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HIV Science and Responsible Journalism XVI International AIDS Conference August 13, 2006

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DANIEL KURITZKES, M.D.: Thank you for coming to this session on responsible reporting on HIV/AIDS. My name is Daniel Kuritzkes. I'm director of AIDS research at Brigham and Women's Hospital and director of the Harvard AIDS clinical trials unit and also the chairman of the board of the HIV medicine association. On behalf of my co-chair, Laurie Garrett from the Council on Foreign Relations and on behalf of the HIV Medicine Association and the forum for HIV Collaborative Research, which together with the International AIDS Society are co-sponsoring this session, I'd like to welcome you to this morning's session.

The HIV/AIDS epidemic has stirred passions and controversies around the world over the last 25 years, and not surprisingly, these passions and controversies have often been reflected in reporting on the epidemic. These controversies have encompassed conflicting political, cultural and religious views on how to prevent the spread of HIV, the rights of persons living with HIV/AIDS, economic disparities between north and south that limit access to life-saving medical therapy for HIV infection, and scientific and medical controversies regarding the origins of HIV, disease pathogenesis and issues such as when to start antiretroviral therapy.

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A recent article in *Harper's Magazine* highlighted another aspect of HIV/AIDS reporting and the peculiar persisting fascination with a group of individuals who insist on maintaining, against all evidence and without providing evidence of their own, that HIV does not cause AIDS and in fact that AIDS itself is not a new or unique medical entity.

The reporting of AIDS denialists has highlighted some important differences in the way in which medical scientists and reporters on medical science and their respective editors perceive and assess the import and accuracy of information. Clearly both have essential roles in free societies. But at what point can scientific controversies be considered settled? What criteria should be used in judging the validity of criticisms leveled by outsiders against the scientific establishment? What are the responsibilities of medical scientists, journalists and their editors, as both scientific journal editors and editors in the lay press, in keeping the public informed on these controversies and on the progress of the epidemic.

This morning we're fortunate to have assembled a distinguished panel, international panel, of scientists, journalists, and editors and policy experts to discuss these critical questions. So without further ado, let me introduce the first speaker, Dr. John Moore, who is a professor at the Weill Medical College of Cornell University, recognized

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expert on HIV and who's recent work has focused on the search for microbicides as a preventive measure for HIV infection.

John?

JOHN MOORE, PH.D.: Thank you, Dan. So I'm going to cover a number of different areas of HIV reporting in the press and specific reference to AIDS denialists, and Nathan Geffen will follow on from me. But let's have no doubt about this – this is dangerous stuff. AIDS denialism kills. I'm going to review who they are, who they are not, how they operate, what are some of the untold stories, and what journalists need to be on the lookout for.

Now when I say that denialism kills, thousands of South African adults and children have died of AIDS because of the flawed government policies on HIV and AIDS. Nathan will talk to you more about that, but the South African government has been heavily influenced over the past six or seven years by AIDS denialists. Any one, man or woman, who's persuaded that safe sex or using clean needles is not necessary and then becomes HIV infected and dies of AIDS, the person advising them inappropriately bears responsibility. Anyone persuaded not to take antiretrovirals and use instead alternative medicines – lemon and garlic, potatoes and whatever – is also dying unnecessarily. Anyone persuaded not to be screened for HIV status and deprived of the chance of treatment or counseling dies unnecessarily.

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And infants whose HIV infected mothers listen to AIDS denialists never got the chance to make their own decisions. The Maggiore case received wide publicity. Christine Maggiore is a person who's proselytized against the use of antiretrovirals to prevent HIV/AIDS. She's a classic AIDS denialist, and she gave birth to a child who died at age three late last year of an AIDS-related infection. The coroner's report clearly reports that the child died of AIDS. That was another unnecessary death.

Now the AIDS denialists abuse the peer-reviewed literature. They abuse science. They cite only old, long refuted papers as if they still represented state of the art knowledge, which they don't. So they argue that TB, malaria, leprosy, pregnancy cause false positive tests in an HIV assay. Now this is simply not true of the modern tests, and it's questionable how significant it was with the early generation of assays. They highlight legitimate scientific uncertainties within AIDS research as evidence for incompetence or worse. So the fact that HIV pathogenesis knowledge evolves over time is twisted in a way that says, "Well, you were wrong, therefore you must always be wrong."

Science evolves, but the denialists are stuck in a time warp. They cherry pick what suits them. Preferential citation is what it's known as in the technical language. They ignore the much greater weight of contradictory evidence

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elsewhere in the literature. And they willfully or incompetently misrepresent the information reported in individual papers. The Perth group did this in Nature in a study on maternal, mother-to-child, transmission in Rwanda. But the denialists don't publish any of their own work. They simply criticize, ignorantly, the work of scientists who do.

Now what are their core beliefs? The core beliefs tend to be somewhat different because different sub-cliques of denialists differ in what they choose to emphasize. One of the more bizarre episodes was the Perth group claims that HIV simply does not exist; whereas Duesberg accepts that HIV exists but believes it's harmless. So when the Perth group put out a competition on their website with a cash prize for anyone who could prove that HIV exists Duesberg actually claimed the price. It gets that silly.

There's another group that believes that HIV exists but cannot be heterosexually transmitted. AZT is held to be a lethal chemical that itself causes AIDS. This is one of the stock in trades.

Lemon and garlic or multivitamins cure AIDS. That's another myth. Duesberg has argued and many people in his clique have accepted his views on this that AIDS is caused by poppers, by drug use, over stimulated immune systems, poverty – anything but HIV. Space aliens will no doubt be a cause soon. One of the views is that Africa is different because

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Africa has to be different because the denialists otherwise can't explain why HIV has killed so many people there. It's held that diagnostic assays simply don't work, which of course isn't true. They hold that PCR-based viral load assays don't measure HIV, which of course isn't true. The details get more and more bizarre, and they're often mutually contradictory.

Now let's go through a few case reports that have been reported in the media. HIVNET 012, a trial of single dose nevirapine to prevent mother-to-child transmission in Uganda. Paperwork discrepancies arose in this trial because of administrative problems at rural African sites. It's not easy to conduct clinical trials to the same administrative standard in Uganda as in Boston and New York. The conclusions of the trial are scientifically valid and they were endorsed by the Institute of Medicine in an independent evaluation. But Celia Farber et al. twists the facts to make it appear as if this important trial equates to Tuskegee-style abuse, criticizing, amongst other things, the lack of a placebo arm, which is nowadays an ethical necessity not to have a placebo. Farber's version of events becomes accepted wisdom in the Boston Globe, the New York Observer over the past few months have simply parroted her views as if they had merit.

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Another one in the press last year was the New York foster homes story. Foster children at the Incarnacion Children's Center in New York City are enrolled in trials of antivirals that are already approved for adults. The trials are closely supervised and are a great success, run by Columbia University. Liam Scheff et al. twists the facts to claim that the children are being used as guinea pigs and harmed not by HIV but by the medicines that are used to treat their infections, again an old denialist myth. Local politicians become involved in this without knowing the facts. The AP's John Solomon jumps in as part of his attacks on the NIH. The New York Times finally exposes the truth in an important story, but again the real version of events is still not fully accepted in the media.

Nancy Padian's paper: Nancy Padian of UCSF publishes a classic study on heterosexual HIV transmission in 1997. It concludes that, "Infectivity for HIV through heterosexual transmission is low because interventions reduced the rate of HIV transmission." It was a study that described the effect of interventions that prevented transmission, behavioral and condom usage. AIDS denialists though conclude that the Padian paper proves that HIV is not heterosexually transmitted and contradicts the author's own conclusions and to the social science literature. A quote from an article by Lauer earlier this year states, "Data demonstrating the

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falsehood of the sexual transmission theory are found in Padian 1997." The bloggers and the websites make similar false statements. They even say that Nancy Padian's work is being deliberately ignored by the AIDS establishment and that she's been ostracized for being politically inconvenient to it. David Rasnick, an AIDS denialist, writes letters to South African newspapers accordingly. Nancy Padian is here today, or said she was going to be here today, and she can speak to this - she's here - and she can speak to this, how her own paper is being abused and twisted.

They sneak letters into newspapers past unwary editors. Only last week an AIDS-related story appeared in the Canadian Press. A mother is convicted of hiding the HIV status for son's birth. An Ontario mother has been convicted for hiding her HIV status, which denied doctors the chance to treat her baby and possibly prevent her newborn son from being infected, a case considered the first of its kind in Canada. That was in the Globe and Mail. A letter appears from a David Crowe saying, "AZT, the drug given to the vast majority of pregnant HIV-positive mothers is one of the most toxic substances known to man." Well of course this is nonsense. AZT is an FDA licensed drug, and I don't think it can be reasonably equated to plutonium, botulism toxin, dioxins, etc. David Crowe is a well-known AIDS denialist. He's the president of the Alberta Re-appraising AIDS Society.

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It's probably him and his dog. He's presently attempting to raise funds over the Internet for a PR firm to promote denialist causes.

So what are the untold stories? Well who are the denialists? It's a meld of the extreme right and the extreme left. They loathe each other, but they're united in a common theme. It's sort of like a Hitler/Stalin pact. If you want to carve up Poland you unite. The right and the left-wingers unite to attack science and scientists. Some of them are frustrated scientists with flawed careers. Vitamin pill peddlers are around nowadays. Matthias Raff exploits the AIDS denialists to help sell his vitamin pills in South African. Some of them are just genuinely eccentric paranoiacs, lost souls. And there are some people who are undoubtedly infected individuals in personal denial.

Now who funds them? They have a few rich donors, right-wing venture capitalist apparently is behind some of it. Vitamin pill salesmen, again Matthias Raff now employs David Rasnick who used to work with Duisburg. Book sales will fund this. Celia Farber needs the PR to sell her new book.

Why did Peter Duesberg go off the rails? Why did he start this, back 15 years ago, 20 years ago? That's a great story. It's there to be written. Ask his contemporaries who he was, who he is, what he thinks, what he did, why this all

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started. The contemporaries who grew up with him, in scientific terms, know the story. What are the links between the South African government and Matthias Rath? That's now emerging in the South African press. Nathan can speak more to that.

