health was, as normal, mailed to all US clinicians. This was the first 'official' public reference to what was later to become known of as AIDS.

It was however hardly the beginning. Many theories abound as to the cause of HIV. Some have it as a virus which crossed the species divide, others state that it is an old tropical pathogen, normally confined to manifesting itself from time to time locally, but which modern transportation carried onto a wider stage. There has been talk of HIV being the result of a medical experiment which went wrong, while some theorists have even questioned the link between HIV and AIDS. Speculation is equally rife about the first manifestations of the current pandemic. One source has the first recorded case of what we now know of as HIV as taking place in Manchester, of all places.[1] So impressed were some clinicians by the symptoms of a man whom they were treating, and who died in 1959, that some tissue samples were stored. As publicity about AIDS mounted in the early 1980's, one of the original doctors involved in treating the case arranged to have the tissue tested and some of it was found to contain HIV. Some doubt has subsequently been cast on the validity of this case. But it is worth noting that there are references to two other instances of serum stored from persons who died, also in 1959, which was later, on testing, found to be HIV positive.[2] In a similar fashion, serum drawn from three members of a Norwegian family who died in the mid l970s was also later found to be HIV positive.[3]

The American gay historian and journalist, the late Randy Shilts, in his epic history of the epidemic *And The Band Played On* records the first case of an HIV PCP death as taking place in Denmark in 1977. He also related symptoms, including one of Kaposi's sarcoma (KS) found variously in France, Germany, Portugal anti Zaire between 1978 and l980.[4] But it is of course to the United States that we turn for the first concrete developments.

The decision to publish an article for the *Morbidity and Mortality Week Report* was taken because a number of American clinicians had already begun to perceive the wider dimension of the cases which they were treating. For example, as far back as September 1979, Dr Linda Laubenstein (who was to emerge as one of the first clinicians to deal with HIV was treating two cases of KS in New York, both of whom shared mutual friends.[5] As 1980 progressed clinicians in New York, San Francisco and Los Angeles found themselves treating more and more cases both of what we would now know of as promdromal, and also of full blown, HIV. As the pace quickened in 1981, two significant steps took place. By late April of that year,

officials at the US Centers for Disease Control had been alerted to what was developing by a curious twist. As Shilts points out, one of its employees was a drug technician amongst whose jobs was the dispatching of the drug Pentamidine for treatment of patients whose immune systems had deliberately been suppressed for operative reasons. The drug technician wrote to her boss in April 1981 pointing out that whereas usually she would expect to get no more than ten requests per year for Pentamidine, she had already received nine requests in the two months prior to April,1981. .The reason for the requests was the treatment of PCP! [6]

And in February 1981. two of the clinicians working in the field, Dr Michael Gottlieb and Dr Joel Weisman of Los Angeles, sensing the urgency of the situation, decided to frame a scientific paper, the result of which was the publication mentioned at the beginning of this chapter in the *Morbidity and Mortality Weekly Report* of June 5th 1981.

The report was simply entitled *Pneumocystis Pneumonia - Los Angeles*, and it stated that all the cases were young previously healthy gay men whose immune systems appeared severely to he suppressed.[7] Such were the small fragmented beginnings of what was later to he known of as the AIDS epidemic.

TWO
The Construction of an Epidemic

1981 was the year in which smallpox was eradicated from the earth. It was also the year during which the few randomised episodes and images of January 198 I had been converted by year's end into the full scale medical emergency which we now know of as AIDS.

The first official public reference to the emerging epidemic (which was alluded to above) which took place on 5th June 1981, elicited little, if any, media interest. However, the publication a month later, ironically on the 4th July 1981, of a second article in the *Morbidity and Morality Weekly Report*, entitled "Kaposi's Sarcoma and Pneumocystis Pneumonia Among Homosexual Men, New York City and California" did, not surprisingly, trigger wider interest. Articles in the New York Tunes and the Los Angeles Times were syndicated throughout the rest of the major US press and the gay press also took op the story.[1]

What had previously been a hidden, stealthy process, known only to a few clinicians, their patients and their friends and families, had now become public knowledge and the first step in the process of constructing an epidemic had been taken. However, in sharp contrast to the media 'blitz' which surrounded the outbreak of Legionnaire's Disease which had taken place in the US in the mid 1970's, the initial media interest in KS and PCP quickly faded although the gay press did keep watch. There was little, if any, attention in the general UK press in 1981 but towards the end of the year, the soon to be defunct Gay News was very definitely "running with the story."

The initial lack of public interest was to be a contributory factor in the growing sense of anger which many of the early AIDS activists in the US, such as novelist Larry Kramer, felt at what they perceived to he the American public's, and Government's, indifference to the emerging crisis. What people such as Kramer, and Paul Popham, the first President of the Gay Men's Health Crisis in New York, objected to was that media attention, and shortly afterwards, Government funds, had been thrown at Legionnaire's Disease, yet there was to be so little public interest or funding, initially at least, in what by the end of 1981 was being dubbed 'Gay Pneumonia'. In this respect it is worth noting that US clinicians, working in the early days of what we would now call AIDS, had to do so against the background of a stringent cost cutting exercise initiated by the Republican Government elected in January 1981.

Yet with hindsight, this parsimoniousness on the part of the US Government was, to say the least, difficult to understand because what the US press was missing, but the activists were being confronted with daily, was the full extent of the crisis as the summer of 1981 passed into the autumn and winter.

