

Witness Name: Michael O'Driscoll
Statement No: WITN2384002
Dated: 4th September 2019

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF MICHAEL O'DRISCOLL

I provide this statement in response to a request under Rule 9 of the Inquiry rules 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Michael O'Driscoll will say as follows:-

1. Introduction

1. My name is Michael O'Driscoll. My date of birth and address are known to the Inquiry.
2. This is my second statement to the Inquiry.
3. This statement will look at the role of the Birchgrove Group in providing support and information specifically tailored to the needs of people with haemophilia and HIV.

4. I will discuss my own part in Birchgrove's work, as well as its broader activities, and argue that the group was set up to fill the gap created by the failure of the Haemophilia Society to recognise and adequately respond to the crisis of HIV infection in the haemophilia community. I will also look at the extent to which Birchgrove lobbied and campaigned for better service provision from the MacFarlane Trust, as well as citing examples of the other kinds of projects and support the group provided.

2. Contemporary Context

1. By 1987, the majority of the 1243 haemophiliacs who had been infected with the HIV virus were getting very little in terms of psycho-social, or specialist medical support. Most of us had been told of our diagnosis in 1985, and, in the absence of effective treatments from our clinicians, had been living in fear and isolation, simply waiting around to die. The one organisation that we might have expected to provide us with support and access to up to date information—the Haemophilia Society—appeared to have washed its hand of us, preferring instead to focus its energies on younger, non-infected haemophiliacs.
2. Although there were a number of HIV specific support organisations such as the Terrence Higgins Trust and Body Positive, their services were mainly targeted toward HIV+ homosexuals, they had very little understanding of the support needs of heterosexuals, and none at all of infected haemophiliacs. It was in this context of an absence of support, that Birchgrove was established, initially in Wales in 1987, by a small group of infected Haemophiliacs who were patients at UHW in Cardiff, and subsequently on a national level in the early 1990s.
3. Since no other agency or organisation was providing it, Birchgrove quickly became the only place available for specific information and support for most people with haemophilia and HIV. Birchgrove offered

a forum for people to meet, share experiences and information, become empowered and channel their energies into raising awareness about our needs through setting up a network of local support groups throughout Britain. Whilst the Haemophilia Society had been reticent in challenging medics, or questioning why so many people with haemophilia had become infected with HIV (and later, Hepatitis C), Birchgrove—because we comprised the very people who had been infected, and we were speaking for ourselves—took a much more challenging approach. In effect, Birchgrove filled the vacuum left by the Haemophilia Society, asking questions not only of Doctors and Clinicians, but of the MacFarlane Trust and of government.

3. Personal Circumstance- Infection and Consent

1. When I was first diagnosed with HIV in May or June 1985, there was very little in the way of post-test support or counselling. I think I had a vague awareness prior to being informed—because of reports coming out of America, of cases of HIV infection in haemophiliacs—of links between HIV transmission and contaminated blood products, but as there was no practical information coming from the Royal Free Haemophilia centre, I tended to turn a blind eye. The truth was that prior to learning of my HIV diagnosis, I wasn't even aware that I had been tested. Blood tests from February and March 1984 indicate that I was being tested for viral infections (see pp. 92-93, Document 3.1-3.152 Royal Free Hospital). I can't recall if it was Doctor Kernoff or Doctor Tuddenham who informed me I was HIV positive, but I do recall their awkwardness, even embarrassment at having to tell me. The prognosis was pessimistic—I was told I would go on to develop full blown AIDS, and that I had perhaps two to three years at best.
2. I was very confused and frightened, and tried to convince myself—as there was some uncertainty about the number of people with HIV

infection that would go on to develop AIDS—that I would be one of the lucky ones. When, subsequently, I went back to the centre with my wife, Yvonne, for a meeting with the senior social worker, Riva Miller, we assumed that it would be for counselling. However Ms. Miller was very detached and unempathic, and far from offering us any positive support, having learned that Yvonne was 4 months pregnant, she advised that we terminate the pregnancy because of the risk of passing the virus onto the unborn child.

