Interviewee: **James McIntyre**

Interviewer: **Lebone Malele**

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LM: As I've mentioned it's a story telling session and feel free, be comfortable and lets chat. Lets chat about what you remember; what stands out the most in your memory, what you like to share with future generations about the history of AIDS in South Africa. So we'll start with the beginning. The story has a beginning. If you were to recall, what would be your beginning with HIV and AIDS?

JM: My beginning with HIV and AIDS started in fact before I moved to South Africa. I was still in Zimbabwe where I had qualified as a doctor and at the time there was talk about grit, this gay related disease that was starting up in the States and as a young gay man living in Zimbabwe there was nothing there and I remember writing to Gay Men's Health Crisis and asking for a list of references which they sent me at that point and so by the time I was working at Baragwanath Hospital in 1984 it, the western epidemic was starting to be described but it was something that wasn't really happening here. The first couple of cases in gay men were being described in South Africa around that time but it seems something that was very foreign from Baragwanath Hospital and the maternity unit and obstetrics which was my background at that point. And then in about 1987 the blood transfusion service got the first tests so it became available to test and they tested some specimens from pregnant women to try them out really and came back to us in a great state of shock to say that they had found 3 positives and at that point nobody knew what to do with anything, this was pregnant, pregnant Sowetan women and nobody knew what to do , how to set up so we started doing, starting to do tests more regularly and built up and built up from that. So I kind of came at it, came towards AIDS if you like from 2 directions, 1 from and then a community interest and the gay community and then secondly from my work as an obstetrician that led into a lot of the work that I've subsequently did.

LM: You had mentioned that you saw it as a disease why would you refer to it as a gay disease

JM: …. this was the first cases that were being described in New York and San Francisco and it wasn't something that anybody thought I think in the early 1980's was going to happen in Africa and if it was going to happen it was happening in well off white gay men who travel. But at that point had any conception of what was facing us in terms of a generalized epidemic across the continent.

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LM: And after you found out about 3 of the women being testing positive the pregnant women testing positive, what came through your mind?

JM: That again I think I realized how big it would get. It was something that was of interest and we started to test more regularly in the maternity services. We had by about 1990 I guess we had about 3 women out of 1000 who were testing positive. By the year 2000 we had 3 women out of 10 so this was the time that it really just went crazy you knowfrom 3 out of 1000 to 3 out of 10 was quite dramatic and that was the time that we started to set up a mother-to-child transmissions research and moving into services and really became very involved in it both as an academic doing the research and a little bit with AIDS Consortium and on the Human Rights and Activism side that we were going through. Of course that affected a lot of the physical turmoil that accompanied HIV and AIDS some good and some bad as we were making progress on understanding the epidemic from a scientific point of view.

LM: Great, we'll take a snapshot of what happened from 1990 to 2000 because you mentioned that the, what's it, the infection rate went from 1, from 3 out of a 1000 to 3 out of 10, what do you think happened?

JM: I think that we were just really seeing the epidemic starting to take off within a general heterosexual population where, where it started in terms of trucking routes perhaps or certain nodes, I think nobody's very sure of certainly we were working in an urban township setting and it really started to spread very fast and so we saw this, this huge trajectory of increase as it went up. I think that all the factors that still exist that work against women and particularly in terms of transmission whether nobody, nobody really understood that women were at risk for a number of years. There was, the only thing you could do was use condoms which women were not able to negotiate. There were all of the structural barriers all of the issues around women, women's rights that were, had to be kind of through and are still not sorted through so everything that makes women vulnerable now was making them especially vulnerable at that time of rapid increase as well.

LM: So what challenges did you face while being with the mother to child transmission prevention plan?