Simultaneously with the publication of the "First Article" in June 1981, the US Centers For Disease Control had managed to establish a Kaposi's sarcoma and

Opportunistic Infection Task Force (KSOI) at Atlanta, Georgia. Researchers at the new unit speculated that the epidemic was caused either by some behaviour unique to the then target group or that it was caused by an infectious agent, presumably a virus.[2]

Armed with these hypotheses, the KSOI Task Force moved rapidly to establish a major epidemiological ‘case control' study. Staff from Atlanta fanned out to New York, San Francisco, Los Angeles and other urban centres where the epidemic was showing up, to conduct detailed and intricate interviewing of patients in an attempt to establish what, if anything, in their lifestyles had contributed to their diagnosis.[3] It is an indication of just how rapidly events were moving in the closing months of 1981 that the KSOI’s study’s first hypothesis was already under threat with provisional data collected by October 1981. Not only had some participants claimed never to have used recreational drugs (amyl or butyl nitrate known as ‘poppers’) which were prime candidates for the target group ‘unique behaviour’ theory, but significantly researchers were already meeting a few participants who were claiming never to have had a homosexual experience.[4] These provisional results not only reinforced the second KSOI hypothesis that a viral agent might he implicated in the aetiology of the immune suppression, but were also the first tentative signs that this might not, after all, he a uniquely ‘gay plague’.

The process of ‘constructing the epidemic’ gathered pace as 1981 passed into 1982. As early as August 1981. the first ‘dedicated’ clinic at the University of California Medical Centre in San Fransisco, had been established.[5] In September, the first conference of clinicians and scientists working in the field was held at the National Cancer Institute at Bethesda, Maryland.[6] And by year’s end, the first ‘formal’ scientific papers, on PCP and KS, written by Doctors Michael Gotlieb of University of California at Los Angeles and Alvin Freedman-Kien of New York University Medical Center were published in the august New England Journal of Medical Science.[7]

In contrast to the hurried and ‘informal’ publications alluded to earlier, whose readership was confined to the US, the New England Journal of Medical Science was mailed to clinicians, scientists and other professionals across the globe. As staff read the two articles, academic departments world wide resonated to the sound of jaws dropping!

January 12th 1982 saw the Foundation of the first major activist group, called Gay Men’s Health Crisis, in New York.[8] Not least of the challenges which it, and other embryonic gay health groups, had to face was that by January 1982 an attempt had been made to bring all the presenting symptoms seen in the epidemic under a generic clinical label the homophobic implications of which were not difficult to see. The term coined was GRID (Gay Related Immune Deficiency) but it was out of date before it was first used.[9] This is because definite evidence was now coming in, in rapid order, that persons other than gay men were being diagnosed with so called

GRID. For example, one of the 152 cases diagnosed by December 1981 in the US was a woman.[10] The American Academy of Paediatricians had already been alerted in December 1981 to at least five infants presenting with virtually the same symptoms as adults with the exception of KS.[11] January 1982, there came the first provisional suggestion that a haemophiliac person. transfused with an anti clotting agent called 'Factor 8', had died of PCP.' [12] At about the same time, there was the brief flurry of cases amongst Haitians living in the US. In June of 1982, the first formal diagnosis in a haemophiliac person transfused with 'Factor 8' was confirmed.[13]

It should come as no great surprise then to learn that this sudden 'jumping' of cases into the wider heterosexual world began to elicit wider media attention. The prestigious *Wall Street Journal* caught the mood with an article published in February 1982 entitled "*New, often fatal illnesses turn up in women and heterosexual men*",[14] while the US Congress got in on the act with the first House of Representatives sub committee hearings on the epidemic which took place in April 1982.[15] Equally unsurprising were the first signs of the panic and hysteria which had already gripped the gay world spreading to the wider American society as the Spring of 1982 blossomed.

Nothing illustrates this growing sense of crisis more sharply than the fact that virtually everyone associated with the Kaposi's sarcoma and Opportunistic Infections (KSOI) Task Force's case control study (which was referred to earlier) thought that the evidence contained in the Report implicated an infectious agent as being the cause of the outbreak. Nevertheless, the political need to calm fears was such that when the Report was finally published, in June of 1982, the wording was so hedged around by qualifications and disclaimers that the Report lost virtually all credibility.[16]

History is not so easily derailed. Two events took place in July 1982 which completed the process of constructing the epidemic. With 471 officially diagnosed cases in the US (of whom 184 had (died) and with cases reported in many European countries and Africa, the US Centers for Disease Control was now officially calling GRID an epidemic.[17]

Finally, at a meeting of professionals held in Washington DC on July 27th 1982, it was agreed that the name GRID was no longer viable and after some discussion, it was decided to use the term Acquired Immune Deficiency Syndrome or its acronym AIDS.[18]

THREE
Crisis!

On the 4th of July 1982, one of the first British people to contract what was shortly to he called AIDS, died. His name was thereafter to be ever associated with the history of AIDS in Britain: Terrence Higgins.

Britain appeared to experience a kind of 'phoney war' over AIDS in 1981-83. Certainly *Gay News* was, by the end of 1981, covering the story, but the initial work was to be of little avail because almost as if anticipating the impending crisis, *Gay News*, Britain's first national gay journal, ceased publication in 1982.

As Simon Garfield, in his exhaustive history of Britain in the time of AIDS, entitled "*The End of Innocence*" points out, most British gay men at this time (1981-83) thought that AIDS was "something that happened to other people, something that might never happen here, an American problem".[1] Only very gradually and insidiously was that perception to change.

By the end of 1982, a free sheet entitled *Capital Gay* had replaced the defunct *Gay News* and had started the process of disseminating AIDS information on a permanent and professional basis. At about the same time, what was initially called the Terry Higgins Trust was formed. Gay Switchboard was also to play an active part in this early campaigning.