3. I appreciate that at that time there was a great deal of uncertainty about routes of transmission of the virus, but at this stage Yvonne had not even been tested. Ms. Miller's attitude seemed to be, "here are the facts, now go away, digest this, and come back with the right decision." The implication being that the right decision would be to terminate. This attitude was, to us, indicative of the paternalistic approach taken by Haemophilia Centre staff in general, suggesting that in terms our health and wellbeing, they knew what was best for us.
4. Subsequently, Yvonne was tested, and waiting for the result was extremely traumatic for both of us. Throughout this waiting period of two weeks or so, the only advice or counselling we received, was to abstain from sexual intercourse, and after either a termination or birth, to practice safe sex. When we did find out that Yvonne was sero-negative, we decided to proceed with the pregnancy.
5. In January 1993, having relocated in 1987 from London to **GRO-C**, I was informed by Dr Ismail at the Swansea Haemophilia Centre, that I was positive for HCV (see p. 62 , 1.1-1.228 GP Records – letter from Dr Al-Ismail to Dr Lewis, GP). However, I had been tested without my consent as far back as 1979 for hepatitis, as indicated by comments on elevated Liver Function Tests, by Senior Registrar **GRO-D** at the Royal Free, who notes "Transient slight elevation of AST" (see p.

48, Document 3.1-3.152 Royal Free Hospital. In February 1987, further blood tests revealed AST levels of 60 (normal level up to 40), and a Gamma Gl of 74 (normal range up to 48), indicating "evidence of non A non B Hepatitis" (see p. 18, Document 3.1-3.152 Royal Free Hospital, letter from S. Janes, Registrar at Royal Free Haemophilia Centre, July 1987).

6. In addition, a request for blood tests on 16 November 1981, reveals the presence of the "antibody is/to(?) NANB" (see p. 119, Document 3.1-3.152 Royal Free Hospital). Shortly before I relocated to GRO-C, because of concerns about my abnormal liver function tests and the possibility of "chronic NANBH infection" I was offered a place on an Interferon trial (see p. 22 Document 3.1-3.152 Royal Free Hospital, letter from Dr Kernoff to myself, 6 March 1987).
7. I had little understanding of what non A non B hepatitis was as I had not been told previously that I had been infected, or tested, and because the letter seemed to suggest that the presence of NANBH was only "possible", I declined to participate in the trial.

4. Impact

1. From July 1985 to Spring 1993, GRO-C there was no one outside my immediate family that I could talk to about my fears and concerns regarding my diagnosis.
2. Throughout that time, I had to live with hearing reports in the media of more and more people with haemophilia becoming ill with and dying of AIDS, whilst at the same time trying to hold down a job, maintain my marriage and raise a child, and trying not to think if I would be next. Essentially, we were living a lie—presenting a face of normalcy to our

friends and colleagues, whilst at the same time knowing that this virus, or Hepatitis C, could, at any moment, cause me to become seriously ill.

3. In fact I had suffered a number of illnesses and infections throughout this time, including two weeks off work in 1986, viral illness in early 1988, hospitalisation as a result of an extreme reaction to Septrin, a PCP prophylactic (see p. 63, 1.1-1.228 GP Records – letter from Dr Al-Ismael to Dr Lewis, GP) and various other periods of struggling with rashes, loss of appetite, colds and flu-like symptoms.
4. In all this time we received no social support or counselling and, faced with the silence of the Haemophilia Society, were unaware of any other organisation that provided information or support to people living with haemophilia and HIV. Up to 1993, the Swansea Haemophilia Centre neglected to inform us of the existence of a Cardiff based support group specifically for people with haemophilia and HIV. In essence, we were our own support.
5. We kept as informed as we could, watching news reports, documentaries and the like, about AIDS and possible treatments, particularly for the host of opportunistic infections, but on the whole, the prognosis remained gloomy. Having lived with haemophilia all my life, I'd developed a resilience to bad news and this, coupled with my generally optimistic nature, meant that to a large extent, we were able to get on with our lives. But it was always there, in the back of our minds, the pervasive sense of mortality, and particularly at times when I was ill, it was difficult not to think about the imminence of death and all that I would miss out on—developing a fulfilling career, seeing my daughter grow and achieve all those goals we normally take for granted—her first steps, her first words, starting school, developing her own personality, secondary school, having a brother or sister, and so on. There was no one we could turn to for support or guidance on

practical matters like how to get life insurance, or a mortgage, whether or not I was legally obliged to inform my employers of my health conditions, how to account to them when I had to take time off work due to HIV related illness. More acutely, there was no one to offer us solace and help take the edge off our fears.