They operate under pseudonyms, the AIDS denialists, all too often. There's a professional lawyer involved in AIDS denialist legal actions. D. David Steele, he runs a blog under a pseudonym, Hank Barnes, with the title "Where we pontificate, unencumbered by the facts," which kind of says it all. He's taken that down recently. But why be a professional lawyer and run a website under a pseudonym? What are you frightened of? Why do other denialists, particularly the really noisy ones post on the Internet in Aetiology site, New AIDS Review, under false names? Are they too ashamed to use their own? And perhaps it's because so much of the Internet postings are just foolish and incompetent, and so much of the dialog degenerates into personal insults. They insult scientists. They insult AIDS activists. And they even insult each other when it all gets too heated for them.

Now conflicts of interest - scientists are routinely castigated by AIDS denialists for alleged links to big pharma. Having an NIH grant is deemed to be a sin. I've been attacked for having an NIH grant. But AIDS denialists

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have conflicts of interest that are ignored. Now a journalist should report the story, not be part of the story. That's an accepted tenet of journalistic ethics. But some journalists are active AIDS denialists and participate fully in the so-called rethinking AIDS group, the sort of overarching leadership group.

Celia Farber is on a book sales campaign by Melvin House and has a PR firm. There are spin off stories from the Harper's article. The New York Post gossip column had a piece plugging her new book recently.

What's been the role of the Harper's editors in all of this? David Rasnick, as I said, used to work for Duisburg, now works for Matthias Rath conducting alleged clinical trials of vitamin pills in South Africa as alternative AIDS therapies. Money talks. If we're all allegedly conflicted by the pharmaceutical industry it works both ways.

They misrepresent their academic credentials to create an illusion of competence. David Rasnick claimed to be a visiting scholar at UC Berkeley when writing letters to South African newspaper. He has no such status. He's been disowned by the university and now instructed not to make such claims. The Perth group, Papadopoulos-Eleopoulos and Turner, claimed to have academic appointments at the

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University of Western Australia. That's not the case, and they're now being disowned by the university.

Roberto Giraldo served in 2000 as a member of the South African president's commission, claimed at that time to be on the faculty of the Weill Medical College where I work and to work at its affiliate the New York Presbyterian Hospital. He has no connection with the medical college, and he works as a technician at the hospital. Professional academics wouldn't get away with this.

So journalists, what can you do? You can check carefully who and what you're dealing with. Expose the lies, expose the twisted and perverse agendas, investigate the untold stories, uncover the truth. Some AIDS denialists work in bona fide universities. Some even teach students. If this happens in your neighborhood ask the university authorities why they allow this and then write about it. There's a case in Chicago I know about.

Science and health journalists should talk to the editorial desk and letters editors and vice versa to ensure that AIDS denialist letters are spotted on arrival and spiked, not published.

Finally, for accurate information on HIV/AIDS, we've set up a new website called AIDStruth.org, and there are many other organizations that give accurate information. Thanks very much.

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[Applause]

DANIEL KURITZKES, M.D.: Thanks very much John. It's now my pleasure to introduce Nathan Geffen who is policy coordinator for the treatment action campaign in South Africa and was formerly the national manager and treasurer of the organization.

NATHAN GEFFEN: Thanks Dan. I want to start off by reading from an affidavit in a court case that we're currently running in South Africa. "My sister died of AIDS on 27 March 2005 at the age of 37. At the time my sister died she was on treatment at Dr. Matthias Rath's practice in Ki Litche[missspelled?]." John mentioned Dr. Matthias Rath in his speech earlier. "She was diagnosed with TB in 2004 and took TB treatment. My sister was soon treated for TB at the South B clinic. She tested HIV positive soon thereafter in October 2004. She was going to start antiretroviral treatment after she finished her TB treatment. In October 2004 her CD4 count was 45 and she had lost significant weight. In March 2005 she came into contact with representatives of Dr. Matthias Rath and the Rath Health Foundation. From the moment she came across the Rath people she stopped any treatment at the Ki Litche South B clinic. Just for those of you who don't know, the South B clinic in Ki Litche is the seminal developing world antiretroviral pilot project run by Medicine sans frontiers. And that's

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where she was getting treated. So she would have been well treated at that clinic. "My sister was already sick when she started the Rath treatment, but from that moment she started getting sicker. I contacted the Rath people whenever my sister got sick. The Rath people came at least three times to pick her up from home and take her to the Rath practice. The first time she came back with food parcels and lots of vitamins. The second and third time she was kept during the whole day from 8:00 to 4:00. During these hours they kept her on a drip. She did not get better. On the contrary, her body got swollen and she had hallucinations. The Rath people had given me their names and numbers. They also encouraged me to call them at any time if needed. They also told me not to call an ambulance, even if my sister was very sick. I informed the Rath people that my sister was getting weaker. One night my sister was very sick. I called the Rath people. They advised me on the phone to go to a pharmacy and buy a glucose serum to give her. They promised to come the morning after, but they didn't. They only came after four days. They told me that my sister was going to get better if she used the treatment from Dr. Rath for at least two months. She vomited the tablets, but they said it was because her immune system was weak. My sister died a week later. After the death one of the Rath people came to my home to collect all the containers and pills that were left. A few days

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before the funeral two women came back to my home to bring me 10 kg each of rice, flour and sugar, 12 cartons of milk and a big tin of coffee. They said they would come back to visit me and counsel me after the funeral but they never did. Since then they have contacted me by telephone only."

AIDS denialism is real. We're not having a theoretical discussion over here. People are dying because of it. I have dozens of cases on my desk in my office at home of people who have suffered at the hands of charlatans and pseudo scientists and quacks. This is a scourge that is undermining the entire response to the South African HIV epidemic because of the political support of the South African government of AIDS denialism.

There are three serious kinds of problems that one finds in the media in the reporting of AIDS. I want to start off though by saying that in South Africa, and in most countries around the world where I've read newspapers, opinion editorials and journalists who are writing on AIDS do so with the best of intentions. They take a very good moral stance on HIV, and without the efforts of the South African media we wouldn't have an antiretroviral roll-out in South Africa today because the media has, especially on the opinion editorial pages, has health the South African government to account.

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But unfortunately when it comes to scientific accuracy, reports, at least in South Africa newspapers and also I'm afraid to say from what I've seen even in Toronto newspaper just yesterday, are not particularly accurate.

Now there are three kinds of errors that I want to point out to you, but one that I want to concentrate on. Let me first start off with the two most obvious ones. First of all, miscommunication of key scientific findings, and I've listed a few examples here, but time's going to prevent me from going onto detail on them. If you look at the notes of the slide show on the AIDStruth website any time from tomorrow onwards, it'll give details of the various examples that are given. But you don't need to look at my examples. You can open almost any newspaper and read the articles on AIDS and you're bound to find a serious scientific error in it.

And these errors are made out of good intentions. They're not done intentionally. They're made from journalists who want to do the right thing, but it's a consequence of poor scientific training and low prioritization of science by editors. And this is a particularly large problem in South Africa.

And then you get the problem of critical omissions - important scientific findings, which simply don't make it into the media or get very low profile in the media. And one

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particular example comes to mind. John actually mentioned it earlier. The HIVNET 012 trial in Uganda and the subsequent endorsement of single dose nevirapine as an effective way of preventing mother-to-child transmission took up a lot of space in South African newspapers on numerous occasions, and it was often surrounded by controversy. And at the last AIDS conference in Thailand our minister of health walked into the conference like a bull in a china shop and made some ridiculous pseudo-scientific comments about nevirapine, and it dominated the South African media for a week.

Then the IOM, the Institute of Medicine in United States did this audit on the HIVNET 012 trial and validated the findings of HIVNET 012. It got very, very little press coverage in South Africa. I'm glad to say Tamar Kahn [inaudible] wrote one of the reports, which appeared in business day, but an editor put it on some back page somewhere. And unfortunately this was a critical finding. It would have put to bed the whole nevirapine controversy in South Africa, and yet it got hardly any coverage in South African newspapers. So it was a critical omission. And one finds this over and over again. Whenever incredibly important scientific knowledge comes to light it gets very little coverage in the South African newspapers. And again it's a consequence of editors not realizing that when their journalists hand them these stories that they're actually

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really important, that they're going to make a difference to the response of the HIV epidemic.

Now how do we rectify poor scientific knowledge in the media? Well saying what needs to be done is very easy; actually doing it is a lot trickier. Editors need to prioritize training. I think editors need to have at least one journalist on their staff trained as an HIV expert. In South Africa this is critical. It's one of the biggest challenges facing our country. We've got more people living with HIV in South Africa than any other country probably. And one would expect that this would have been done by now.

NGOs like TAC need to do more training with the media, and we need to make sure that we develop a competent core of science journalists. But the problem is that because there's a lack of political leadership in South Africa on HIV, because of the denialism at the highest levels of government in South Africa, editors haven't realized that they actually need to prioritize the science. If our president and our minister of health are to be getting onto radio and television and are to be saying "HIV's an emergency, we need to prioritize this epidemic," I reckon that every single major newspaper in South Africa would have a competent science journalist.

And then there's the worst of the three types of inaccuracy that one finds in the media and that's the pseudo

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science, which John spoke about in quite a lot of detail. And I want to look at this in a bit more detail as well. Some examples in the South African media over the last few years that I've come into contact with – South African journalist by the name of Rian Malan, who's more well known for writing music columns in Rolling Stone, wrote a column in a South African magazine called Noseweek, not to be mistaken with Newsweek. And he also wrote an article in the British Spectator arguing that the AIDS statistics were completely wrong, that there wasn't a serious AIDS epidemic in Africa, and that people weren't dying of AIDS in great numbers. He claimed that he wasn't an AIDS denialist. He says he didn't dispute that HIV caused AIDS. He just thought that this was massively exaggerated. I ended up writing a detailed response to him, which resulted in a lot of public debate. And today I'm glad to say that Malan's exited the debate, and he's considered to be quite a fool by the South African media now, quite correctly.

