

AIDS Activists and Scientists File Complaint Against the BBC over HIV Disinformation

On January 10, 2007, AIDS activists and scientists in the US, South Africa and London filed a complaint against the BBC (British Broadcasting Corporation) over a piece aired in 2004 called "Guinea Pig Kids" that was written and produced by HIV denialists--the people who claim variously that HIV doesn't exist, that it is harmless and not the cause of AIDS, that AIDS doesn't exist, that vitamins and patent nostrums can cure AIDS, and that antiretroviral medications used to treat AIDS are actually the cause of the syndrome.

The inflammatory film and companion written piece on the BBC website misrepresented as "human experimentation" on vulnerable children of color what were in fact crucial and successful efforts to make lifesaving treatments available to desperately ill foster children with AIDS through compassionate use of clinical trials of HIV drugs already approved for adults. Although the film was broadcast over two years ago, an article about it on the BBC website and the video, circulated by HIV denialists, continue to spread false and dangerous ideas about AIDS, antiretroviral treatments, the care provided to children at Incarnation Children's Center, and the importance of making lifesaving medications available to desperately ill children regardless of their family circumstances. The legitimacy accorded these erroneous ideas by the authority of the BBC facilitates the spread of disinformation, which in turn undermines prevention efforts and impedes treatment access, both by individuals and as government policy.

The complaint follows, and provides additional information.

Chitra Bharucha
Acting Chair of the BBC Trust
BBC Complaints
PO Box 1922
Glasgow G2 3WT
United Kingdom

10 January 2007

Dear Ms. Bharucha,

RE: "GUINEA PIG KIDS" AND "NEW YORK'S AIDS EXPERIMENTS"

We are herewith filing an official complaint against the BBC over the inflammatory, deceptive, error-filled and dangerous film "Guinea Pig Kids," written and produced by Jamie Doran, directed by Milena Schwager, based on research by Liam Scheff and Celia Farber, and broadcast in November 2004, and the on-line article "New York's AIDS Experiments" by Jamie Doran, still posted at http://news.bbc.co.uk/2/hi/programmes/this_world/4038375.stm. "Guinea Pig Kids" and "New York's AIDS Experiments" are both misleading, make false and damaging claims, defame the New York City Administration for Children's Services (ACS) and Incarnation Children's Center (ICC), and promote dangerous, pseudo-scientific views about HIV/AIDS and treatments for HIV/AIDS.

We request that the BBC organise an independent investigation into the above reports. Should the film and the article be found to be substantially misleading and false—and we are sure beyond a reasonable doubt that they are—we request the BBC to implement the following sanctions:

- 1) Publish an apology and immediately withdraw editorial support for the video report and the written article.
- 2) Place a link to this apology in a prominent position on news.bbc.co.uk for a minimum of thirty (30) days.
- 3) Remove the text "New York's AIDS Experiments" from the BBC website and place a link to the apology in its place on http://news.bbc.co.uk/2/hi/programmes/this_world/4038375.stm with the accompanying text "This article has been found to be inaccurate and the BBC has withdrawn editorial support for it. We refer readers to our apology."
- 4) The apology should include specific corrections for deceptions presented, most crucially:
 - The horrific claim that denying medications to children with AIDS will improve their health while appropriate treatment will kill them.
 - The implied claim that New York City's Administration of Children's Services, Incarnation Children's Center, Catholic Charities, Columbia Presbyterian Hospital, and the National Institutes of Health effectively conspired to force helpless children of color into inappropriate and sinister "experiments" when in fact they made life-saving drugs already approved for adults available to children living with HIV/AIDS who were in the foster care system.
 - The assertion that the children of HIV-positive Christine Maggiore,

featured prominently in the film, were healthy and indeed “never sick” because she had refused to have them tested for HIV and by extension would deny medication if they were HIV-positive. In fact, Ms. Maggiore’s 3 1/2 year old daughter died of AIDS last spring (see report by Department of Coroner, Los Angeles <http://www.aidstruth.org/ejs-coroner-report.pdf>).