5. Birchgrove

1. Things changed in the Spring 1993, when I was put in touch with Birchgrove Wales by Tim Hunt and Nia Wyn Jones, two specialist Haemophilia and HIV social workers attached to the Haemophilia Centre at UHW. Birchgrove Wales had been set up in 1987 by a handful of HIV+ haemophilia patients at UHW. Essentially, they had started out as a group of guys who, having previously been isolated and unaware of other men in the same situation, were brought together by a social worker to chat and share their experiences and concerns. The wife of Paul J, one of Birchgrove's founding members, was largely responsible for getting funding for this social work post.
2. The group began to meet in a local bar on a weekly basis, offering each other peer support and sharing information.
3. By the time Tim and Nia introduced me to the three or four individuals running Birchgrove Wales (a number of the original founding members already having died of AIDS related illnesses), they had already established National Birchgrove and were producing a bi-monthly newsletter disseminating the latest news and information on therapies, research, and political responses to the AIDS crisis in different countries.

4. Birchgrove Wales had an office in Whitchurch and though it received some local government funding, the organisation was run entirely by people with Haemophilia and HIV on a voluntary basis. At the time I was introduced to Gareth, Paul and David, two or three other guys also became involved.
5. I discovered that the people running the group were very well-informed—they were in touch with European and American AIDS support organisations, and were accessing up to date research on treatments and drugs—and they were disseminating this stuff through the newsletter. On a more practical level, they were organising events that brought people together—co-infected haemophiliacs and their families—for social events, helping break down barriers and overcome the stigma.
6. They organised Christmas parties, social events for partners, childrens' events and so on. The reality was that, having lost a number of the founding members, Gareth and Paul needed to bring in new people to help run the organisation, both at a local and national level.
7. For me, meeting these guys was both an eye-opener—I think I had been expecting a bunch of stereotypical AIDS victims, sitting around swapping sob stories and feeling sorry for themselves, but the truth was these guys were proactive, vocal and determined to ask awkward questions and to advocate for better support and treatment—and an entirely positive experience. Up until then, Yvonne and I had taken a very insular approach, keeping informed as best we could, but never discussing AIDS or my diagnosis outside the family, and more or less burying our heads in the sand. Being put in touch with people who had been through the same things we were going through, who had faced the same struggles and had to live with the same fears, was empowering.

8. It took little persuasion on Gareth and Paul's part, for me to become actively involved with the work of Birchgrove. Pretty soon, Martin—a new recruit like myself, one who would become a close personal friend—and I were coming up to Cardiff twice a week to help run the office, plan events, fund-raise, write and edit the newsletter. I became treasurer of Birchgrove Wales and co-editor, with Paul, of the national newsletter.

9. SWISH: At the same time I became involved with Birchgrove, Tim Hunt introduced me to a HIV+ support group based in Swansea. This was SWISH, an acronym for South Wales Immune-deficiency Self Help. It had been set up by two gay men and an ex-intravenous drug user, all of whom were HIV+ and who been brought together by the HIV specialist at Singleton Hospital's GUM clinic. I was the first person with haemophilia and HIV to become involved with the group, and though initially my involvement was as a service user, I later became much more closely involved with the management of the organisation. Partly funded by the local health authority, SWISH provided access to a range of alternative therapies like acupuncture, aromatherapy, yoga, meditation, counselling, as well as information and a safe place to meet and share concerns and experiences with other infected individuals from a diverse range of backgrounds.

6. Advocacy and Campaigning

1. As time went on, I successfully stood for election to National Birchgrove's steering committee, and got to know other key figures in Birchgrove's history and development, men like Cady, GRO-A and Robert James. Together we planned and organised national conferences in Manchester, Birmingham and Bath.