The recent example of Sam Mhlongo and David Rasnick writing an opinion editorial – sorry John, you mentioned it was a letter. It was actually an opinion editorial piece in the Citizen newspaper, a major South African daily newspaper read by government bureaucrats in Pretoria because that's where it's published, claiming that heterosexual transmission of HIV didn't happen. Tim Modise is one of the most popular

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radio talk show presenters in South Africa. He has a stream of quacks on every topic coming into his talk show at 9:00 peak hour time to listen to the radio in South Africa on one of the most popular radio stations in the country. There's another show, the Chriselda show on Khaya FM – luckily it's come to an end. Also she was an outright denialist who was very popular and would spread pseudo science over the radio, and this is a big problem because radio is the most popular form of media in South Africa.

Why is this happening? One of the reasons is that some of the newspaper editors have sympathy for pseudo-scientific views. Martin Welz, who's the editor of Noseweek in South Africa, is sympathetic to AIDS denialism. The current Citizen editor is also apparently sympathetic to denialism. Radio presenters pretty much have the autonomy to do their own thing. So while Tim Modise might work for a radio station that actually often has very good stuff on AIDS, and where the people who run the radio station aren't happy with AIDS denialism being on the air, Tim Modise pretty much has autonomy on what he has on his show.

And then there's just plain lack of editorial knowledge, so for instance a very good, or very popular, South African magazine ran a piece a few months ago comparing Judge Edwin Cameron who's been on antiretrovirals since 1997, who's doing very well, compared Edwin Cameron with Nozipho

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Bhengungu, who's the daughter of a member of parliament in South Africa and who was using the garlic treatment promoted by the minister of health, and a woman by the name of Tine van der Maas. And these were presented as equal choices, you know, make your choice - there's antiretrovirals or there's garlic. Decide which one you prefer. Well Nozipho Bhengungu died a few weeks ago, and Edwin Cameron rode the 108 km August cycle tour around Capetown at the age of 50-odd. So that's where the different choices led them.

Pseudo-science in the media is not a lack of training. It's a failure of ethics. And this is where I want to put forward a number of quite controversial proposals. One can compare AIDS denialism to denialism on global warming, denialism on evolution and natural selection and denialism on the Jewish holocaust, which thankfully the last of these is almost never seen in the newspapers anymore. But these are all scourges. All journalists who think that by doing a few hours of research on the Internet they can overthrow millions of man-hours or millions of person-hours of research done by scientists. And that is a failure of ethics. That's an arrogance that demonstrates a failure of how science works and a failure of one's own limitations.

So obviously the role of media in science, as I see it, is to explain scientific findings to the public. How do we know that HIV causes AIDS? How often does one see an

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article in the newspaper explaining it? Or how do we know that global warming is real? Or how do we know that natural selection is effective? How often do we see newspapers taking science – instead of trying to expose scientists as frauds, as people conducting strange things that we shouldn't trust – how often do we see newspapers actually taking important subjects and making them accessible to the general public? There are some newspapers that do a good job of it, the New York Times for instance. But very few newspapers actually do, do it.

The other, of course, important job of the media is to report fraud or poor ethics in scientific conduct. So the New York Times ran a very good opinion editorial on two journals, JAMA and Neuropsychopharmacology, running articles which failed to declare conflicts of interest. There was the recent Hwang Woo-Suk scandal in South Korea where the media correctly exposed the [inaudible]. There's the current running Vioxx scandal. And then Health-e, a South African news agency, ran an excellent exposé of Matthias Rath, for which they won an award.

But what I want to ask, and what I want to propose, is should we be having a new ethic in journalism? Is it really the role of the media to challenge scientific consensus? Is it really the role of the media to say well the scientific consensus is wrong – the scientists have got

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it wrong? My personal view is that it's almost impossible for the general media, for the mainstream media to be able to override the scientific consensus. The scientific consensus, if it's wrong it's going to be challenged by scientists in scientific journals. It's not the role of journalists to be challenging the scientific consensus. Does the media have the expertise to challenge the scientific consensus? In my view it doesn't. And that's something I think that we should, when we have the floor discussion, be asking. Should we be seeing articles in the general media that challenge science? And in my view it isn't the role of journalists to do that.

I just want to do a plug for AIDStruth as well, just as John did, and I hope other people who are presenting at the conference will also do a plug for AIDStruth. Thanks.

DANIEL KURITZKES, M.D.: Thanks very much. I'll now turn the session over to my co-chair Laurie Garrett.

LAURIE GARRETT: Hi there. Thanks to you all for coming here. I know that there are a lot of other things going on, and there were other choices you could have made. I hope you'll find this session useful. I just want to make a couple of quick points and then hand it over to a really extraordinary group of journalists who are going to follow up. I kind of straddle in between.

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Back in the early 1980s there was a young man – I'll just call him Michael and not tell you his last name for the sake of his privacy – who I knew very well, who was a very prominent AIDS activist in New York who decided that AIDS was caused by poor nutrition, that AIDS was about his diet, and when AZT came into availability he strongly protested the use of AZT throughout New York. And even as I watched him wither and die before my eyes and begged him to please reconsider his assessment, he in his last dying days became a virulent denialist. And I came to understand that there's more going on there psychologically than any of the issues we've been talking about because there's the victim's side of the denialist argument. Why is an individual willing to die with their final breath still believing in something that, when they look in the mirror, patently cannot be true?

I wanted to point out one person here in the audience because when Nathan said there should be more education of journalists, more training specifically about HIV and about science in general, I felt it necessary to mention that Bob Myers is here who runs J to J, Journalist to Journalist, which just completed a three-day exhaustive training exercise for 98 journalists from all over the world. I believe 40 of them from China alone. And the Kaiser Foundation also runs very large-scale training programs for journalists from developing countries.

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So there are efforts afoot, but journalists need to have the opening made by their editors, to be allowed to take the time away from their daily reporting or their weekly magazine duties in order to attend such training. And sometimes large roadblocks are put up.

The other thing I wanted to say is that we need to broaden our discussion I think a bit to understand that this isn't a phenomenon unique to the HIV situation. I remember when I was, in 1997, in the former Soviet Union, and at that time there were 250 thousand active cases of diphtheria. And it entirely stemmed from one pseudo-scientist who, beginning during the Gorbachev Soviet period, claimed that all vaccines contained lethal doses of mercury, and as a result Russians, in particular, and Ukrainians, had stopped allowing their children to be vaccinated. We're now seeing the same thing with resurgence of whooping cough, measles and polio, all related to various pseudo-scientific claims associated with risk. And indeed we were on the cusp of eradicating polio until E-moms[missspelled?] in Northern Nigeria convinced their people that polio vaccines were contaminated with HIV. And what did they draw upon as one of their major sources of information to support such a claim, but the work of a reporter named Ed Hooper from the UK who wrote a book called *The River*, which claimed that all HIV in the world essentially stemmed from an American and French campaign to

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vaccinate Africans against polio in the 1970s and even earlier with a vaccine that was contaminated with HIV.

So we see these circles play over and over, and a so-called message that has been eradicated from the media for a period, comes back again 10 years later. Some of us, particularly Marilyn and I who've been in this game since the earliest days, find it amazing that we're revisiting a denialist debate that we wrote about extensively in the first round of that debate.

So let me tell you who you're going to hear from in the next few minutes. It's a very distinguished group, very exciting. Marilyn Chase, in my opinion, is one of the greatest journalists in the English language today. I have been in her fan club for more than 20 years. She writes for the Wall Street Journal, based in San Francisco. She's had many different positions in the Wall Street Journal over the years. But she has fortunately been sent by the journal to cover most of these gatherings and the major HIV/AIDS meetings over the last two and a half decades.

After Marilyn we will hear from Tamar Kahn, who is the science editor of the newspaper that I would say is the best English language newspaper on the African continent. It is roughly the equivalent of the Wall Street Journal called Business Day in South Africa. Business Day has done some of the most important groundbreaking journalism regarding Thabo

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Mbeki, the president's, position on HIV and the whole difficulty of rolling out medication for people in South Africa. Did William Gumede work for Business Day? I think so. If any of you are trying to understand – by the way, just as a side note – why Thabo Mbeki has taken the stance that he has, one of the best explanations I've ever seen is in a recently released book, soon to be released in North America (I think next week) by William Gumede called *Thabo Mbeki and the Battle for the Soul of the ANC*.

And then we will hear from Kim Honey who is the health and science editor of the Toronto Star. She's been in this business covering science and dealing with science and health coverage for more than 20 years. And I'm sure those of you who have now been here a few days and had a chance to look at the Toronto papers would understand the Toronto Star is really one of Canada's greatest newspapers.

I will simply ask each of you to try to hold to 10 minutes in your comments, and come up in the order in which I introduced you. Marilyn.

[Applause]

MARILYN CHASE: Thank you so much, and Laurie you embarrassed me. Thank you for that overwhelming introduction. I was hired by the Wall Street Journal in the late 1970s when I was a wet-behind-the-ears 20 something reporter fresh from grad school with my masters degree in my

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hot little hand. And within a few months of my arrival, fresh from my other job as a stringer for the New York Times to apocalyptic events in San Francisco where I work took place. One was the assassination of George Moscone and Harvey Milk in what was widely believed to be a homophobic attack. And the other event was the unleashing of a strange new disease, originally called grid, later to become HIV/AIDS.

It's very good of the IAS panel to ... I forgot to thank the IAS for holding this press panel to allow us to reflect on our work as reporters on the eve of this 16th international AIDS conference. First, a little personal reflection – when I covered the first AIDS conference in Atlanta as a novice medical reporter for the Wall Street Journal in 1985 I was very naïve about epidemics. I was almost literally barefoot and pregnant. Half of that is true. I was pregnant. And that baby will next year be a senior in college. So you can see that we've all really grown up in this epidemic. And I see Victor Zonana[mispelled?] a former colleague of mine nodding in the audience. So we've all learned the lessons that HIV/AIDS has had to teach us harsh lessons of the virus itself and other equally important lessons about equity and compassion –fierce lesson, often tender lessons taught by the people that the virus affects.