As the gay movement slowly began to get its 'act together', so also did the wider media, whose reaction initially had been muted and sporadic. In the spring of 1983, the BBC ran two programmes on the subject, which, judging by their impact, have surely earned their place in television history. The first was a Panorama magazine, but it was a second Horizon broadcast, entitled, somewhat melodramatically, 'Killer in the Village' which was to have the most effect. Despite the very careful, factual and non-judgemental mood of the programme, those reviewing it began to display the first signs of that hysterical tone which was shortly to characterise most of British reportage on the subject. Novelist and journalist Martin Amis, reviewing the programme for *The Observer*, averred that "AIDS is a visitation which makes you believe in the devil",[2] while Sean Day Lewis described AIDS as "newly fashionable" in The Daily Telegraph.[3]

'Killer in the Village' also struck home, as, after its showing, STD clinics and Gay Switchboard logged substantial increases in gay men calling or phoning in, worried about the possibility of having 'caught AIDS'. The personal psychological implications of the growing crisis were becoming clear and the result was the convening of the first conference to be held on the subject of AIDS in Britain which took place in London on 21st May l983.[4]

What gave the Conference, and indeed the Horizon programme, their edge and urgency was of course, the increasingly apocalyptic news emanating from the USA.

On 2nd February 1983, the psychologically dangerous 1,000 mark was reached in terms of those diagnosed in the US, of whom 394 had died.[6] By the time that the London Conference 'was convened three months later, the figure had reached 1,361 confirmed cases of whom 520 had died.[6] As the Horizon programme had shown, the American diagnostic growth rate was exponential, doubling every few months. Moreover, at this point in the history of the pandemic, although an infectious, sexually transmissing agent was increasingly being identified as the cause of the disease, nevertheless, nobody was sure. The possibility of other wider routes to infection could not at this stage be ruled out, a point of view which the clustering of non gay cases appeared, in the absence of more sophisticated data, to support.

Not surprisingly, when the London Conference was convened. it was decided to invite an American over to report, so to speak, from 'the front line', In an arresting (if somewhat over used) metaphor, Mel Rosen of Gay Men's Health Crisis, New York, talked about a "Locomotive coming down the track and it is leaving the United States", the prospect of which, Rosen hoped, would make people "very scared."[7]

FOUR

Vulture Club

"The poor homosexuals - they have declared war on nature and now nature is exacting an awful retribution". This 1983 remark of Pat Buchanan, American political commentator and twice candidate (1992 and 1996) for the Republican Party's Presidential Nomination, is prohably as vintage an example as one could find of that sensitivity and degree of taste with which some persons in the media approached AIDS in the mid Eighties.

On the 19th of August 1983. the Terry Higgins Trust was relaunched as the Terrence Higgins Trust as a result of initiatives led by Martyn Butler, Julian Meldrum and Tony Whitehead. 1984 saw the establishment, by Jonathan Grimshaw, Peter Randall, and others, of Body Positive in London, while in Edinburgh, Derek Ogg and others had already established Scottish AIDS Monitor. Few if any of these pioneering AIDS activists had any illusions as to what to expect. The anguish of previously healthy gay men, having suddenly to confront an early death, was becoming palpable, as was that of haemophiliacs now cruelly aware that 'Factor 8', the anti-clotting agent whieh had so immeasurably improved the quality of their lives, was contaminated. The experience of intravenous drug users on realising that they had shared contaminated needles, of those recently transfused with infected blood and of mothers suddenly concerned about their babies' health as much as their own, was harrowing in the extreme.

This was a reality of AIDS in 1983-5. But to the personal crisis of being diagnosed as 'having AIDS' in these times was added an extra dimension, namely that of living out one's diagnosis against the background of one of the most intense, sustained media 'blitzes' in the history of British journalism.

As early as January 1983, the *Sunday People* had told Britain that it faced 'A Killer Love Bug Danger'. By late 1983, *The Sun* was limbering up with references to how AIDS 'flew in' on cheap transatlantic charter flights. By 1985. headlines such as 'A Million will have AIDS In Six Years' and 'Gay Plague Kills Priest' and 'AIDS; Three British Airways Crew Die' vied with equally felicitous story-lines such as 'Tattooists Draw The Line At Gays' and 'Gays Put Mrs Mopps In A Sweat Over AIDS' and 'Scared Fireman Ban Kiss Of Life, in AIDS Alert'. The problem with this reportage was not just its sensationalist and distortive effect, it was also one of intrusion into people's private lives at a time of immeasurable grief The headline concerning the BA staff alluded to above was secured, for example, as a result of the newspaper concerned procuring death certificates and publishing names and addresses of next of kin.[1] Another paper paid to obtain confidential hospital records which identified two physicians in an article entitled *Scandal of the Docs with AIDS* which was published in 1987.[2] Journalists recorded that Stephen Barry, formerly valet to the Prince of Wales, was "trembling with distress" when they called at his home before his death in l986.[3]

In short, the words ‘AIDS’ and ‘Gay’ became so synonymous in at least parts of the media that a classic ‘social panic’ was created in which gay men, who had become used to much greater apparent acceptance in the 1970s, suddenly found themselves, along with others, remarginalised and restigmatised. In an atmosphere reminiscent of the McCarthyite era of 1950’s America, calls to make AIDS a ‘notifiable’ disease, for compulsory testing of all those in ‘risk groups’, and for possible quarantining, grew.