- The misleading photo of a child with a terrible skin condition, shown while the narrator states that Stevens-Johnson Syndrome, a serious rash, is a side effect of AIDS drugs. Despite the implication, the child in the photo was not an ICC resident and no evidence is presented that ICC clinical trial participants ever developed this rash.
- Another photo of a small child receiving medical attention from several masked medical personnel. The narration implies that this image is of an ICC child receiving a tube for medications. The image is not from ICC. Moreover, medical delivery systems that ease ingestion, especially for children, are not inhumane or unethical as the film suggests. Use of such systems is not a punishment for refusing to take medication.
- The implication that only economically and socially vulnerable children would participate in clinical trials. Vera Sherav, a self-described advocate for human subjects, rhetorically asks in the film, “Why didn’t they provide the children with the current best treatment; that’s the question that we have. Why did they expose them to risk and pain when they were helpless? Would they have done those experiments to their own children? I doubt it.” In fact, the medications offered then only through clinical trials were the “current best treatment.” Moreover, her doubt is misplaced. Many parents with terminally ill children are eager, even desperate to get them into clinical trials—this is true for cancers as well as other diseases.

The facts are as follows:

- Most of the HIV-positive children under the care of ACS who were placed on the antiretroviral clinical trials discussed by Doran are alive today because they were placed on these trials. The Vera Institute for Justice, an independent organization hired to investigate these charges, has released preliminary findings showing that the final discharge from ACS was a consequence of death for 15% of the children in care who participated in the HIV/AIDS trials. An astonishing 85% survived and were adopted into families, returned to their own families, aged out of the system, etc. (see: Vera Institute of Justice Clinical Trials Project Progress Report # 5, page 11). Children born with HIV who do not have access to the antiretroviral drugs that ICC children received have a very short life expectancy. A third die by the time they are two years old. Hardly any survive to become teenagers.

- The medicines that were the subject of the trials were approved by the FDA for adults, but at the time the trials began they were not approved for the treatment of children with AIDS pending the determination of appropriate dosage levels—the main point of these trials.
- Children with life-threatening illnesses who are not in state care can participate in drug trials with their parents' permission, giving them the opportunity to access potentially life-saving treatments. In 1988 when ICC was founded, children in state care were denied the right to participate in drug trials. This meant that those with HIV/AIDS would almost certainly die without even having the opportunity to try potentially life-saving medicines. ICC and other advocates for children in foster care successfully campaigned for a change to the law that allowed such children to participate in clinical trials on the basis of ethical principles of humanitarianism and non-discrimination on the basis of family status.
- Doran's characterization of the children as guinea pigs placed in experiments without parental permission is false and misleading. The children in question were the responsibility of the state because for various reasons their parents could not look after them. In the many cases where the parents were alive, written informed consent was obtained. However, where parents were unavailable, the state and the children's institutional guardians had the responsibility for determining what was in their best interests. ACS and ICC determined that the best medical option for the children with HIV under their care was the same as for other children with HIV: to place them on antiretrovirals. But this option was only possible through participation in carefully monitored clinical trials. Otherwise these children would have almost certainly died.
- The trials were terminated in 2002 because the drugs tested were approved and the children participating in the trials could therefore access them directly from physicians without participating in clinical trials. The film presents the termination of the trials as somehow secretive and sinister—it shows ICC staff closing the door on a cameraman who claims to want to ask why the trials ended. In fact, the trials ended because they were successful. The on-line article by Doran, however, claims that the “experiments are still being carried out on the poor children of New York City.” This is false.

A properly conducted investigation into ACS and ICC would have revealed that at ICC, highly competent staff have provided the best care and treatment available to vulnerable children with HIV. Instead, Jamie Doran appears to have pursued a pseudo-scientific agenda. The film's researchers Celia Farber and Liam Scheff as well as Christine Maggiore and David Rasnick who appear in the film, reject the solid scientific evidence that the virus known as HIV is the cause of the

complex immune system breakdown known as AIDS, and that without treatment—the very treatment the children in ICC received through clinical trials— almost all HIV-infected people will die of illnesses related to the disease. None of them have any standing in the scientific community. Consequently, Doran defamed several institutions doing competent and important work. Doran's documentary is ignorant of the ethics of clinical trials, the role of state institutions who look after children and the science of HIV.

We call on the BBC to rectify immediately this betrayal of the public trust by taking the steps outlined above. Please respond at the earliest opportunity.

Yours sincerely,

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Mark Wainberg, Professor and Director, McGill University AIDS Centre, Montreal, Canada and Co-Chair International AIDS Conference 2006

Polly Clayden, Director, HIV i-Base, London, UK

Gregg Gonsalves, AIDS and Rights Alliance for Southern Africa

Andrew Feinstein, Chairperson, Friends of Treatment Action Campaign, UK

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