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It seems to me as a reporter that AIDS has, in a way, changed everything. It's changed the way we look at disease and its spread. It's changed the way we look at research, how research is conducted, how we share the fruits of that research with the people who volunteer for studies, how the developed world shares with the developing world. It's changed the way we look at treatment - its development, its pricing, its evolution, the way it's administered. It's changed the way we think about access to care. It's changed the way we think about public health, outreach, control of illness. When does public health control become intrusive and coercive? It's changed the way we think about patient participation and informed consent. AIDS, in short, is a kind of crucible in which old protocols and assumptions are melted down and remade.

Of course a lot of these lessons that we see about scapegoating, denialism, blaming the victim, blaming the patient, are issues that have been with medicine since the beginning of time, certainly the great plague saw the same kinds of scapegoating. Jews were blamed for plague, for the Black Death in Europe. Similarly in San Francisco in 1900 when there was a small but interesting outbreak of bubonic plague Chinese residents of the city in Chinatown were blamed for bringing in what was then called Chinese cholera. So

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these are the kind of issues that recur in cyclical fashion, over and over and over again.

Each new round of drug trials, for example, has brought new questions and new lessons. In the era of AZT one of the great controversies was the use of placebo controls: why were they necessary? When were they necessary? When could we stop using them? When a new standard of care came in activists made sure that standard of care became the control group agent. In the era of the new prevention pill trials, the so-called prep trials, new scientific and ethical challenges have popped up. How to ensure test volunteers get all the protective gear that they need to even the playing field, whether that be female condoms or something else, and how to ensure that they get the needed care that they require afterward, should they become infected during the course of the trial. These are all lessons that reporters learn in real time as we report the stories.

How science gets reported – and again I should have to state that I'm speaking just from my personal point of view as a reporter and not representing editorial policy of the paper for which I work, the Wall Street Journal. It seems to me that we work in much the same way that all science reporters work. When we try to learn about a new field we read research reports, attend conferences, talk to the smartest scientists who will give us a call back –

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doctors, activists, people with HIV, those who represent them and defend their interests under law or in hospitals.

How stories are judged can vary. As reporters, we like to think of ourselves as crusaders for truth. Our editors may have a somewhat less exalted view of our role. As my colleagues often state, it's their world and we just work in it. So as the pace of the epidemic matures our challenges as reporters get more complicated. Editors get choosier about stories. And that means many projects that are eminently worthy as therapeutic and humanitarian projects in the world, which are worthy, may not be deemed newsworthy. So that just requires us, as reporters, to be smarter and more strategic in uncovering unique angles that make clear what really are the breaking compelling news developments in the epidemic. At the Wall Street Journal, for example, the paper where I work, every single story that runs goes through a proposal process. And sometimes we spend weeks just reporting the proposal to convince editors that a story is really as compelling as we believe it is and to get prime feature space reserved on page A1 or B1. If a story feels familiar to an editor they may say "no thanks". Embargoed news, news that's doled out in mass press releases is frequently less exciting to editors than, obviously, an exclusive or an enterprise story.

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In 1985 at the first AIDS conference at Atlanta I recall many, many lively debates with my editors about wanting more space than I was able to reserve. And that's probably the one thing that hasn't changed in 25 years.

As a reporter I stand among doctors, patients, advocates who are all my teachers and yet somehow apart from them, striving always to be an objective and impartial observer as a writer of a first draft of history and certainly not the final draft. A lot of times sources and readers confuse the messenger with the message. Often this will result in blistering phone calls and emails that burn up my Outlook mail file. Sometimes letters that are poignant, for example, one I received just the other day that began "Dear Sir," obviously from a personal friend. I'm going to conceal the identity and country of origin of this person. "I admire your work for HIV positive people. I am 33 years old, from a decent educated family. I found out I am HIV positive and have not disclosed my status to anyone, and not even my family. Now I am healthy and on medicine. I'm five foot eight, good looking, healthy, single and working as a software engineer. I would like to ask if you could help me find a life partner who is educated, decent, good looking, from a nice traditional family. I appreciate your help."

I hated to break it to this wonderful gentleman that I'm not a matchmaker. I quickly referred his email to the

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person I thought could best help him, a wonderful trail-blazing clinician named Suniti[misspelled?] Solomon in Chennai[misspelled?] who in fact does do that kind of work, helping HIV positive people looking for mates find the partner of their dreams and also helping them through the difficult process of disclosing their status to potential fiancés and dates.

Many of the lessons of AIDS, as I said – scapegoating, discrimination, inequity of care, constrained resources, the drive to find useful tools – have all been with us through the ages. Maybe with AIDS if we all work very hard, some of these lessons will stick. I don't know – it's too soon to tell.

With regard to Nathan's very pointed and important lessons about denialism, I guess I stand as one who has perhaps not written enough on this subject. It's very difficult because there are so many stories to cover, basically – transmission prevention, therapy, drugs, vaccines, preventive strategies, epidemiology, new risk groups, drug companies, pricing, above all the human stories that we need to tell to make clear to our readers the brute force of this epidemic as it continues to roll through the world. It's difficult to write about denialism in a definitive and final way if one isn't given space to do stories that are advocacy pieces and editorials. So that's a

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professional challenge that we face sometimes, although I do recall, when covering the Amsterdam AIDS conference there had been a story that broke across the pages of a prominent US news weekly about non-HIV AIDS. Perhaps some of you remember, and I got an urgent call from a colleague in New York saying "Doesn't this prove that the denialists are right?" And I remember having a furious argument all night long on the telephone trying to explain why people with random immune deficiencies and virus-like particles in their blood did not necessarily have non-HIV AIDS, and that in no way did this buttress the arguments of denialists.

But it's difficult, and another challenge that we face is that when a contrarian point of view or, in this case denialists might be roughly put in that class, is profiled, the demands of objectivity sometimes require almost line-for-line balancing of the story. And sometimes stories, without meaning to, can almost exalt the position of denialists by making them seem like just some sort of independent intellectual contrarian who's views really should be heeded. So if one does not have editorial control, 100 percent, sometimes it's difficult to ensure that even a story intended to expose a distortion on significant abuse of science actually delivers the take-home message that the reporter might intend.

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I should probably stop here and give you all the gift of brevity. I really can't improve upon the things that Laurie and Nathan have said and I'm sure my colleagues on the panel. I'll just thank you at this point for attending and wish you all a wonderful conference. Thanks.

[Applause]

TAMAR KAHN: In true journalist fashion I'd like to start with a story, and I'd like to take you back a couple of years to a late spring afternoon. It's fast approaching deadline hour at my newspaper when I get a phone call from a well-placed source who tells me that the health department has just posted its latest HIV survey on its website. Now this is very odd because political parties and AIDS activists have been clamoring for this survey for months, accusing the government of suppressing it because it contains bad news.

Every October since 1990 the South African health department has conducted an HIV survey amongst pregnant women who attend free state-run clinics. The survey covers all nine provinces and provides an important snapshot of the state of the epidemic. It's used by demographers to model the prevalence of the disease in the general population. And it's also a key indicator of how well government is doing with its prevention campaigns.

So this quiet, almost surreptitious, publication of the report is really big news. Just as strange is the report

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itself. The data on the tables and graphs doesn't match the text. The reports authors say that the epidemic is stabilizing, and yet the data shows nothing of the kind. In fact the report shows that HIV prevalence among pregnant women has risen 1.2 percentage points to almost 28 percent. And the report also includes an estimate of how many South Africans are infected at this time. And it's 5.6 million people, the highest government estimate to date.

So I call my front-page editor and alert him to my story just as he's heading into evening news conference. That's where the section editors finalize the order of stories for the next day's edition. And I start working on my story, pushing the health department's spokesman to explain why the report is being released in such a strange manner, without a press conference or press alert, just 24 hours after a political party has taken legal action to try and force it's release. And I try and get him to explain the difference between the text and the data, which he declined to do. Now you can imagine my surprise and my dismay when after all my racing adrenaline I get a message from the news desk to say that my story's going to be nipped. That's close to being spiked. It's a two-line paragraph on the right hand side of page three. The page one editor says to me, "Well evening conference decided that since there was only a 1.2 percentage point increase on what was already a very large

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number – well it's not much of a story." So we had a pretty heated debate and I eventually convinced one of my colleagues who edits the inside news pages to give me the lead on page three.

Now I've told this story not so much to illustrate the frustration of getting a story onto the pages of a newspaper, which happens to all reporters all the time, but to try and highlight some of the deeper problems around AIDS reporting in South Africa. In addition to a host of operational difficulties, which I'll come to in a minute, there's often deep ambivalence within newsrooms about how and what to report on the AIDS front.

Although the public controversy has moved away from the sometimes bizarre debates about whether or not HIV really does cause AIDS, but headlines in full force five or six years ago, thanks largely to the president's questions on the issue. We have plenty of others, and in fact we're still mired in highly politicized debates about the numbers. Nathan mentioned Rian Malan's conspiracy theories around inflated numbers.

But there are more. Four or five years ago the medical research council triggered a massive row with a study looking at how AIDS was affecting adult death rates. The study found 40 percent of adult deaths were due to AIDS and it was the first South African study of its kind. Yet it was

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immediately trashed by the government's main statistics agency, Stats SA, which questioned the author's methodology and findings. And the agency fed into a political agenda that was trying to deflect attention away from the lack of treatment at the time by minimizing the disease's effects.

And top politicians still regularly question whether millions of South Africans really are infected with HIV and how many are dying from AIDS-related illnesses. And denial about the effects of the disease filters right through to our newsrooms. And there's no doubt in my mind that pressure has been brought to bear on almost all news organizations at some stage over the AIDS coverage. So for reporters this means that in addition to the sometimes very difficult and fraught debates we have about whether our readers are getting bored with grim stories of the ravages wrought by the epidemic. They have to battle with newsroom editors who are inconsistent in their approach to AIDS stories. Many of my colleagues in the health beat can describe tough reporting periods when they were instructed by their senior colleagues to tone down their coverage of activist campaigns against government for its steadfast refusal, until November 2003, to provide AIDS drugs.

And many reporters can also tell you about important AIDS stories that have been spiked or suppressed by the news organizations. Now that's an incredibly stressful situation

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to be in as it compromises one's integrity as a journalist, and it can ruin trusted relationships with sources and contacts overnight. Reporters often work on their own in fiercely competitive organizations, and they often don't have the backing of a team to support them in these kinds of battles.