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JM: I think that we, I think we made in retrospect quite rapid progress in understanding what was happening with mother to child transmission and understanding what might be possible to do. So when the first trials came out in the US of the use of then AZT to prevent it we were already part of a kind of International African Research Network that was starting to try and understand what we could do because at that point AZT was costing 1500 Dollars or something it was a huge amount of money so, so it was felt that nobody could do that within the settings that we needed to work in. So we were looking for shorter courses, we were looking for cheaper regiments such as Nevirapine and we did quite a lot of that research along with way along with colleagues in Uganda and colleagues across the world. And once we knew that we had something that would work especially in Nevirapine a single dose we thought it would be easy to get implemented. Unfortunately that's when science and the politics collided and so we went from, from in fact being you know doing research that everybody welcomed that the country saw as being beneficial to trying to start a programme in Soweto against major resistance from the politicians at that point particularly at a National level not from local people. So we in 2001; in 2000 we started giving the Nevirapine at Baragwanath in 2001 we started to roll it out across Soweto and that was exactly the point when Minister Tshabalala-Msimang was trying to stop anybody doing this and that had continued even before her. Nkosazana Zuma when she was Minister of Health had said 'that the country just could not afford AZT and would not do it' and so we were arguing as many others were including the birth of the treatment action campaign that this was really a right that not providing a drug that could stop children being infected, it was against all principles so we had, we were increasingly becoming vocal, vocal kind of activists for the right to prevent mother-to-child transmission and then trying to roll it out. We had external funding and we in fact were the first programme across a whole district like Soweto to do that much to the dismay of the Minister who was not happy about it at the time to put it mildly. So I think that by the time we came to the 2000 Conference we were already in the thick of it because we were seen as being protagonists for either AZT or Nevirapine and for moving towards treatment issues as scientists and I think that's, I think that's something that we've lost to a certain extent that the AIDS scientists of that really early era the researchers were really also activists and I think that you know the people that, that I'm sure you've met the Mary Crew's, Jerry Coovadia and Glenda Gray's they were all as much activists for what we were trying to do as scientists who were giving the scientific background for where we were going.

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LM: Great, lets track back to the time when science and politics collided. Do you want to share some of the resistance that you received while working with your colleagues in rolling out Nevirapine or getting access for other mothers and children.

JM: I think that the, in fact the collision started before Nevirapine. It started first off around the Sarafina play and the perceived misuse of funds there and that put a lot of people on a collision course with Minister Zuma at the time. It then, we then came to Virodene and all of the saga around this, this so called magic cure that was found in Pretoria that was backed by Mbeki and which really I think started most of the huge fight that was happening because that led in turn to the denialist years and the AIDS panel of 2000 and all of that was a background in which Nevirapine was coming forward to the extent that there had to be a constitutional court case around the provision of Nevirapine brought by TAC and Erin Saluti and others that eventually the court ruled that the Minister had to give it. So all the way through that there was a great deal of fighting going on between the prevention of mother to child people and the Minister at that point. Intensely personal at times and very destructive you know along the way and even when the constitutional court ruled that Nevirapine would have to be given, there was a lot of delay in trying to move it out and at the Barcelona AIDS Conference in 2002 Minister Tshabalala-Msimang said to a journalist apparently that 'she not going to be forced to give poison to her people'. She subsequently denied it but the journalist came to me 5 minutes later and told me about it so I think I believed it and so that it really was a, in thinking back it was a very difficult battle because we were absolutely convinced we were right and we were right from a scientific point of view and that everything that subsequently happened around avoiding treatment, around HIV doesn't cause AIDS that around all of the dark days of what the Mbeki Government was doing in trying to avoid moving towards antiretrovirals which resulted I'm sure it's true as we're told in 300,000 odd deaths was a very difficult period and it was difficult not only because of the science was being questioned, you know science is there to be questioned, it was difficult because all sorts of strange things were happening on no scientific basis whatsoever…

LM: The dynamics and the garlics and lemons...

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JM: Ja and the garlic and the lemon and the olive oil and the beetroot, all those things that no one eats anymore.

LM: Let's go back to when you were mentioning that it actually started with Virodene, so what actually happened? What do you think happened at a National level that pushed South Africa to end up being where we're saying pulling it to year 2000 with the denialist era having being at its climax?

JM: I think the Virodene story is probably still much more complex than anybody realized it at the time. Quite how the people behind Virodene were able to convince leading people in the ANC that this was the answer, I think some of it sounded attractive. This was a period of when the Government was fighting drug companies where they perceived a lot of this to be driven by western drug companies wanted to sell drugs and so along comes this Pretoria group who claim that they have found this wonder cure and to non medical people I think it probably sounded quite compelling.

LM: Yes they were also quite desperate.