For about four years then (1983-7), there appeared to be a very real possibility that an authoritarian approach to AIDS would succeed here as elsewhere. The Clause 28 controversy could he seen as part of this climate. (“We question those who claim an inalienable right to he gay” (Margaret Thatcher, Conservative Party Conference, October 1987.) In the end, however, the hysteria was eventually to subside as the highly specific way in which HIV is transmitted became more widely known, and a liberal consensus around AIDS was to emerge.

Yet nothing illustrates more adequately the pathos of these times than this ‘red hot’ *Sun* ‘exclusive’ of 1985 which told us that a minister of religion had vowed to shoot his son if he got AIDS![4]

FIVE

The Battle for 'the Cause'

"Today's discovery represents the triumph of science over a dreaded disease." Thus Ms Margaret Heckler, US Secretary for Health and Human Services, in Washington DC on April 23rd, 1984, as she announced the discovery of the cause of AIDS![1]
10

That it took less than three years, from the discovery of outbreaks of immunosuppressive illness in 1981, to the isolation of its cause in 1984, is a remarkable achievement. What is not so edifying is that this breakthrough has to he set against a background of national rivalries, political in-fighting and, in particular, a bitter personal conflict between two men, Dr Robert Gallo of the US National Cancer Institute and Dr Luc Montagnier of the Insfitut Pasteur in Paris.

That AIDS might he caused by a virus had been hypothesised right from the start of the pandemic in 1981, along with the other ætiological explanations which quickly fell by the wayside. But what some perceptive scientists, such as Dr Don Francis, one of the CDC's most eminent epidemiologists (who incidentally had helped in the eradication of smallpox in the 1970's), were already 'on to' as early as 1981 was that the immunosuppression might he linked tn a particular kind of virus, namely a retrovirus.

By the early 1970's, the possibility that viruses might be implicated in the ætiology of leukaemia and even some forms of cancer was gaining ground and it was against this background that Robert Gallo began work on retroviruses. By the mid-1970s, he was among those scientists who first described 'reverse transcriptase', the enzyme which retroviruses need to secrete themselves in the host cells, Despite a setback in 1976 when some of his research findings proved to be wrong, Gallo was able to announce in 1980 the discovery of a retrovirus which caused leukaemia and which was labelled the Human T-cell Leukaemia Virus (or HTLV). (In 1983, another scientist discovered a second variant of HTLV which was named HTLV II).

Because of his work on retruvirus, Gallo was approached by those hypothesising that retroviruses were implicated in AIDS and did some work for them. By November 1982, Gallo's laboratory had indeed found evidence of reverse transcriptase in the infected lymphocytes of AIDS patients but could find no sign of retrovirus. The reason for this is, of course, now understood. When staff added blood drawn from AIDS patients to the stored lymphocytes, the cells were being killed off. Frustrated, Gallo pulled out of this initial AIDS research.[3]

Meanwhile, in Paris, the Institut Pasteur's leading virologist, Dr Luc Montagnier, was already researching HTLV. He and his colleagues hypothesised that the best place for a search of the virus was not in the blood hut in the lymph nodes of those diagnosed with lymphadenopathy. During the winter of 1982-3, work took place at the Institut on the monitoring of biopsy obtained lymph node material, On 26th

January 1983, one of Montagnier's research assistants, Dr Francoise Barre, noted that radioactive tests to detect the levels of reverse transcriptase in her sample was measuring a rate of 23,000 counts per minute. There could be no other explanation for the high count: this was evidence of retroviral activity.[4]

Montagnier's work was published in *Science* magazine in May 1983. By that time he had already run further tests to determine whether his retrovirus was the same as Gallo's. which it did not appear to he. Montagnier determined not to call his retrovirus HTLV and after some delay settled on LAV (Lymphadenopathy Associated Virus). Montagnier had also by this rime come up with an explanation for the slow gestation of the retrovirus, namely that many of its attributes appeared similar to a family of viruses found in animals known as 'lentivirus', or slow acting virus.5

All this activity on the part of the French was not lost on the Americans. Contact had been maintained between the two national teams, and indeed Montagnier had sent Gallo some lymph node material to study. The result was that in spring 1983, the Americans decided, after some procrastination, to return to rerooviral research.[6] Speaking at a conference at the US National Cancer Institute on 11th April 1983, Robert Gallo signalled his return to AIDS research with

these dramatic words "I believe a retrovirus is involved and we're going to prove it or disprove it within a year."[7]

Clearly Gallo had been galvanised by the French and the story of AIDS research from 1983 is not all entirely edifying one. An acrimonious rivalry between the Americans, with their prototypical HTLV, and the French with their LAV had by now developed which diverted attention away from the main purpose of the research.

Having conceded the early start to the French, the Americans were finding it very difficult to catch up. As early as September 1983, the Institut Pasteur scientists had developed a test to detect LAV antibodies in blood, and were even experimenting with an anti-viral drug entitled HPA-23. But attempts to publicise their work were constantly undermined in the US. One American reviewer, for example, described LAV as the 'French Virus'[8] while Gallo himself had been said to dismiss LAV as a laboratory contaminant'.[9] This was because by the end of January 1984, the French had convincing proof that LAV caused AIDS, ironically as a result of American research data. Thirty blood samples had been sent to Paris from the US in October 1983 divided into three groups of ten: from the San Francisco hepatitis B cohort which had developed AIDS, ten from gay men with Lymphadenopathy, and ten from others not at risk from AIDS. The samples were sent blindmarked only with code numbers. The results? Positive LAV antibody tests in twenty of the samples and negative results in ten. In other words, the French had accurately distinguished between the blood of AIDS and lymphdenopathy patients from the blood of non-

infected persons in the samples. The cause of AIDS had been found.[10] Gallo was by this time desperately trying to catch up. He was claiming that the retrovirus was the third variant of the Human T-cell leukaemia virus which he had discovered in 1980 and was calling the new retrovirus HTLV III. By the spring of 1984, Gallo had six papers published in *Science* magazine showing that he had isolated the virus in forty-eight patients. Dr Jim Curran, of the CDC at Atlanta, Georgia, argued that Gallo's retrovirus was the same as that isolated by the French a year earlier.[11]