And even a few isolated incidents when stories are suppressed can have an insidious effect because burnt out reporters, wary of conflict with their newsroom bosses can also easily fall into the trap of self-censorship when the pressure is off.

The past year has seen health reporters in South Africa attacked on a new front, from a source that I think few of us would have predicted at this stage – the AIDS dissidents who you've heard lots about already. German born scientist Matthias Rath began waging an energetic campaign in Capetown about 18 months ago. He set up a local office, began handing out vitamin pills to AIDS patients after encouraging them to stop taking antiretrovirals, and within months he'd placed adverts in the newspapers, including incidentally, the New York Times claiming to have reversed the course of the disease with his mysterious pills. He claimed he'd conducted clinical trials but none were ever registered with the authorities. And his research was not published in scientific journals.

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Now his activities were widely covered by the media, and he took great exception to much of the coverage and launched legal action against many of the countries main media houses, including Business Day and Health-E, who you've heard about. He also held a press conference where he announced that he was reporting several health reports as to the War Crimes Tribunal in Hague for crimes against humanity. Apparently we were complicit in the pharmaceutical industry's plot to foist dangerous drugs on poor unsuspecting Africans. And he published a wall of shame on his website, which thankfully everybody ignored. And one of his partners in crime, a lawyer turned self-proclaimed AIDS expert, Anthony Brink[misspelled?] has also waged personal campaigns against a handful of health reporters and scientists.

Now the problems I've highlighted here relate to a broader range of problems within our newsrooms on the operational front, particularly when it comes to reporting emerging science. There's limited understanding of scientific research methods, risk assessment and the central role of peer review and peer review journals. So I often spend time educating colleagues and even downplaying stories from time to time. I think I'm probably one of the few reporters of my paper who fights to get off the front page.

Looking beyond the newsroom, getting information for balance, context to life science stories in South Africa has

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its own specific problems. Given that so much of the newsworthy scientific discovery work takes place outside the country, local reporters often battle to find local experts who can explain and interpret the research and spell out its significance for locals. We often struggle with the press offices at universities and technikons who tend to be fierce gatekeepers more intent on promoting their vice chancellor's latest speech than helping reporters find media friendly scientists. And scientists themselves in South Africa are often reluctant to comment, partly because they are a little wary and suspicious of journalists – often with good cause – but also because they are bound by institutional rules and procedures which frequently preclude them from speaking to the media without permission from their superiors.

Now throw politics into the story, particularly on the AIDS front, and good luck in finding an academic researcher who will talk about the results or methodology of a new study at short notice. South Africa's got a relatively small group of scientific experts, and sometimes there really aren't that many qualified scientists to choose from when you need comment.

To make things even worse, it's often extremely hard to get comment from government departments on HIV and AIDS-related issues. More often than now, for example, the health department's communications team is unavailable, doesn't

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return calls and issues email statements only after most journalists have gone home. And what this means is that often the only people who are willing to talk to journalists are the spokespeople for opposition parties and AIDS activists like the Treatment Action Campaign, who needless to say, each have their own agendas. It makes balanced, informed reporting extremely difficult and leaves journalists, many of whom are very young and inexperienced, particularly vulnerable to manipulation.

And just as a footnote, in interest of accurate reporting, I just want you to be aware that the figures I've used for my story are from about two years ago, and the most recent figures from government are that 30.2 percent of pregnant women attending government clinics are HIV positive, and 5.54 million people are infected. Thank you.

[Applause]

LAURIE GARRETT: As Honey is approaching, the acoustics up here are so hideous that I can barely tell what anybody is saying. Are you able to hear? It's clear out there? All right, so it's just the echo up here. We can hardly understand anything, so I just want to make sure that you're hearing okay. Honey, sorry.

KIM HONEY: My name is Kim Honey and I am an editor, the new scourge of the earth. It is true we're responsible

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for deciding what gets covered and how the reporters ask us or pitch stories.

And as health editor at the *Toronto Star*, it's a large newspaper, I've been entrusted with letting higher-ups know what's happening so that they can decide what's important. I'm there so that they don't have to worry about all those millions of papers and abstracts that come in. They don't want to look at them. They want someone else to do it for them. And I want to tell a little story about Gaetan Dugas who was a gay Air Canada flight attendant who died of AIDS in 1984. I think you'll remember the book by Randy Schultz, *And the Band Played On*, which was published in '87. And it pointed to Dugas as the patient zero who spread AIDS to the United States. He had sex with multiple partners, hundreds of partners, and kept a diary.

I'm using this story, it was based on a CBC study by William Dera[misspelled?], which was later repudiated and he had said the methodology was flawed, and he thought Schultz had misrepresented the data. But by the time the book was published, obviously, scientists knew that AIDS had an incubation period of a couple of years and later found out it was many years. I'm only using this example because I'm asking was it responsible of Schultz, as a journalist, to publish a book that at the time reflected what the science knew about HIV. And one of the Toronto doctors who was a

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pioneer AIDS activist said, "All of us wanted an easy answer, and a few wanted someone to blame." And the point I want to make is that journalism is history written on the fly. Who can say whether news today will be disproven tomorrow? Science is all about incremental increase. Hypotheses are posited, studied, proven and disproven.

The *Toronto Star* is a big paper. It's the biggest in Canada. It goes through 1.3 million hands on Saturdays. It had an AIDS reporter once back in 1989, and that year there were 1,300 stories written about AIDS in the paper. She personally wrote over a hundred. The next year again over a hundred – compare that to last year we had about 600. So AIDS has fallen off the radar in Canada, North America too, in part because it's seen as a chronic, manageable disease. It's something that people take drugs for but they live longer.

The question is how do we cover the story, and who are the people covering it? I think Nathan mentioned a lot of reporters don't have any experience in science, no science background. It is true of editors. I have some – I have a little, but I don't have a master's degree. I do not have a PhD. I do not have an MD. Most reporters who cover this beat are interested in it just from a personal level. This is how they get the jobs. They get some experience after a few years, then they gain some expertise. They learn things

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like double-blind stories are good, random is good. Large sample size, good. They get the basics, and they learn from volume of knowledge. The problem is the newsroom is a very high turnover place, and the minute a good reporter gets on a beat they'll get hauled off to do something else. Editors get shuffled around. So a lot of that knowledge is lost and has to be re-learned over and over and over again.

I think that's some of the frustrations of scientists when they're being interviewed by someone who's not Marilyn Chase. You know this is the problem. How do they convey what they're doing and how important it is? I think as editors and reporters we have to make sure that we go to, when we're reporting on a study that we have to go to another scientist and another scientist to ask them what is important about this. And this is what I've been trying to do with HIV/AIDS. It's not something that was really on my radar screen. We've written stories about people in Toronto who have HIV, but it was mainly about the effects of living with it long term.

The story in Africa is in the pages of the Star, but it's a city paper. It's not the top of people's minds. And there's intense competition to cover science stories too, including HIV/AIDS. There's four daily newspapers in Toronto. We're getting bombarded daily with a hundred emails I get as health editor for stories that need to be covered.

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The stream that comes at me is so intense that you're plucking things and hoping and trying to find out if it's important or not.

And I just think that as Nathan said, should we be in the business of reporting on science? Should that not be left to the journals? And I would just answer you can't stop the machine. The newspapers are in the business of making money, and their readers are telling them they want health news. And in every readership survey that comes it's top of the file, and they listen to them.

And that's why I'm in the position I'm in, our paper's devoting more coverage to health, and wants to give it more prominence for that very reason. And that's also the reason why I convinced them in September to make an outside hire, which in a union shop is very difficult to do, because I wanted a health reporter who had a science background. So I'm getting one in September. My other two reporters, one has been on the beat for a long time, she has a body of knowledge so she knows what's going on – and the other one has reported on science as well. But I made an argument to my editors that the day of the generalist is over, especially in science and medicine. It's too complicated. The science is getting down to the molecular level. Genetics is huge. You have to have someone who can understand it, who's biology 1000 is not 20 years old, as mine is. We have to have a

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specialist here, and once there was a time when the thought was that a good reporter could report on anything. And I still think that's true to a certain extent. But I also think that in this day and age we need to see a few more specialists out there.

And I'm going to wrap up because I know we're running a little late. And I'd just like to thank you for allowing me time to talk to you.

[Applause]

LAURIE GARRETT: Fantastic Kim. Thank you. What we want to do is have a lot of time for questions and for the engagement of all of you in the audience. And as you can see there are stand up microphones for you to use. But first, the moderators are going to take the privilege of tossing off the first couple of questions, and I'm going to seed the first opportunity to my colleague.

DANIEL KURITZKES, M.D.: Let me pick up on a point that both Marilyn and Kim raised, and that is the difficulty of getting access to scientists and medical researchers to be able to verify stories or to provide background information or information. What do you think that we as medical researchers can do to really help you to do your job more effectively and to help get stories out? And I'm not talking about pitching individual stories of our own, but to provide

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the kind of information that you need to be able to do your job.

LAURIE GARRETT: Let's have all three of you give a shot at that.

KIM HONEY: I'll just say quickly one of the big problems we have on a daily journalism basis is getting a hold of doctors. They're impossible to get on deadline. And that's a problem for us. The other thing is I think that you have to think of most journalists as being these uneducated scientific people. You have to explain it to them from the beginning, so they can explain to the public, which is also uneducated for the most part. So I think in that case when you're giving speeches, copies of the speech really help - facts, information sheets that go along with that. Some journalists that we were talking to in the conference room just before we came down here, that's what he was saying.

What gets reported? I'm going to report on a speech that has supporting documentation, so I can check what I'm doing and what's happening here. I know at the start the one thing I really want to do is try and get a little advisory panel together of scientists in the field so that they get quoted in the paper, but they also are the people we bounce stories off, so that we can have some confirmation of how important something it is and where it fits in the coverage.