2. These conferences, brought together HIV+ and co-infected haemophiliacs, their partners and families from all over Britain, many of whom had previously been isolated and had little access to peer support or social interaction.
3. The conferences ran numerous seminars and workshops on different aspects of living with HIV/AIDS, covering the latest therapies, safe sex practises, whether or not to have children and the risks involved, sperm washing, adoption, what opportunities there were for education and retraining, benefits advice, how to apply for grants from the MacFarlane Trust etc.
4. They also provided opportunities for people to try out a range of alternative therapies, as well as listen to talks given by leading clinicians in the AIDS field, and to hear the personal stories of others who had been living for a number of years with AIDS or Hepatitis. More importantly, the conferences were a forum for those who had struggled with the implications of AIDS, and those who had lost siblings, children or partners, to come together in an informal and relaxed social setting and feel safe in sharing their stories and experiences.
5. Birchgrove also ensured that we had a presence in the HIV and Hepatitis C sectors to promote the needs of haemophiliacs with HIV and HCV. Birchgrove in Wales had initially shared offices with the Cardiff AIDS Helpline, and later we shared premises with Cardiff Body Positive.
6. At this time I was becoming increasingly involved with SWISH, first as a volunteer—cooking meals on a Friday afternoon, organising social events, buddying new members—and later as a trustee/director.

7. By this time, SWISH was able to employ a full time manager and a volunteer co-ordinator. The manager was line-managed by the board or trustees, though this responsibility was largely delegated to the Chair. In 1996 I was elected to the position of Chair of Trustees of SWISH and took on direct responsibility for line-managing the centre manager.
8. This was a challenging, and sometimes fractious role, particularly when decisions had to be made in the best interests of the organisation, but which members sometimes resisted—an example being to move premises to a more convenient location in the centre of town.
9. Nevertheless, I was able to bring the skills I had developed at Birchgrove, to my work at SWISH, particularly in helping establish an outreach programme to provide support to HIV+ individuals living in more isolated, rural communities in West Wales, where the stigma about coming out as gay, let alone acknowledging one's HIV status, was far greater than in the towns and cities.
10. In addition, the work we were doing showed that even within the gay community there was a stigma toward gay men with HIV from other gay men. Through my involvement with both organisations I was able to arrange a number of partnership events between Birchgrove and Swish, where service users from both would meet to share experiences and provide mutual support.
11. In addition, Birchgrove played a crucial role in raising awareness not only of the treatments and therapies available for AIDS patients, but also of the dangers of many of those early treatments, particularly drugs like AZT and Septrin. We encouraged people to ask questions and to challenge decisions made by clinicians. In my own case, having been put on a course of Septrin to prevent PCP, which, at the time I

had shown no symptoms of, I suffered an extreme allergic reaction which ended up with me being hospitalised for two weeks. After this, I, along with many other haemophiliacs, began to question the efficacy of many non-proven or risky treatments, demanding to be made aware of side-effects, contraindications and any other associated risks.

12. Birchgrove was also the driving force behind the Woodland Memorial. This project, in partnership with the Woodland Trust, saw the Birchgrove Group sponsoring the planting of 1200 trees in 1996 at the Woodland Trust's woodland creation site in Stratton Wood, near Swindon.

13. This grove of trees is a living and lasting tribute to the lives of people with haemophilia who were infected with HIV via contaminated clotting factors. Despite requests for financial assistance with the project, the Haemophilia Society repeatedly declined, citing their own memorial at a church in London. Paul J, Cady and Alan B were instrumental in bringing this project to fruition, persuading HIV+ haemophiliacs and their families to sponsor individual trees, and organising a charity bike ride in order to raise the £12,000 needed to fund the grove.

14. Birchgrove intended that this grove of trees should become a peaceful place for people to visit and remember those who had their lives so profoundly affected by HIV. Not only is it a memorial to those who have died, it also shows the resilience and strength of those who are still affected and living with HIV/AIDS. In May 2004 an Open Day was held at the grove, to formally unveil a memorial stone. The event, which representatives of the Haemophilia Society failed to attend, saw Gareth and others speak about the 1200 haemophiliacs who had been infected. It was attended by more than 100 people, who saw a huge red ribbon—made by Haydn and his wife Gaynor—comprised of hundreds of smaller red ribbons stuck onto a green backdrop, draped

over the memorial stone. This was unveiled by Gareth to reveal the inscription: "Birchgrove - this grove celebrates the lives of the 1200 people with haemophilia infected with HIV".