Proof that LAV and HTLY III were the same finally came in April 1984 through the use of election microscopy. At the same time it was demonstrated that the new 'AIDS virus' bore no resemblance to the two earlier leukaemia retroviruses, HTLV I and ll.[12] Despite the acrimonious atmosphere between the American and French researchers, many American scientists, to their credit, felt that the French now had the right to the naming of the virus, but the US government, with an election pending, needed no encouragement from Gallo to get in first. The result was US Health Secretary Margaret Heckler's statement on 23rd April 1984, announcing the discovery of the 'AIDS virus' as "a miracle" of American medicine and science.[13]

These battles between Montagnier and Gallo to prove priority over the virus eventually led to a compromise at Presidential level between the two countries. Gallo's reputation was seriously to be undermined by newspaper articles which proved that Gallo had based his original claims on a virus sample which he had, in fact, obtained from the French.[14] The Institut Pasteur now quite rightly enjoys greater credit for priority in the discovery of the cause of AIDS.

Britain's role in all of this was not entirely prodigal. In December 1983, Abraham Karpas, a Cambridge haematologist and colleagues published an electron micrograph of a virus found in the blood of a young man with AIDS. Karpas had in fact found the virus after the French, but before the Americans.[15]

The final chapter in this not entirely edifying story took place in May 1986 when an accord between the French and the Americans resulted in the term Human Immunodeficiency Virus or HIV being adopted."

SIX

‘ The Queen Wishes It!’

“The buck is being passed round Whitehall like a hot potato,” wrote the journalist Peter Jenkins with respect to the UK government’s vacillating attitude towards AIDS policy-making in the early to mid 1980s.[1]

It was not until January 1985, two and a half years after the first deaths from what we now call AIDS had taken place in Britain, that the UK government began to respond. As Virginia Berridge, the leading British social historian of AIDS, put it, “AIDS had been an issue for gay men, for clinicians and scientists since 1982.”[2] Obviously, certain minimal statutory requirements had been met by the government: tracking started at the Communicable Disease Surveillance Unit in 1982 and the first official Medical Research Council grants were awarded in 1983. But what was lacking from these early years was a co-ordinated and resource driven response to the crisis. What was to change all that was firstly the increasing awareness of heterosexual spread through the blood supply; secondly the discovery, after the introduction of antibody testing in 1985, of the ‘clinical iceberg’; and thirdly, of course, the growing media blitz of the mid Eighties (described earlier) which had been highlighted by the deaths of such celebrities as Rock Hudson and Liberace.

The first significant move by the Government at a policy making level was the convening in January 1985 of the ‘Expert Advisory Group on AIDS’ by the recently appointed Chief Medical Officer, Sir Donald Acheson, upon whom substantial pressure was, by this time, being exerted by such AIDS clinical specialists as Drs Michael Addler, Charles Farthing, and Anthony Pinching. Although not a high profile body, the absence of any alternatives meant that ‘EAGA’ was able to set an early agenda: against an authoritanan approach, opposition to compulsory testing, and with an emphasis on counselling and confidentiality.[3]

An early success here was Health Minister Kenneth Clarke’s announcement in February 1985 that AIDS would not, for the moment at least, become a notifiable disease.[4] By year’s end, Social Services Secretary Norman Fowler had announced a £6.3 million package of measures, including £2.5 m for a national campaign and the establishment of an AIDS unit in the Department of Health and Social Security.[5]

1986 was to see a dramatic escalation in the policy making response to AIDS to a level which some commentators felt recalled a wartime footing. The information campaign duly began in spring 1986, and ran to December of that year, consisting of national newspaper and television advertising together with a leaflet for the general public and for professionals, and a telephone information line. But this initial campaign was criticised not for its boldness but its obscurity and lack of impact. As Dr David Miller,[6] one of the earliest AIDS counsellors put it, “People will have to he shocked, if we are going to save lives”.
It was at this point, autumn 1986, that Peter Jenkins was moved to feel that the buck was about to stop. In desperation, Sir Donald Acheson finally gained access to Sir

Robert Armstrong, Secretary to the Cabinet and Head of the Civil Service, who in turn persuaded the Prime Minister, Margaret Thatcher, to set up a committee at the highest possible level, sub-Cabinet, and of the need for action across a range or policy areas. In Virginia Berridge's words, 'Mrs Thatcher's involvement, although minimal - one conversation, according to a civil servant, was also crucial. It legitimated a high level response which followed."[7] The cross Department subcommittee. under the chairship of Deputy Prime Minister Lord Whitelaw, had its first meeting on 11th November 1986, which was immediately followed by that event, unique in British history. when a Cabinet Minister, Norman Fowler, stood on the steps of number 10 Downing Street, and exhorted the people to "wear a condom" !.[8]

So, in the winter of 1986, the British Government finally rose to the challenge of AIDS, five years after its emergence. National co-ordination and advertising were in place and substantial suits of money were at last triggered. It was at this point that the famous "AIDS, Don't Die of Ignorance" message was mounted on a nationwide poster campaign, which included a leaflet drop on all UK households. Early in 1987, television advertising, using the ubiquitous tombstone image, and subsequently the iceberg motif, also took up the message.