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MARILYN CHASE: I couldn't disagree with anything that Honey just said. For starters, return our calls if you can. We're well aware that your first responsibility is not to teach us journalists, and we're also well aware that we're taking time away from the research you do and the patient care that you deliver. But just return our calls. Email us stats. I could just echo the things that Honey has said. And also the very important point that she raised about being willing to serve as a sort of ex officio panel of wise women and wise men that we can consult on a moments notice to bounce something off or to do a gut check, and just say, "I just read this paper about a certain research project, and does this sound legitimate to you? Does this sound important to you? Is this really as groundbreaking as it claims to be, or is this merely incremental? Is it completely off base? What do you think?" And that could be enormously helpful also.

TAMAR KAHN: I suppose my comments are probably more specific to South Africa than here, but I would give my eye teeth for a database of scientists who are willing and able to talk to the press because it doesn't exist in South Africa. And when I worked briefly in the UK, I had a database. I had books published by universities of people who could talk to the media. So it's two-fold. It would be great to have people who don't have to clear the

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authoritative hurdles and who could speak freely, but also we need to know who they are.

Laurie Garrett: My question's a slightly philosophical one, and I'm going to ask – in the interest of time – for just two of you to respond, for John to respond and for Tamar to respond. Here's what I'm interested in – policy gets made based on a set of sources of inputs. Two of the big inputs for policy and decision-making by political leadership is what's coming from the science and medical community and what's coming from journalism. And the truth of the matter is that journalism has a whole lot more impact. News, in terms of the sense that the constituency out there has been affected by the information, and they bounce it back to political leadership. But in truth what we see is that how you define the search for truth, what the methods are for getting there, how you assess whether or not something is accurate, is true, is very different if you are a scientist verses if you're a journalist, even if like me you are a former scientist turned journalist. Our methodologies differ. To what degree do the methodologies affect the bottom line, whatever tension may exist between the scientific community and the journalism community over how we do our jobs and what we decide is truth? John.

John Moore, Ph.D.: Well I'm not sure that there's a lot of tension between professional scientists and

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professional journalists. I'm sure all the journalists in this room are covering the subject skillfully and honestly. I don't see tension there as a general rule. The journalists I was criticizing are the ones with biased and inappropriate agendas, not the mainstream.

But you refer to public policy, and obviously public policy is influenced by the press, often rightly so. But if your public policy is flawed to start with the press can be used to reinforce it, and government press offices can be used to plant stories or to manipulate and twist science. And science can be twisted in this way by government, and clearly in South Africa, as Nathan and Tamar have said very eloquently, government policy is twisted by perverse science. It's the same in the States. Any of you who've read Chris Moonie's book *The Republican War on Science* or Michael Specter's [misspelled?] article on a similar subject in the *New Yorker* a few months ago will see how much the Bush administration twists science for political reasons on all sorts of issues. And the democrats I'm sure have done the same thing in the past when they were in power.

So we're all vulnerable to being manipulated for different reasons to promote agendas. And really science is about truth. It's not really about an agenda. And journalists need to get at the underlying truth and report it faithfully and honestly.

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TAMAR KAHN: While I'm going to agree with John on the point about them, I don't think there's fundamentally a tension between good skilled journalists and good skilled scientists. They're both curiosity driven, and they're both looking for evidence to support their arguments.

I think the problem in South Africa around policy is that that's precisely what's lacking. We wouldn't consider Matthias Rath a complete crank if he was providing evidence for the claims he was making. The problem is he isn't, and the question is why, in the absence of that evidence, does he have the ear of our senior politicians?

JOHN MOORE, PH.D.: Just to follow up on that point about Matthias Rath, he doesn't get any time in mainstream American newspapers. But he takes out full-page color adverts to buy the advertising departments of the New York Times and other major American newspapers. And these full-page ads with his avuncular face beaming out in a white coat railing against the United Nations and big pharma in the way that Linda Maruche[mispelled?] does, also contained things like clinical trial data that's clearly not peer reviewed, that is probably done under inappropriate conditions. But it's published in the New York Times and other magazines, other magazines because it's paid for as advertisements.

Now I know journalists don't necessarily have a lot of influence over the advertising departments, and money

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talks in this kind of context, but that's another way of twisting and perverting science in the context of major newspapers, and maybe there should be some more dialogue between the journalists and the advertising departments. And maybe money shouldn't be the sole determinant to what gets advertisements in New York Times.

LAURIE GARRETT: And maybe pigs will fly. I mean come on. We have a policy in the news world we call the firewall. And that is that no one on the business side of the paper is ever supposed to come over to the editorial side and vice versa. There's a bit of a farce to it a lot, but it's supposed to be there.

So let me give a chance for the audience to respond, and interestingly we're talking about government spokespeople, and you were talking about the inaccessibility of South African government spokespeople. We have, standing at microphone number three, the former government spokesperson for Donna Shillelagh[misspelled?] when she was our minister of health, if you will, in the United States. Vic Sonona[misspelled?] you have the first question.

VIC SONONA: Thank you. And I really want to thank all the panelists and the organizers. This was a very good panel, very thought provoking and very emotional. I remember Michael quite well. That was AIDS mono-therapy. We were trying to get him to take though, so who knows whether it

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would have made a difference. But your point was very well taken, Laurie.

The question is this, and I guess it's addressing it to the journalists. How does the journalist, and you [inaudible] about your editors not knowing the absolute truth or of the facts at hand. But the conventions of journalists, he said/she said journalists, cover both sides of the story, etc., how do you just shut down the lie, the absolute lie? Is it even possible? And if you've shut it down, doesn't that leave you open to accusations of cover up?

LAURIE GARRETT: Any one of you want to take that?

TAMAR KAHN: That's a huge debate on the paper that I work for. We talk about that all the time. Does balanced reporting mean you give the lunatic fringe equal weight or right – do they have right to reply? And we don't have a policy as such, but one of the solutions we've made about the AIDS dissidence is that we don't cover blow-by-blow every activity they do. We try to be selective. But when these people are given an audience by your health minister, your readers need to know that. And I think it's a difficult decision for any media organization, and the decisions that are made will also depend on their audience. So the kinds of stories we can run in a business newspaper and the level of education and scientific literacy of our readership is very

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different to a community radio station, and they would have a different debate about it.

DANIEL KURITZKES, M.D.: Marilyn, go ahead.

MARILYN CHASE: I have a slightly different perspective. You alluded to editors not knowing the facts or perhaps being more generalists than specialists. My position is slightly different. I work for and report to a Pulitzer prize winning science reporter turned editor, Alise Tenoi[mispelled?], who's very smart. And who reads the scientific literature very widely. So for me the challenge is simply getting enough space to tell all the stories that I want to tell. There are simply far too many stories, more stories than space. So that's my continuing challenge. And also I think you've raised a very good point. And I think one that is not easily resolved about balancing the conventions of structural objectivity, the built in line for line balancing paragraph by paragraph balancing, which you call he said/she said journalism, stories are allowed to have a point of view, but in the news columns we still try, in so far as it's humanly possible, to abide by the tenets of objectivity and partiality, which again run the risk of turning the denialist into a merely interesting contrarian who's worth everyone's interest, and perhaps should be listened to and heeded. So there's always a risk implicit.

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LAURIE GARRETT: Well something interesting on that ... there's a story in today's Globe and Mail. It's part of their package of set up of this conference. The story is all basically alluding to the conference as being a total waste of time, just a bunch of glitz. Why is everybody here? Maybe that explains why there's no banners welcoming us to this city as we come into the airport, why this is the first international AIDS conference I've ever been to where there's no visibility, no red ribbons, nothing about AIDS on the streets. You don't see it. You'd think we'd gone to the moon. But put that aside. The Globe and Mail piece has a long article that's basically one voice. It's Robert Gallow[misspelled?] saying this conference sucks and that's why I didn't come. Why didn't they interview the organizers to find out that Gallow was insisting he could only come if he could have a plenary speech. And when he was denied a plenary spot because he'd be previously offered one in Durban South Africa and then didn't show up, that is why he is not here. So you have this report that biased towards giving everybody the perspective or the sense that this is a trash meeting, that one of the great scientists in the world says there's no reason to come. And there wasn't sufficient delving to really get to the bottom. They didn't ask the organizers why isn't he here.

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DANIEL KURITZKES, M.D.: Let me go to microphone two and if you could please introduce yourself and say where you're from.

ELLA DECANN[misspelled?]: My name is Ella DeCann. I was a research scientist most of my life, and I'm from Ontario. I'm speaking as a member of the public. What really worries me is that you don't seem to make a differentiation between science and technology. Now everyone imagines science as squeaky clean and you mustn't challenge science. We must leave it to the spokespersons of science. Well coming from the science lab, science is full of prejudice as Laplant[misspelled?] said. Scientists don't change their minds. Old scientists die, and young ones come to take their place.

Science is also full of laboratory politics. But for all that it's objective up to a point. And so is medical science objective up to a point. But biotechnology and technology in general is business. And many of the journalists who stood up talked about business of journalism. Now, business is very much tied up with promoting it's self-image, it's profits. That all comes before the actual acknowledgement of the truth. It's very much tied up with obscuring risks and obscuring anything that would be bad news.

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Now I would just like to turn to AIDS research. Where does it fit in with science and other medical subjects and fields, or does it fit in with business? Well the trouble with AIDS research is it depends upon retrovirology. Retrovirology is the backbone of genetic engineering. Genetic engineering is the backbone of biotechnology. And biotechnology simply dominates all biology and biology funding. So AIDS research is unfortunately tethered to biotechnology.

DANIEL KURITZKES, M.D.: Why don't we take that as a question now and have Nathan Geffen respond. Thank you.

ELLA DECANN: The question I would like to ask you is do you understand that AIDS research is actually tethered to biotechnology rather than to science and medical research?

NATHAN GEFFEN: I'm not sure I do understand your question, to be quite honest with you. But just one point to make in response to that is that I don't think anyone here is suggesting that science doesn't have agendas, that scientists aren't human who bring their own biases to their research and that scientists don't make mistakes and that scientists choose to do research in areas where there might be vested monetary interests. But the point that we are making here is that it's for the scientific community to correct errors that result from that. The role of journalists is to explain science but also to expose or to publicize fraud and

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dishonesty or even a failure of ethics when it occurs in science, an example being the New York Times editorial a few weeks ago on undeclared interests in articles that were published in two scientific journals. That's the role of journalists as I see it. I might be wrong on that. A journalist or a media house doesn't have the skills or the knowledge to overturn scientific consensus on a particular issue. So I hope that resolves your question.

