TAC Electronic Newsletter

By *moderator*
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Summary

- **Global call to action on TB:** TAC, AIDS Law Project (ALP) and ARASA call on clinicians and activists around the world to endorse our demands for improved TB prevention, diagnostics and treatment ahead of the Union World Conference on Lung Health.
  To endorse, send an email to info@tac.org.za with your name, organisation and contact details in the subject line or body of the email.

- **Research shows how to make antiretroviral programmes successful in resource-poor settings**: A TAC analysis of the factors that lead to high patient retention in antiretroviral programmes in sub-Saharan Africa.

- **Andrew Feinstein, chairperson of Friends of TAC, UK, will release his new book *After the Party*: *A Personal and Political Journey Inside the ANC*** on 31 October 2007 (5:30pm for 6pm) at Relish Restaurant, cnr New & Upper Buitengracht Streets, Cape Town. To book, please call Firdous on 021 423 3911 or email: firdous.latief@jonathanball.co.za

- **Submission to Department of Health by the ALP and TAC on regulations relating to the labelling and advertising of foodstuffs**. The submission deals particularly with the need to regulate health claims on foodstuff labels.
  - Link to submission on TAC website

- **Submission to the Panel for the Independent Assessment of Parliament by ALP and TAC:** The submission raises serious concerns we have over the failure of Parliament to carry out its oversight duties.
  - Link to submission on TAC website

- **Memorandum handed over to health officials at Frere Hospital by TAC Eastern Cape:** On 16 October 2007 TAC led a march to Frere Hospital and handed over the memorandum below to Eastern Cape health officials.

- **BBC upholds complaint by activists against programme with AIDS denialist content:** In 2004 the BBC ran a documentary by Jamie Doran called *Guinea Pig Kids*. The documentary contained incorrect AIDS denialists assertions. A group of activists lodged a complaint with the BBC against the documentary and an associated web article. The complaint was initially rejected in its entirety but on appeal, all the key aspects of the complaint were upheld. However, even though the BBC upheld the complaint on 31 July 2007, it has still not published its findings nor has it removed an associated web article.

- **Transcript of former Deputy Health Minister Nozizwe Madlala-Routledge's press conference on 10 August 2007**
  - Link to transcript on TAC website

Global call to action for the 38th Annual Union World Conference on Lung Health

Save lives: Transform TB prevention, diagnostics and treatment

The 38th Annual Union World Conference on Lung Health is being held in Cape Town on the 8-12 November 2007. It is the first time in its 125-year history that the conference will be held outside of the northern hemisphere. This is important as Southern Africa is experiencing an extremely large and deadly TB epidemic, fuelled by a HIV epidemic. The response has been inadequate; new infections and needless deaths continue unabated.

We call on the delegates to adopt a Global Call for Action and Declaration on TB:

1. Every year TB kills more than 2 million people worldwide. In Southern Africa it is by far the greatest killer of people living with HIV.
2. In South Africa, over 70,000 death certificates recorded TB as a cause of death in 2005.
3. Despite regional governments declaring an emergency in 2005, TB control and AIDS programmes in Southern Africa are failing to adequately deal with the twin epidemics of TB and HIV.
4. This inadequate response is no longer acceptable.
5. Current diagnostic techniques and drugs are out-of-date; we need simpler, more effective and accessible tools for testing and treating TB.
6. TB prevention, care and treatment programmes must adopt a decentralized, patient-centred approach with treatment literacy, adherence support and community education.
7. More resources for TB research are desperately needed.
8. Provision of a decent public health system that is based on the right of every person to life, dignity, health and equality is the duty of every state and the advocacy work of every HIV/TB activist.
9. Access to decent housing, employment, social security and nutrition are indispensable to the elimination of tuberculosis.
10. The TB crisis has caused tremendous suffering and generated confusion, fear and stigma. Protecting public health is not incompatible with promoting a human-rights approach to dealing with this contagious epidemic. It requires a plan and community consultation not repressive measures against individuals.
11. Support services for health professionals and allied workers engaged in saving the lives of people living with TB must be researched and funded immediately.
12. This conference must serve as a platform for consensus on key issues related to the treatment, prevention and care of TB, including MDR and XDR TB. We must review and update our national TB and HIV plans and through partnerships commit the necessary resources to begin implementing the following key areas for action:

* Improving infection control
* Getting more people living with HIV tested for TB and people infected with TB tested for HIV
* Integrating and decentralizing TB and HIV services
* Preventing and treating drug resistant TB (MDR/XDR TB)

We demand vision, research, funding, action and activism on TB/HIV and the crisis in public health now!

Join the global TB and HIV March
8 November 2007, 5pm at St. Georges Cathedral, Cape Town

For more information contact:

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To endorse this call please email: info@tac.org.za

AIDS Law Project (ALP)
AIDS and Rights Alliance of Southern Africa (ARASA)
Treatment Action Campaign (TAC)

[END OF GLOBAL CALL]

Research shows how to make antiretroviral programmes successful in resource-poor settings

Important research has recently been published on operational results from antiretroviral treatment programmes. There is emerging evidence showing what factors contribute to successful programmes with high patient retention rates.

- Rosen et al. 2007. *Patient Retention in Antiretroviral Therapy Programs in Sub-Saharan Africa: A Systematic Review.* PLoS Medicine, 4(10).
- Boulle, A. 2007. *Lessons from Southern African treatment programmes.* Presentation to PACT Conference, Johannesburg 2007.
- Smart, T. 2007. A follow-up on follow-up: shifting to a community-based response to improve retention in care. HATIP #90, 31 August 2007.

The above articles collectively demonstrate that antiretroviral treatment programmes can be and are successful in sub-Saharan Africa. The key factors for success are decentralisation of service delivery to community level, patient education and the free provision of drugs and diagnostics. To scale up programmes further, innovative strategies for improving the human resources shortage in health facilities across the continent will have to be implemented.

The review published in PLoS Medicine analysed patient retention in 33 cohorts in 13 African countries. The review contained results from seven South African antiretroviral programmes including Gugulethu, Khayelitsha and Lusikisiki. The findings show that these programme have managed to achieve impressive rates of patient retention, as high as 90.3% after 12.3 months follow-up in the case of the Gugulethu roll-out. Overall the review found that the average retention rate among patients participating in the 33 cohorts analysed was approximately 80% after six months on ART. After two years however the percentage of patients retained on treatment across the continent averages roughly 60% but this average, "masks a great deal of heterogeneity" between cohorts, from 85.4% in Khayelitsha to a disturbingly low 46% in a cohort in Kampala, Uganda. The South African sites all achieved good results.

The survey's authors note that the achievement of an average of 60% retention at two years for antiretroviral programmes in resource-limited settings is an "extraordinary accomplishment", particularly within a global context where adherence to medication for chronic illnesses in developed countries only averages 50%.

Andrew Boulle's presentation presents details on the South African roll-out. Particularly interesting is that pre-antiretroviral treatment mortality in the Gugulethu cohort is 33 per 100 patient-years. Early antiretroviral treatment mortality is 19 per 100 patient years and late antiretroviral treatment mortality is 3 per 100 patient years. 46% of the Gugulethu cohort patients died without ever receiving antiretroviral treatment. In the Free State 87% of patients die before receiving treatment. This demonstrates that much more needs to be done to get HIV-positive patients into programmes much earlier, i.e. before they have developed AIDS. Clearly too many people are starting treatment too late or not at all. On the positive side, seven out of ten adults and eight out of ten children who started antiretroviral treatment are still in care at five and three years respectively. Furthermore, there is emerging evidence from work by

Laubsher et al. (SA AIDS Conference Presentation, 2007) that antiretroviral treatment is having a positive impact on AIDS mortality in South Africa. This can a source of great hope and consolation to health workers, activists and people with HIV across the country.