Among the other initiatives was the replacement of the ineffectual Health Education Council and National AIDS Foundation by the more proactive Health Education Authority and National AIDS Trust. Also, in 1987, the AIDS Control Act was passed, which despite its draconian sounding title, simply required health authorities to submit an annual report of their AIDS related work.

Readers would be heartened to know that according to one source, the stimulus for the crucial autumn 1986 initiative, which finally got things moving, came not as suggested above, from the Chief Medical Officer, Sir Donald Acheson, but from no less a person than the Queen![9] Readers will be equally comforted to learn that, in response to a Parliamentary question about her Government's policy on AIDS given in March 1988, Prime Minister Margaret Thatcher said "I think we've got it about right!".[10]

SEVEN

‘ Gay Men in Suits’

“If I see one more gay man sitting around in a Heal’s chair, I will scream”.[1] This comment, attributed (by Berridge and Garfield) to Virginia Bottomley, at the time Health Secretary, on a visit to London Lighthouse, nicely illustrates why some gay men did not feel entirely confident about UK AIDS policy making.

Two factors must consistently be kept in mind when considering the contribution of gay men to the history of AIDS polities. Firstly, by 1981, lesbians and gay men had grown accustomed to a decade of growing personal self confidence and political acceptance. The coming of AIDS appeared, initially, at least, to threaten these achievements. Secondly, most of the political work done on AIDS had to take place within a culture set by cost cutting and socially conservative ‘family orientated’ governments in both the US and the UK, some of whose members felt not at all at ease with homosexuality. When these two themes are taken together, it explains why many lesbians and gay men felt that they were, in some cases, literally fighting for their lives and for the community which they had helped build up.

In the early years (1981- 85) the “Gay Plague! GRID” mentality meant that most of the political work done on AIDS was gay driven, with London Gay Switchboard and the, at that time, heavily gay orientated Terrence Higgins Trust to the fore. But from 1985 onwards, following the government’s decision finally to commit resources to the fighting of AIDS, gay men were forced increasingly to choose between ‘working within the system’, or outside it.

This emerging interplay between the gay and the straight ‘establishment’ did occasionally produce Some comic moments. For example, one of the members of Lord Whitelaw’s Cabinet Sub-Committee on AIDS policy, set up in 1986, asked, with reference to oral sex, “How many people do that sort of thing?”[2]

Not so comic was the sense that many, although not all, gay men had that they were being sidelined as the battle against AIDS took on a wider dimension. As S Garfield writes, “Work For gay men at THT lost its direction at this time”, whilst the London Lighthouse also experienced similar problems.[3] Nothing illustrates the concern felt by gay men more adequately than the decision taken by Social Services Secretary Norman Fowler to axe, in 1986, the National AIDS Foundation on the grounds that it was ineffectual; what was not stated was that this ineffectuality was due to the very marginalisation of gay men alluded to the above. Its replacement, the new National AIDS Trust, was committed at the outset to campaigning on a wider front.[4]

Another example of the concern which gay men felt at this time, namely that specifically safer sex messages were not being targeted towards gay men, was found in Prime Minister Thatcher’s vetoing of safer sex material, because it referred to anal sex. The anger of many gay men is more easily understood when one learns that it was not until 1989, eight years after the pandemic started in the UK, that government

funded safer sex campaigns targeting gay men appeared. The themes of gay empowerment and the consequent frustration of many gay men within the AIDS movement were to reach a head in 1992 when a number of gay men left THT and set up Gay Men Fighting AIDS (GMFA). Some of the feelings of those times is caught in this comment of Peter Scott, one of the founders of GMFA, 'What made it worse, was that there was a sort of collaborating class of gay men who 'degayed' themselves. It looked like there were gay men in positions of influence, but they were either ineffectual or totally outnumbered by people who didn't have the faintest idea about gay politics."[5]

The position of those who chose to continue to work 'within the system', in other words the 'gay men in suits', was succinctly expressed by Tony Whitehead, first Chair of THT when he said, "It was clear that the button you had to press to get more money was the one labelled 'everyone at risk'"[6]

EIGHT

The Scottish Dimension

For a time in the 1980's Edinburgh was known as the 'AIDS capital of Europe'. This was so because HIV had spread rapidly throughout the drug using community there, through the practise of needle sharing, with the consequent inflation in the infection rate. It also explains why Scotland's initial experience of HIV, drug, rather than gay related, differed from that undergone elsewhere in the UK. By the 1990's however, more typical epidemiological patterns had established themselves in Scotland, with gay men being the largest category of infected persons.

The first cases of HIV infection in Scotland were recognised in 1984 amongst haemophiliacs, while routine HIV testing began in 1985. However, as early as 1982, a number of concerned people had decided collectively to 'monitor' the situation. This was the genesis of Scottish AIDS Monitor, the founding trustees of which were Derek Ogg, Edward McGough, Nigel Cook and Simon Taylor. Medical services have over time been delivered in the Lowland of Scotland through two primary outlets – the Edinburgh City and Glasgow Ruchill Hospitals. In Glasgow's case, Ruchill had been the city's venerable fever hospital. It had been somewhat underutilised since the triumphs against TB and polio in the 1950's but was now pressed back into use. In 1994 Glasgow also opened an outpatient unit, along with a gay men's health clinic, The Steve Retson Project. at the Royal Infirmary. Leading Scottish HIV specialists have included Drs Ray Brettle, Clifford Lean aad Sandy MacMillan at Edinburgh, Dr Tony France at Dundee and Drs Richard Hillman, Dermot Kennedy, Alan Pithie, and Anne Scoular at Glasgow.