ELLA DECANN: Well that's not quite the point I wanted to make. I understand the problems with science and I think that generally journalists try and cope with that. The question I'm specifically asking is do you understand - you're here presumably to report about AIDS research. Do you understand that AIDS research is actually tied to technology, rather than to science?

DANIEL KURITZKES, M.D.: John, why don't you address that and then we'll move on?

JOHN MOORE, PHD: I don't accept that premise at all, and it also implies that there's something wrong with biotechnology, which I think is certainly a controversial opinion and it's not one that I share. I think biotechnology's an extremely good thing for society nowadays. But in terms of the relations with industry that you refer to, a lot of things the pharmaceutical industry does make a lot of scientists uncomfortable, particularly marketing

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practices. Very few scientists I know are comfortable with some of the antics of the industry. In the context of the AIDS epidemic though, the pharmaceutical industry has saved an enormous number of lives. And it's the pharmaceutical industry that make the drugs that save the lives. It's not university scientists. It's not clinicians who dose the drugs, it's the industry that makes the drugs. And that's not a trivial accomplishment.

So on the one hand the marketing of the drugs is something we're very uncomfortable with, but the manufacture of the drugs, and the discovery of the drugs is something that could only be done by big pharma. So there's two perspectives to this, and I think you need to bear in mind both of them.

DANIEL KURITZKES, M.D.: Marilyn, do you want to comment?

MARILYN CHASE: I would just second that, but also say that as journalists the questioner has raised a very good point. And it is our job to make clear the difference between basic science, for example the virologists and the epidemiologists who do basic research and the people who do translational research or applied research and turn those basic findings into potential products that can be used to test and treat and eventually to prevent HIV. And furthermore there is an important role I think for stories

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that look into the profit making machinery of big pharma, so I think those are all legitimate areas of enquiry. I don't think you can say that a retrovirologist studying replicative machinery of HIV is necessarily a tool of big pharma. However, it is an appropriate area of enquiry for us to examine pricing policies.

DANIEL KURITZKES, M.D.: Just make a comment and then call on Nancy Padian at the second microphone, that is that I think all science depends on technology to some extent whether you're doing nuclear physics and rely on the construction of large particle accelerators or whether you're doing cell biology and rely on development of powerful electron microscopes and other devices, or whether you're doing research in virology and depend on the tools of molecular biology, which have really played a huge role in our ability to tackle this. I also think that while we can certainly categorize different kinds of scientific enquiry as being more fundamentally basic or more translational or more clinical and applied, that as a rule these different kinds of investigation all follow the same general principles of being evidence-based, of setting up hypotheses to be proved or disproved by the critical examination in as impartial a way as possible of sets of data that are accumulated and then can be adjudicated by one's peers.

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LAURIE GARRETT: You know it's interesting, when you think about HIV, I noticed this is the 25th year since the original recognition of the existence of this new disease. And when you think about that 25-year period, you'll notice on the agenda there's a couple of sessions that are looking back 25 years, where are we, where have we gone. None of them actually really look at how the quest to understand HIV has moved science in general. The very first ever use of polymerase chain reaction or PCR for forensic purposes was to determine whether or not a dentist in Florida had given HIV to his patients. And that caused a huge explosion worldwide in the use of PCR for police, for all sorts of identification purposes and just completely moved that field.

HIV in the early days led to fantastic changes in the use of ELIZA assays and western blot[misspelled?] taking the whole field of diagnostics for viruses to a place they had never been before and rapidly improving that entire understanding. And of course thanks to HIV we now understand a whole range of issues in the immune system that were completely black boxes. When I was trained as an immunologist we referred to the entire cytokine structure, chemokines, virtually everything except antibodies and T cells as "accessory" components, as if they were meaningless, as if they had no import. And now, thanks to many scientists, including the gentleman on my right, we

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understand that actually that's where the ball game is. And we have a whole set of understandings of receptors on cells that we didn't even know existed, and whole sections of chemicals and proteins relevant to the immune response that we didn't know anything about before. And I'm sure if we really made a list of how HIV research has fundamentally shifted all biology research, it would be long enough that we could spend a whole session just delineating that.

DANIEL KURITZKES, M.D.: Dr. Padian?

NANCY PADIAN: I'm Nancy Padian from UCSF. I'm one of the papers that John talked about. I don't really have much to add to his slide, but certainly if anyone would like to discuss that I'm willing to do so.

But what I wanted to do is to make a comment and that is you're talking about journalists being trained and having a cadre of scientists. But I also think the reverse has to happen and that scientists need to be trained as to their responsibility to journalists and their responsibility to make their views known through the public venues as well as scientific venues. What really strikes me about this is I'm shocked actually at how few people are here. Now I don't know how well this has been advertised, but to me this is such an essential thing, especially as we've all talked about. I mean we're working in an anti-science era, and we

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have our role to play. And somehow I think we need to do better, involving other scientists in this process.

[Applause]

LAURIE GARRETT: I would agree that scientists have to become better communicators with the media, with reporters. I think there are several obstacles in the way. One is the old way, the peer reviewed journals, commandeering the way the news is released. And we've also seen with the recent debacle of South Korea that the journals aren't always right. It's very worrying for us. And I think that it would help a lot. I know some are better than others, and some get it, but they need to get this information out, but I think that they could help a bit more. I think the problem is the constraints of time on a newspaper are difficult. We need calls back immediately and that's not always possible. Scientists are traveling, doctors are busy. So that is a problem. And I think that it does need to work in the reverse. I completely agree.

JOHN MOORE, PH.D.: I agree with Nancy, and I agree with your response to this that there does need to be better dialogue and better access, and it is true that many scientists are poor communicators because we're not trained in it. We're trained to handle test tubes. And then there are multiple agendas. University press offices and journal press offices have the goal of filling newspaper column

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inches and they will put out stories that are in the best interests of the institution or the best interests of the journal but are not necessarily important. And yet they're rammed down journalists' throats and then the wood gets lost for the trees. If everything is a breakthrough, nothing's a breakthrough. So there needs to be more discipline. And again, like Laurie said, when pigs fly, these things will happen. But there are many things that are put out in the press as AIDS stories that shouldn't really be there. They're bread and butter, run of the mill stuff, but they fill column inches, and I don't know any answer to that. And there are sensationalist stories that are put out, the super virus that ate New York was the big thing of about 18 months ago. The final report on it was issued last week by the CDC and the MMWR and absolutely got no column inches. So what's out there is big sensation, everyone in New York's going to die of this rapidly progressing virus. And the final outcome of the story was nothing.

There's all sorts of bad stories out there and all sorts of good stories that don't get written, but it's an imperfect world, and we're all responsible for that.

NATHAN GEFFEN: One of the issues I think is that academic institutions, most of them, reward their staff by the amount of research that they publish. And in my view there should be a separate track that one can follow where

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one concentrates less on research, but more on being and educator for both one's students and the public. And universities actually need to do more work on that, on encouraging the stereotype scientist who likes to sit in a room and just doing scientific research to do what he or she does best, but also to encourage other scientists, who are probably not great researchers, but are good at explaining things and are good at teaching, to actually have career paths.

DANIEL KURITZKES, M.D.: Microphone three.

RICHARD HORTON[misspelled?]: Thanks very much. My name's Richard Horton, and I work at a medical journal. So before I start criticizing anybody else I should just say I plead guilty to all of the things you say that journals are responsible for. It is an imperfect world. We do our best, and every week we make mistakes.

However, I'd like to pick up on a couple of points, one from Nathan, one from Laurie. Nathan you raised a very interesting question about is ethics the problem? Should journalists refrain from challenging the scientific consensus? I think journalists should be challenging the scientific consensus every day. And I wish that journalists would challenge the scientific consensus on files[misspelled?], on SSRIs being used in under 18s, and in all the instances of research, which 18 months, two years or

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longer down the line turned out to be fraudulent because if it wasn't for journalists acting as a test of science that's published in journals, such as the one I work for, the Lancet, then actually we don't have a balance of power in the way science gets reported. So please don't ask journalists not to challenge the scientific consensus. So that's the first thing.

The second thing is Laurie's point. Back in the '90s I remember spending time with Celia Farber and Peter Duesberg, writing about what they were writing about for the New York review of books. And your question at the very beginning, why are we still doing this is the one that we actually haven't answered in this session, and we should be looking to an answer for that question. Why has it survived?

I think part of the reason is we're too polite. When [inaudible] steps up onto a world health assembly panel in Geneva she's listened to with deep respect. People don't walk off the panel. The director general of WHO doesn't not invite her to that panel, he welcomes her. So part of the reason is we tolerate these dissenting views. We respect them, and we actually pay tribute to them because those people who embody them are still invited to events and given a world stage. The day we stop doing that is the day we start to at least push that off the mainstream agenda.

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But part of the problem is also our responsibility in this room. Science reporting – you're right John, we do put press releases out every week from journals. And you know what, it amazes me that journalists write those press releases up almost word for word in the newspapers the following day because science is treated not like politics or trade or industry or any other department of state. Science is treated as truth, that anything that's published in a journal has to be right. That's wrong. We publish stuff that's wrong every day. And the idea that science is about truth on a daily basis is a complete flaw, so I worry about you calling your website AIDStruth. That creates an expectation. It fuels the myth that science is delivering truth on a daily basis. And we know it doesn't. All of us who've done science know it doesn't. So please let's be humble. Please let's be modest. But please let's go out there and not be polite with people that we know are wrong. Thanks.

[Applause]

JOHN MOORE, PH.D.: Actually I agree with almost everything you said in that speech. I think you said very many really good points, and I certainly don't want to see general scientific consensus go unchallenged on many things. But on the fundamentals of whether HIV causes AIDS, I think it is so certain that that is a true statement that

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challenging it to create trouble really does harm people. And that's where I don't know if we disagree with each other, but I think we probably do agree with each other. But I certainly don't think that science is an ivory tower that should never be questioned. That I'm completely in your camp with for very many reasons. So I think having said that I'll turn it over to Nathan.