15. In 2004, National Birchgrove, through Robert James working alongside nurse specialist Sian Edwards, was instrumental in a project that began collecting the life stories of people with haemophilia and HIV. Many of those who had been involved with the Birchgrove group from its inception to the present took part, and their personal experiences and responses to the life-changing events of HIV infection were recorded and stored for posterity in the National Sound Archive at the British Library.

16. In 1998 Birchgrove Wales put together a successful funding application to the National Lottery for an outreach post. This project had been initiated by Paul J before his death, and was subsequently taken on by myself and Gareth. We initially employed two people on a job-share basis—later one person—to go out into the community and provide support and information to people with haemophilia and HIV, and their partners and families who—for a variety of reasons, from fear or illness, to isolation—had little direct access to our services. This programme, which ran for three years, enabled us to get in touch with a number of previously isolated individuals, and facilitate their access to better treatment and support.

17. On a National level, as a direct result of the Manchester conference, individuals from Birmingham, Manchester, Scotland, London, Nottingham and elsewhere across the UK were recruited to work for and set up their own local Birchgrove groups. Mick and Caroline, Paul H, Alan, GRO-A GRO-A and others were crucial in running these new local groups, and also in supporting National Birchgrove to plan and organise future events. Throughout this time strong friendships were

forged through working closely together and having a shared sense of purpose. Sadly, it was also when I first began to experience the loss of close friends, men of my own age, who succumbed to AIDS. The first, and hardest to take, was Paul J, a kind, considerate and intelligent man whom I had known from my first involvement with Birchgrove. He, as much as anyone, embodied the compassion, resolve, and spirit of togetherness and support that Birchgrove was about, and his loss at age 39 was a real blow.

18. After Paul's death, I took over the editorial duties of the newsletter, and continued my participation in the steering group. By this time, we had recruited a number of new guys to the steering group, and they continued to advocate for better treatments from clinicians, more financial support from the Trust and government, and to call for investigations into how we had become infected, and for parity with compensation schemes for infected haemophiliacs in other countries.

7. Haemophilia Society and the Macfarlane Trust

1. Birchgrove came into existence to fill the gap left by the Haemophilia Society. The group was established, first in Wales, and then on a National level, to provide the kind of information service and support network that the Society were failing to provide. When the Macfarlane Trust was set up in 1988, entirely funded by the Department of Health to provide practical support and financial assistance to HIV+ haemophiliacs, their partners and families, the Haemophilia Society appeared to take this as meaning we were now being adequately provided for, and that they could get on with the business of looking after the needs of their 'proper' cohort—uninfected haemophiliacs.
2. Apart from the occasional tokenistic gesture like a religious service up in London on or close to World AIDS day, the very organisation that we

perceived should be campaigning on our behalf, holding government to account for 1200 haemophiliacs getting infected, advocating for better treatments, for compensation, and so on, had turned its back on us.

3. It was common among people involved with Birchgrove, to find that they had experienced the same negative reactions in their dealings with the Haemophilia Society, reactions that only served to reinforce the very real stigma about HIV/AIDS.
4. The implication seemed to be that, because of its prevalence in the gay community, as well as among intravenous drug users, the disease was somehow 'dirty', and that it shouldn't be spoken of in the context of the parents of uninfected infants with haemophilia for fear they would be tainted by association. This neglect was in stark contrast to the sympathy and support later shown by the Society to those people with haemophilia who had been mono-infected with Hepatitis C. The latter were seen as terribly 'unlucky' in being infected with this devastating disease, whilst HIV+ haemophiliacs were perceived to have been lavished with sympathy and cash by the Macfarlane Trust.
5. It was as a result of hearing about the negative experiences of HIV+ haemophiliacs in their dealing with the Haemophilia Society and MacFarlane Trust, that Birchgrove became more involved in campaigning and advocacy. That element had been there from the start, particularly in our lobbying of haemophilia centres for better care and treatment, but through the newsletter and the national steering group, Birchgrove was able to be more vocal on behalf of people with haemophilia and HIV.
6. Because Birchgrove had a mandate to speak on behalf of those infected, their partners and families, the Haemophilia Society had no choice but to engage us in dialogue. Representatives of the steering

group would meet on a regular basis, with the Society to advocate for financial support for events that we would organise. As a consequence of these meetings, the society did contribute to a number of social events.