Factors affecting success

There are several factors that underpin the success of antiretroviral treatment programmes. Key among these appear to be:

- **Decentralisation:** Moving antiretroviral treatment delivery closer to patients positively contributes to treatment adherence and patient retention. This means making treatment available at primary health care facilities rather than centralised hospitals. For example, in a report on the scale-up of treatment in Lusikisiki, Médecins Sans Frontières (MSF) found that whereas 19% of patients who were initiated on treatment at St. Elizabeth Hospital were lost to follow-up in their first 12 months on treatment, only a 2% lost-to-follow-up rate was reported for patients who accessed treatment through the surrounding clinics. The obvious benefit to patients of decentralisation is that they do not have to incur the time and costs of travel.
  The lesson for the government is that the slow centralised antiretroviral health facility accreditation process must be moved from the National Department of Health to provincial departments so that more primary health facilities can be accredited quicker.
- **Patient education and responsibility:** The Khayelitsha, Gugulethu and Lusikisiki programmes have all been successful at least in part because they place large emphasis on patient education. Massive treatment literacy programmes have been implemented in these areas. Patients are also, for the most part, treated with dignity by giving them the responsibility of adherence. Patients on these programmes are encouraged to have treatment supporters, usually a family member or friend, rather than the patronising directly observed treatment methodology of many TB programmes, which in any case could not work for antiretroviral medication which requires lifelong adherence.
- **No fees:** In general, programmes which make patients pay for drugs or diagnostics, have lower retention. Many patients are forced into the invidious position of having to choose between buying medicines versus other essential goods.

But the scaling up of antiretroviral treatment even further in low-resource settings will depend heavily on the adoption of new and innovative models of service delivery in order to overcome crippling shortages of human resources. Task shifting, both from doctors to nurses as well as from nurses to community health workers and people with HIV is critical for scaling up treatment provision and retaining patients at the primary health-care level. Allowing nurses, as opposed to scarce doctors, to prescribe and dispense antiretrovirals was a critical to the success of uptake and retention achieved by MSF in the Lusikisiki roll-out. Likewise, the involvement of the community and people with HIV in antiretroviral service delivery is crucial for encouraging patient adherence and retention.

[END OF ARV ANALYSIS]

Memorandum handed to Eastern Cape Health Officials following TAC march to Frere Hospital

16 October 2007

We are marching today to express our concern at service delivery in Frere Hospital. On 12 July 2007, the Daily Dispatch exposed conditions at Frere Hospital that have led to high infant mortality. This was followed by a task team investigation by the National Department of Health into conditions at Frere Hospital. The task team published a report in July with several recommendations. In our view the task team's investigation was inadequate. For example, it made insufficient concrete proposals for how the hospital would rectify its staff shortage. Nevertheless, the implementation of

the task team's recommendations would help improve conditions at Frere Hospital.

We also disapprove of the disciplinary action against and dismissal of Dr Nokuzola Ntshona. Dr Ntshona carried out her civic duty by bringing the awful conditions in Frere Hospital to public attention. Her dismissal is a sinister attempt to silence the voices of concerned public health professionals.

Some (but not all) of the task team's recommendations were:

* Doctor vacancies should be filled.

* A supervisor for the nursing students should be appointed.

* The shortage of nurses should be rectified.

* More clerks and general assistants should be hired.

* Incubators should be replaced.

* A blood pressure machine should be introduced.

* The number of CTG machines should be increased.

* The ultrasound machine should be replaced.

* New scales should be procured.

* An equipment register should be introduced.

* The quality and infection control policy should be enforced and several recommendations for improved infection control should be implemented.

* Maintenance, including resolving plumbing, painting, dampness, gutters and broken ceilings, of should be carried out.

* The electronic nurse calling system should be replaced.