NATHAN GEFER: I'm not so sure I do agree with everything you said. I agree with about 50 percent of it. For instance I think the fact that [inaudible] is continuously invited to WHO conferences is disgraceful. She's going to be here at 3:00 today, and I think that's a disgrace. And I hope that she'll get a hard time.

But you can't convince me that the British Spectator has the competence to challenge the notion that there is a vast HIV epidemic in Africa. You can't convince me that the Citizen newspaper in Pretoria has the competence to challenge Nancy Padian's findings. That seems completely unreasonable to me. In fact I'm not aware of a single case where a journalist has gone and done a few hours of research and written an article which has suddenly overturned the scientific consensus. I might be wrong. There might be one or two out there in history, but I'm not aware of them.

I'm certainly not suggesting that scientific consensus shouldn't be challenged. All I'm saying is that

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the mainstream media doesn't have the skills and competence to do it there. The scientific consensus should be challenged by people writing to your journal and saying well you've got it wrong on this, or you've got it wrong on that. Maybe I'm wrong on this. I admit it's controversial, but right now living in South Africa and seeing the effects of the utter drivel that's published daily - or maybe not daily - but regularly in South African magazines pushing nonsensical views that HIV doesn't cause AIDS or that vitamins can treat AIDS and the lives that are being lost from it, and it's coming through the mainstream media, and it's a big problem.

LAURIE GARRETT: I think that part of what's going on here is context. And there's a reason there are two people from South Africa on this panel. South Africa, Russia, China, to some degree India, these are all places where getting truth to the populace, especially uncomfortable truths about what's going on internally with HIV in their countries, is extremely difficult - difficult for NGOs, difficult for journalists. And it's a unique situation. So let me just make a couple of quick points.

First, there was a fellow - and I'm sure that Marilyn will remember this - named John Cruitson[misspelled?] one of our fellow journalists in the United States worked for a newspaper called the Chicago Tribune. For reasons I don't

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think any of us ever understood, Cruitson dedicated a fair amount of his life – I'm talking about eight, nine years of his life – to trying to destroy one particular scientist, Bob Gallow, and to prove that Gallow had stolen his samples of HIV from the French and robbed the French of credit for discovery of HIV. We could talk forever about what would motivate one journalist to try and bring down one scientific god and make it the major function of his life. But along the way when Cruitson got a lot of criticism from other science reporters who said basically, "lay off already you've made the point, move on," his response was, "Science reporters aren't reporters. They're stenographers," implying that we didn't really do digging. We didn't really do research. All we did was say exactly what scientists wanted us to say, which of course was a shock and a surprise to scientists. But I do think there was a certain validity to his point in the sense that a lot of science writers do overly rely on the journals and basically translating things straight from the journals without much critical analysis, and on scientific institution press releases, and again, without sufficient critical analysis. And I think that the point being made that part of the role of journalism, regardless of whether it's science journalism or business journalism or whatever the beat is, is the accountability

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role. It's the job to be skeptical and to always insist on show me the numbers, prove the case.

And now why would that feel different in North America verses say South Africa? I don't know if everybody in this room understands what's going on in South Africa, so let me give you the outsider tiny little nut version. I was recently in Kwazulu-Natal, in a part of Kwazulu-Natal where 27 percent of females under 18 are already infected with HIV, and where 66 percent of females aged 25 to 29 are HIV positive. This is genocide. This leads you to ask where will the next generation come from? It is in that same region that the former vice president of South Africa comes from. He is a major hero of the people of that region, the Zulu. He was arrested while I was in South Africa for raping a woman he had known since she was a child. And he had essentially been a sort of a surrogate guardian for when her father, who was a hero of the ANC, died. You folks can correct me if I'm getting any of these details wrong. And he allegedly raped her in his home with his wife in the home at the time. Of course typical male response when first arrested he said I never touched anybody. When the rape kit showed his DNA he said, "Oh, well she wanted it."

In the trial this man who, by the way not only is the former vice president but was the head of the National AIDS Commission of South Africa, said "I knew she was HIV

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positive." She was publicly HIV positive. "But I didn't need to worry about it because I took a shower right afterwards." Put aside that he completely justified the rape as "she wanted it."

Now what that means is that in a place where the prevalence is 66 percent for women aged 25 to 29, the most prominent political leader of those people has said all you have to do is take a shower. So you have the president saying HIV's harmless and irrelevant, and you have the former vice president saying well even if it is harmful, all you have to do is take a shower.

So it's in that context that I think this debate about how do you decide who's giving accurate information suddenly the stakes rise. For us in North America it's almost an intellectual debate. But if you're in Russia today where the president is insisting that HIV is an irrelevant problem, and yet they can't get military recruits anymore because 75 percent of young recruits are failing the entry exams for health reasons, with HIV, tuberculosis and drug addiction ranking as the chief reasons, it's hard to be a journalist covering HIV in Russia.

So we're trying to globalize this discussion and take it out of the comfortable place of Toronto into something larger. And I wonder if either of my South African

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colleagues would want to say anything or correct anything I've said.

TAMAR KAHN: No major corrections, just a point though. He was acquitted, which should probably be noted. And something that never has been reported, but Jacob Zu[misspelled?] is a Zulu, so having no intimate knowledge of the man, he probably isn't circumcised. So actually the fact that he had a shower after having sex was probably not such a bad thing. Now you try getting that across to the general public.

DANIEL KURITZKES, M.D.: We have a question from microphone two.

JACQUELINE BATERINGE[misspelled?]: Thank you. I'm Jacqueline Bateringe from the International AIDS Society. I just want to refer back to a comment made. So it's not really a question, but I'd like a little bit more discussion on it - that AIDS has gone off the radar. And I'm wondering what that means exactly. You did quote in terms of the numbers of articles and I think that gives me a little bit of a picture, but where is it coming from? Is it because we think we've heard enough? Is it the public is not interested? It doesn't sell? Because coming from an international and coming from Africa, we are always constantly concerned that we are not getting enough coverage; whereas, for example, issues of security will get a lot of

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coverage. Yet at the same time I feel that the level of sophistication on reporting on AIDS has improved, in that you will get detail. You will get analysis. You will get the kinds of coverage, of themes, the breadth that we never used to get before. I think over the last 25 years there has been a lot of improvement. So I just wanted to get a little bit more discussion from all of you in terms of getting us to understand where we sit on that issue.

DANIEL KURITZKES, M.D.: Thank you for that question. For the sake of time, I'm going to ask Kim and Marilyn to respond to that briefly. We have only a few minutes left before the session has to end.

KIM HONEY: I'll just be quick. I made that comment in terms of Toronto. The faces of AIDS in Toronto are primarily still gay, white. We have some people from countries where it's endemic. Those percentages are rising. Heterosexual females are also being affected. It's not like it's not a story here, but what I worry is that the story in South Africa is not a story here. And I think that's a function of the Star being a city paper. The foreign coverage is not something that is huge. I think even having a conference like this come to Toronto has increased my knowledge level by 100 percent. I'd say that the same of my reporters. This is how we accrue the knowledge, and I feel that it will be on the radar now because now I know and now

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my reporters know. And I think that it's a story that has to be told, and has to be told over and over. I think some people do have fatigue about it, especially the African stories are so heart rending that I don't know how many they can take.

DANIEL KURITZKES, M.D.: Marilyn would you like to make a final comment?

MARILYN CHASE: Sure just a quick view from the States, from San Francisco where I live. I would say that it is not true that in any way AIDS is off the radar screen. I think it is true that the epidemic is maturing, and so the pace of discoveries - back in the very early '80s every new incremental finding made banner headline news. And I say that literally, and I'm sure Nancy Padian and others who've been there since the first days will back me up. When it was found in saliva it was headline news. It was perhaps overplayed. It's not off the radar screen. It is maturing, so that every individual finding doesn't get the same type of banner headline display that it once got.

It is complex though. There is reader fatigue. There is compassion fatigue. Our editors are more demanding. I constantly hear "the bar is raised". The South African story, I have some very able and extraordinary colleagues, Mark Shutes[misspelled?], Roger Therough[misspelled?], Mike Philips, who've done stories out of sub-Saharan Africa

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including a recent story about the balance between nutritional assistance and being on ARVs to demonstrate the depth of the plight. Mike Philips did a story about a woman who actually went off her ARVs because she, unbelievably, lost nutritional assistance because she looked too healthy. So only by becoming sick once again could she restore her family's food supplemental benefit. So we do try to keep that part of the story before our readers' eyes in San Francisco. The story hasn't gone away. We don't see men becoming very cachectic and ill in the same way that they did in the early days of wasting and capensis[misspelled?] sarcoma. We do, however, see lots of men on the street with lipodystrophy who are seeking other kinds of treatment as a side effect of ARV care. So we do try to keep it before the public eye, and hang in there with each major development. We just have to be smarter, more strategic, more creative about the ways that we frame our stories to keep in the public eye.

DANIEL KURITZKES, M.D.: I think unfortunately our time is up. I'd like to first of all thank the panelists who each gave really very insightful and thought-provoking talks and to thank you for your discussion in the audience as well. I'd like to thank my co-moderator Laurie Garrett for her help in putting the symposium together, and particularly thank the HIV Medicine Association, the Forum for HIV Collaborative

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Research and the International AIDS Society for co-sponsoring this.

I think we've heard a lot of very interesting and challenging ideas, and hopefully these will stay with you through the conference and help inform the debate about these important issues, and we clearly all have a lot of work to do and a big responsibility, each from our own perspectives in terms of making sure that accurate and timely information is provided to the public and the policy makers who need that information.

LAURIE GARRETT: And I guess my final comment would be that there is absolutely nothing wrong with a journalist being passionate about their work. In fact I think they should be. I think if you don't passionately care about the stories you're doing, then you're probably bored and ought to move on. And we heard some passionate questions from the audience, which display a similar sense of things. The trick and the importance here is to distinguish between the passion and advocacy, between the passion and walking over the line into taking a position where you're aligned beyond where the facts and the data support. That's the bottom line.

And thanks again for all of you and to the organizers and the IAS for putting this together, and I hope that you all have a good time at the conference. Thank you.

[Applause]

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