7. In 1999, Birchgrove was a key player in the setting up of the Partnership Group. This came about after one of a number of MFT reviews which Birchgrove had been lobbying for since 1990. Paul J and Cady were involved in getting the MFT to do one review in 1995, and Cady's partner, Debbie wrote a report on problems at the MFT that helped bring about a strategic review in 1998 or 99, that eventually led to the founding of the partnership group.
8. The group was made up of representatives of the different stakeholder groups registered with the trust, and included representatives from Birchgrove and the Haemophilia Society. Ironically, given that the Trust had been set up to support people with haemophilia and HIV, one of the first events organised by the partnership Group, was an "update day designed to inform MFT Trustees about haemophilia and HIV, and to present the different stakeholders' needs to them."
9. Birchgrove, through the lobbying of the Partnership Group—as well letters written by individual members, including Robert James—were instrumental in persuading the Trust to allow user representatives—that is, registrants—to sit on its board of Trustees.
10. Birchgrove continued to advocate for better financial assistance and a more transparent grant application process from the Macfarlane Trust. Many of us had had similar experiences with the MFT, particularly when it came to applying for grants. Their application system seemed designed to make it difficult, and the criteria for a successful application seemed to be constantly changing. There was also a great level of

inconsistency, with some registrants being successful in applying for specific things for which other applicants had been turned down. A common excuse heard by many registrants, was that there was a lack of funding, and members of Birchgrove who sat on the Partnership Group, witnessed both the Chair and the CEO state on more than one occasion, that the MFT was unwilling to advocate for more DoH funding, for fear it would rock the boat. It was through hearing about a broad range of experiences that we were able to speak with one voice and criticise the Trust through the newsletter.

11. Subsequently, the MFT began a rolling programme of events for haemophiliacs with HIV and their partners, and we were actively involved in their planning and organisation, often speaking or running workshops as well.

12. By 2003 I was combining full time foster caring responsibilities with part-time studies for an MA and was no longer involved with either organisation. I continued to follow the work of both, and later, after Birchgrove Wales dissolved, of the South Wales Haemophilia Group.

13. It was through my involvement with these organisations, particularly Birchgrove, that I discovered I was not alone in my situation, that it was legitimate to challenge the decisions made by clinicians about managing my health, that I could take back some measure of control over my life, and, that by working together with others who had experienced the same ill-treatment and neglect, that we could make ourselves heard.

8. Conclusion

1. Had the Haemophilia Society provided the proper psycho-social support and access to information that people with haemophilia and HIV needed at the time, then it is unlikely that there would have been a need for Birchgrove. As a national organisation whose remit it was to advocate and respond to the needs of all people with haemophilia in the UK, they were in an ideal position to ask questions of the Department of Health about how the tragedy of infection with HIV and HCV through contaminated blood had come about. Not only should they have been asking these questions, but they should have been campaigning for better access to non-infectious Factor VIII treatment for all haemophiliacs, the provision of social work support and access to counselling, access to the latest treatments for HIV infection, and raising of awareness among the general public about HIV and in particular how people with haemophilia had come to be infected.
2. Just as important, the Society could, and should have lobbied government for financial compensation and assistance for people with haemophilia and HIV, their partners, widows, parents and children.
3. Instead, the Society turned their back on us, forcing individuals with HIV to seek each other out and come together to provide our own support and advocacy networks.
4. Whatever its intentions in setting up the MacFarlane Trust, the government's funding of the MFT proved wholly inadequate to the evolving needs of its beneficiaries. Since the Haemophilia Society failed to challenge the MFT on its many shortcomings, some of which—eg, the Byzantine and discriminatory nature of its grant application process—I have cited, it fell to Birchgrove to take up the slack and advocate on behalf of registrants. Some registrants who were active participants in Birchgrove, were treated with contempt by

the Chair and CEO of the Trust, but through the persistence of our Steering Group we did succeed in bringing about a change in attitude.

5. The setting up the Partnership Group, and later, the inclusion of registrants on the MFT's board of trustees, were significant developments in allowing the voices and opinions of people with haemophilia and HIV to be heard.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed

GRO-C

Dated

12/9/2017