The major player on the Scottish AIDS political scene between 1983 and 1996, in terms of advocacy, resourcing and prevention work, was the Scottish AIDS Monitor (SAM) Initially, it operated only in Edinburgh offering basic support services, but by the end of the 1980's, it had grown to include branches in Lothian, Strathclyde, Tayside and Highland. With Maureen Moore as its long term Chief Executive, SAM offered welfare rights, buddying, training and prevention work, The initial thrust of this prevention work 'was toward the heterosexual community but following pressure from the gay community, SAM's Gay Men's Project was launched in March 1994.

Internal tensions led to the end of SAM Strathclyde funding in 1995, with the subsequent closing of its Glasgow operations in the autumn of that year. A similar 'shut off' of funds in Edinburgh, resulted in the closure of Scottish AIDS Monitor in its entirety in 1996. A new agency, PHACE West (Project for HIV/AIDS Care and Education) spearheaded by, among others, the late Ken Cowan, Maureen Moore and John Wilkes, won funding in 1995 for West of Scotland work, while early in 1996, Gay Men's Health took on the role of prevention work in Edinburgh. SAM's work in the Highlands had already been taken over by Reach Out Highland.

Over the years, a number of other agencies joined SAM and its successors in the

fight against HIV in Scotland. There has been, for a while, a proliferation of agencies in Edinburgh such as the Waverley Trust, with its Solas Centre and Milestone House (Scotland's only AIDS hospice) and the sex workers groups Scot-PEP and SHIVA.

Glasgow has benefited from its HIV/AIDS Carers Support Group and from having a branch of ACET, (they also have a branch in Dundee). Also in 1991 an inter faith group was established out of which came the much loved Haven, the drop-in facility at Ruchill Hospital. Glasgow also has the Positive Accommodation Team and recently 'Food Line', and Networks, (an HIV and sexual health education group), have been established in the city.

But no overview of the history of HIV and AIDS in Scotland is complete without reference to Body Positive. Body Positive had been established as an offshoot of the Terrence Higgins Trust in 1984, and certainly, by the end of the decade, an active group was operating in Edinburgh. Centres have also been established in Dundee and Fife.

It was John McClelland. for many years Chair of Body Positive Strathclyde, who took the initiative of establishing the group in Glasgow in 1988. Among other leading members in these early days were Kim Ferguson, Jamie McTaggart and the late Ken Cowan, Jamie Draper and Pat Gangel.

Initially, Body Positive Strathclyde consisted of a Wednesday night support group meeting in SAM's Glasgow offices. But, with the help of the late Steve Retson, by this time SAMs Strathclyde Project Manager, and of Eric Kay, who became SAM's first Gay Outreach Worker ia Strathclyde in 1991, Body Positive Strathclyde's remit widened to include prevention work, complementary therapies, advocacy and the famous Millport weekends.

Eric Kay became Body Positive Strathclyde's first full-time Project Co-ordinator in 1993. A year later, in 1994, the group moved into its own premises in the basement of 3 Park Quadrant. In January 1995 the move upstairs to the present opulent premises took place.

In looking back over the history of HIV and AIDS in Scotland, it should be remembered that, in the Eighties, acquisition of an HIV diagnosis was a far more terminal prospect than may be the case now. There were no grounds for any optimism at all. Moreover, to 'go public', even in a discreet way, about HIV, was a tremendously risky thing to do at this time, with the popular press in full sanctimonious cry, and with the ever present risk of exposure of one's status. Furthermore, the self-empowering and self-enhancing ethos of Body Positive was threatening to some.

When these factors are borne in mind, then the courage of the pioneers of HIV and AIDS politics in Scotland, whether infected or affected is to be applauded: people

such as the late Ken Cowan, Kim Ferguson, Erie Kay, Maureen Moore, John McClelland, Jamie McTaggart, Derek Ogg, the late Steve Retson, and all the countless others who stood up to be counted about HIV in Scotland.

NINE

The Dawn of Hope

The increased use of Pentamidine was one of the harbingers of AIDS. Over a short period of time in the spring of 1981, it was required in increasing numbers of cases in New York, San Fransisco and Los Angeles. This alerted the American medical establishment that an epidemic of immunopsuppressive disease was on the way.

Demand for Pentamidine was to rocket throughout 1981 as clinicians who were desperate to find something to slow down the relentless pace of AIDS, turned to the one drug known to have some efficacy in PCP eases. Throughout the early Eighties, Pentamidine was the only drug known to be of any use.

In the early Eighties, this then was the reality facing persons diagnosed with what we now know of as HIV. There was no test at this time; and it was far too early to speculate on whether or not some people might survive; the only hard evidence appeared to point to a rapid and painful decline to death following diagnosis. The medical profession who were confronted by the shock of a new, insidious and apparently fatal syndrome and by cutbacks to its funding in many countries, scrambled to find an answer. But, apart from Pentamidine, in the early years it was very much a case of trial and error.

Yet from the standpoint of 1997, sixteen years on, the story of science's response to HIV is both an exciting and ultimately very optimistic one. The first breakthrough came in 1986 with the licensing of AZT (zidovudine), a drug manufactured many years previously for purposes other than HIV, which was now found to have some success in slowing down viral replication. However, nobody remotely suggested that AZT was a cure, merely that it gave an additional life expectancy of about nine to twelve months, However, in April 1993, the European wide "Concorde" trial found that AZT, alone, had no real lasting benefit. By this time however, other drugs such as ddI (didanosine) and ddC (zalcitabine) were on the market and when taken with AZT in a 'cocktail' were found to be having beneficial results.