* A preventative maintenance programme plan should be implemented.

* Various measures to improve hygiene and infection control should be introduced.

We therefore ask you today to clarify what steps have been taken to implement the recommendations of the task team. We also ask you to indicate what additional resources, particularly financial, the national and provincial departments of health have given Frere Hospital in order to implement these measures.

We ask for your response by 29 October 2007.

[END OF FRERE HOSPITAL MEMO]

BBC Admits that ?Guinea Pig Kids? is Misleading, Erroneous

Apologises for HIV Denialist Bias and False Allegations about NYC AIDS Drug Trials

- Link to BBC letter apologising for and admitting errors
- Article in *The Guardian* about this incident

The British Broadcasting Corporation has investigated and affirmed complaints that ?Guinea Pig Kids,? an independent

video aired on the BBC in 2004, made false and misleading claims about paediatric clinical trials of AIDS medicines that included foster children with HIV/AIDS living at New York City?s Incarnation Children?s Center (ICC). The drugs, which were already approved for adults and in some cases for HIV- children, were being tested to determine the safest and most effective dosages for children living with HIV/AIDS. Some ICC patients and were among those enrolled in the trials, with the written consent of their parents or guardians, as the only way to get life-saving medications. The acknowledgement of the video?s bias-driven misrepresentation is the latest in a spate of recent editorial scandals at the BBC.

?Guinea Pig Kids,? the BBC affirmed, wrongly implied that the HIV-related medications that were being studied were futile and dangerous, and it intentionally ignored their life-saving efficacy. The BBC acknowledged that the video was biased towards the views of ?HIV denialists,? who don?t accept the scientific evidence that HIV exists and that it causes AIDS. Fraser Steel, the Head of Editorial Complaints, concluded that these are serious breaches of the standards set out in the BBC?s Editorial Guidelines concerning accuracy and impartiality, and he extended and apology for the deficiencies in the program and the associated website material. The affirmation of the complaint is very important because the credibility of the BBC had lent undeserved legitimacy to false accusations against ICC and to disinformation about HIV/AIDS, clinical trials and antiretroviral treatments that is spread by HIV denialists.

The BBC?s retraction and apology followed months of intensive investigation in response to repeated complaints filed by AIDS scientists, doctors and activists, who denounced the video?s attack on Incarnation Children?s Center as a hoax designed to spread disinformation about HIV/AIDS. The film and the associated web pages alleged that healthy African-American and Latino children at ICC, a specialized care facility for children with HIV/AIDS in New York City, were harmed and even killed by bizarre and unjustified medical experiments involving lethal drugs, and that if their parents or guardians objected to the experiments they lost custody of their children. These allegations, the complaint argues and the BBC agreed, are untrue and unjustified, and were motivated by HIV denialism.

The BBC has not yet publicly posted the retraction and apology, which were presented in a 12-page letter, dated 31 July 2007, from Fraser Steele to Jeanne Bergman, Ph.D., the lead complainant and an AIDS activist with AIDStruth.org and the Center for HIV Law and Policy in New York City. ?The BBC has been very slow to respond to our urgent concerns,? she said. ?We have pressed our charges that the video is HIV-denialist propaganda with no basis in science or fact since the video was aired in 2004, and it took until this year for the BBC to investigate the piece. It has now been two-and-a-half months since we received Fraser Steel's letter apologizing for the video's misrepresentations and bias, but the BBC has still not issued a public retraction and apology, nor stated what actions it intends to take. I am horrified that the BBC would air a lurid independent video about HIV clinical research and treatment without a proper scientific review in the first place, and I am angry about the BBC?s inexplicable delay in retracting publicly the very dangerous lies to which it has lent its fading legitimacy.? Dr. Bergman has been informed that the BBC?s actions are subject to the outcome of on-going "discussions at the highest editorial level" given the "very serious issues raised by this matter,? but, she said, ?They need to act now. The BBC webpage promoting the video is still up, promulgating HIV denialist lies. There is as yet no effort by the BBC to correct the systematic disinformation about HIV and its treatments that it aired, and that has damaged the public's understanding of HIV and impeded HIV-infected children's access to lifesaving care.?