These drugs then, AZT, ddl and ddC, the 'earlier' family of anti-retroviral therapies., are technically known as 'reverse transcriptase' inhibitors because their function is to inhibit an enzyme called reverse transcriptase which HJV needs to convert its RNA into DNA.

However, as early as the mid 1980's, an American virologist, Dr David Ho, was looking at the life cycle of HIV in a different and ultimately very rewarding way than that of his peers. The orthodoxy which had emerged at this time was that, following infection, HIV went into a ten year 'latent' period, and then a variety of factors triggered viral activity. Ho was to challenge this viewpoint. From his research on newly diagnosed persons, he concluded that HIV was active, prodigiously so, in the body from shortly after infection, and that it, HIV, and the body's immune system, were immediately locked into a pitched battle which, in most cases, HIV appeared to

win. Ho and his colleagues had hypothesised that if one could stop HIV's cycle of reproduction, the immune system would be expected to rebound. The problem was that the existing drugs were insufficiently powerful and, in any case, were targeted towards an earlier stage than that which Ho was looking at.

In 1994 however, the first cautious results from research into an entirely new class of drugs were published. These new chemicals, following Ho's line of reasoning, were designed to try to block the actual process of viral replication. Specifically they were programmed to inhibit another enzyme, protease, which cuts viral proteins into smaller pieces so that they can readily be incorporated into new virus.

Throughout 1995, new techniques of investigating viral activity, called the viral load test, began to show startling results from the new drugs. Tests on persons taking the new therapy began to come back with signs of the virus particles in the blood being 'undetectable'. The more traditional CD4 counts were also showing, in some cases, dramatic improvements. Called protease inhibitors, these new drugs were to be rushed into use and their success was announced, with acclamation, at the Vancouver AIDS Conference in 1996.

And so, the early years of despair, and the long fallow period of disappointment have given way at last to some optimism. Of course, this optimism has to be tempered with some caution. Some of the new drugs can have dietary and other side effects. The regimen can be time consuming and we still do not know what, if any, might be the long term resistance. Already the excessive 'hype' surrounding combination therapy, which led some sections of the media to talk about a 'cure' for AIDS has been discounted, but nobody who has observed the turn round in the health of friends can fail to be impressed by the new therapies.

TEN
Homage

Let us **"state quite simply what we learn in a time of pestilence, that there are more things to admire in men than to despise."**[1]

If there is ever a cure for AID, if the 'AIDS years' do eventually pass into history, then this quotation from Albert Camus' ***La Peste*** ('The Plague') could well serve as homage to the courage of those who have died of, and those who have been affected by, AIDS.

In bringing this history of AIDS to an end, it seems appropriate to try to draw the various strands together and to highlight certain themes.

First, the role of the medical and nursing professions has to be acknowledged. A virus which actually shut off something as basic and fundamental as the immune system led an incredulous and disbelieving world to liken AIDS, when it first appeared, to something out of science fiction. There would indeed be no 'quick fixes', no 'magic bullet', for AIDS. For many years, clinicians and scientists found AIDS baffling and deeply frustrating. But some of the best minds in science and medicine have worked on it and, haltingly at first, with AZT in 1986, hut then in full measure with protease inhibitors in 1995, solutions have begun to he found. The story of how science has eventually unravelled the mysteries of AIDS is one of the great chapters in the history of medicine and those remarkable men and women, scientists, doctors, nurses and other health professionals, who have dedicated their lives either to deciphering HIV, or caring for those with AIDS, have to he saluted. And from the vantage point of 1997, one can only wonder how firstly in small numbers, but then in ever increasing strength, an army was assembled of volunteers and professionals alike which has done so much to create the now sophisticated structures through which services are provided and self help generated. The volunteer always quick with the ready word of support at the 'drop in facility',the sharply dressed worker whose laughter cascades through the agency office, the harassed bnt ever smiling administrator, the 'chief exec', balancing the books and planning, always planning ahead, the activist courageously standing up to be counted, the buddy, just 'being there', these are the unsung heroes in the war against AIDS.

It hardly needs restating that AIDS devastated the lesbian and gay community, a sub culture which, by 1981, had grown accustomed to a decade of relative political progress and increasing social acceptability. In the early to mid Eighties, with the popular media keeping up an almost daily barrage of homophobia, lesbians and gay men had to contend not only with the anguish of seeing lovers and friends get ill and die, but also with the chill threats to their communal enterprise, with hints being made of compulsory testing, quarantining and a possible recriminalisation of gay sex. It is to the everlasting credit of lesbians and gay men that at this supreme defining moment in their collective history, they, so to speak, 'held the line', found

in crisis new resources of individual and collective strength and proceeded to fight back and to rebuild their shattered community with tenacity, resourcefulness and above all, pride.

No words can adequately do justice to the love which those affected by AIDS, the partners, spouses, parents, siblings and friends, who ‘were there’ for those who have died, gave.

Every person reading these lines will have their own private, treasured memories, hut the crowning homage which has to he paid, is to those who have died of AIDS, and how many of them, whatever their private fears and pain, managed to put on such brave, courageous and at times humorous faces to the world.

And so now, and whenever the extraordinary tale of AIDS is told, the names of those who privately we mourn and of those who collectively we miss, shall be remembered.

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