No children have died as a result of the clinical trials. Enrollment in the trials was conditional on the likely benefits to the child and a low probability of harm. Written consent was obtained from parents and guardians, who were not paid or otherwise improperly influenced to enroll their children. The National Institutes of Health, Columbia-Presbyterian Hospital, the New York City child welfare agency (the Administration of Children?s Services, or A.C.S.), and other institutions provided multiple layers of oversight. And while two non-parental guardians interviewed in the video did have foster children with AIDS removed from their custody on the grounds of medical neglect, those children were not involved in the clinical trials. (These foster parents lost custody because they had refused to provide the children with the approved standard-of-care treatments for HIV/AIDS that they had been prescribed, and without which the children would have become ill and died.) The BBC affirmed that there was no evidence that children were taken from their families because they resisted ?experimentation.? The filmmakers falsely tried to ?create an association between [the

clinical] trials and a loss of parental rights,? the BBC found.

The film was written by, produced by, and featured interviews with HIV denialists, but it never identified them as people whose beliefs contradict everything that scientists, doctors, and the communities most affected by AIDS have learned about HIV and its treatment over the last 25 years. HIV denialists have distributed copies of the video widely since it was aired and posted an edited version on the Internet. Jeanne Bergman explained, ?The HIV denialists who made this film invented these charges against ICC. They cynically exploited African-Americans? real and historically-based fears of abuse by medical research and child welfare agencies. Their false allegations about sinister medical experiments on foster children were a Trojan Horse created spread lies and deadly disinformation about HIV in the communities most devastated by AIDS. These allegations about ICC have become an ?urban legend,? untrue but widely believed, mainly because people trusted the BBC. The fact is that ICC used the clinical trials framework to make life-saving medications, already approved for adults, available to children with HIV who would otherwise have died.?

HIV denialism is a collection of contradictory and scientifically unsound beliefs?that HIV does not exist, that HIV it exists but is not the cause of AIDS, and that AIDS does not exist. Pediatrician Nicholas Bennett was critical of the BBC?s decision to air a video that was based on beliefs that are without scientific merit. ?If someone had simply researched the individuals involved in promoting the story, and those interviewed during the program, it would have been quickly apparent that their views were not only those of a fringe element but also demonstrably wrong,? he said. ??Balance? in the media does not mean giving equal air time to poorly-researched and biased material with the goal of gaining viewers with a sensational story. The saddest thing is that this story was sensational only due to the errors and bias inherent in it. The fact that it was produced by the BBC gave it an air of respectability that was wholly undeserved. Clearly the BBC needs to review its fact-checking practices.? John Moore, an internationally renowned HIV researcher at Cornell-Weill Medical College, added, "An important lesson for the BBC is the need to have its highly professional science and health reporters review documentaries like this one before they are released for public viewing. No scientifically literate journalist would ever have endorsed this one's contents and slant."

The BBC?s retraction of the video was also applauded in South Africa, where the Health Minister?s AIDS denialist views have seriously hampered HIV prevention and access to HIV treatment. Nathan Gefffen of the Treatment Action Campaign there said that ?The BBC ruling, albeit late, is welcome. The lies peddled by pseudoscientists like [film-maker] Jamie Doran and David Rasnick [a denialist who was featured in the film] have caused confusion and death. They try to appeal to minorities and vulnerable groups by misusing human rights language to portray themselves as progressive. But behind most AIDS denialists lies either a desire to sell untested snake-oils to sick people or an incapacity to consider evidence rationally.?

For further information, contact:
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[END OF BBC APOLOGY]

- AIDS Denialism

- AIDS Denialism