JM: Exactly they were desperate, it was an African solution, it was all part of the African renaissance everything else and somewhat strange on the basis of what it was and then as soon as there was push-back that's when I think things went wrong. Instead of listening to the scientific community, the Medicines Control Council who were against pursuing it and everyone was saying 'this is crazy' they went into this defense mode and Mbeki actually wrote letters to the newspaper, he wrote opinion pieces in the newspaper as Deputy President. Magnanti who was the Secretary General at the time was defending these things so and the researchers the so called researchers went and presented it to Cabinet and the next day it was a full page on the Star. So I think it became very difficult for them to back track and what that did it created a backlash against mainstream scientists and mainstream researchers and a level of paranoia that you couldn't criticize any one piece of what the Government was saying what I've been seeing as a traitor to the whole Government. And so that's what I think was really sad because most of the people who were at the forefront of the AIDS denialist fight were in fact the same people who had been in the struggle against Apartheid and who had been part of determining ANC policy just before '94. Jerry Coovadia you know Glenda Gray people like me so everybody had come from the same background and I think that in some ways that added to the betrayal that Government felt was that how can you be against us, you know what, how

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can you let us down, how can you turn against us but it just went so completely crazy in the opposite direction until we ended up with the panel and the meetings of the panel just before the Durban AIDS Conference.

LM: What, what ground existed that denialism actually you know grow and grow and have the impact that we would now live in?

JM: I think that some of it was driven by President Mbeki who was, who is, was and is clearly a very intelligent man and who without the right lens of interpretation came across a lot of the denialist theories and without fully understanding all of the virology and everything else that went with it to be able to understand that it didn't make sense took those on board and they were very compelling debaters shall we say. They, you know that it's, you couldn't, it was really, it's really difficult to argue with them because they, what they were doing was quoting little sentences from journals and so to rebut it you would have to go back and kind of say 'but this is not what it is not what it is' which is all possible but it was, it was a picture that was being assembled from different pieces that didn't make any sense that the fundamental basis of what they were saying didn't make sense. However things that they said I think resonated with, certainly with Mbeki at the time with Peter Mokaba, with various other people which is how did a virus; how can a virus know what colour a person is? Why is this happening to blacks and not to whites and why in the US is it white men and in Africa its blacks? In fact it's the other way around the fastest growing now epidemic in the US is in young black men so you know now that argument probably wouldn't hold but, but because it wasn't going back and understanding the context of where this virus was being transmitted and how it was being transmitted. It also, there was a document called "Castro Hlongwane" I can't even remember the whole thing "Castro Hlongwane Geese" something like that, I think I've blocked the title from my mind which, which was written at least in part we know by Peter Mokaba and many people believed that Mbeki wrote parts of it. Some of it really reads like Mbeki and a lot of it was a tirade against researchers, against drug companies, against the people who believed that HIV was virus driven. It named, named I think four people specifically, Glena Graceland, Kurame and somebody else and a part of it was around this whole thing that the west had started to perceive black men as incapable of sexual control as just beasts and was all fed into that and again that was the conspiracy kind of theories that were going around and were describing it. I think what then

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happened though was that nobody, nobody could challenge Mbeki so there were anecdotal reports that in a Cabinet meeting he'd said that there 4 doctors on this cabinet at the time and he challenged them to tell him 'how a virus could cause a syndrome', this was his big quote and non of them could do that and so he told them 'that if they didn't know what they were talking about they should keep quiet' so, but I think it was just part of the politics of the day as well. He was becoming unassailable in some ways he was and really was holding control and so there are lots of people now, Frank Chikane's book says it, but lots of people now who claim that they didn't believe and they didn't support it within Cabinet but nobody was, everybody was too scared to do it and the Health Minister completely bought into it all and with great verve so it was a, it was a really strange time I think and I'm sure that people around the world were looking at us all saying 'what on earth is going' on it just didn't make sense at that point. Well having said that they were, there was a President in West Africa who claimed to have discovered his own cure which he was selling at the time. I mean there were lots of other things happening it wasn't just here and I think what was sad here was that South Africa had, still has but had even then probably one of the strongest contingence of HIV researchers in the world respected globally for the work that they did and yet that's the group that Government turned against and rather put their faith in a bunch of cranks quite honestly.

LM: Like all the Mbeki's and every other…

JM: Exactly.

LM: You mentioned earlier, on that there's certain parts that you tried to block out (any particular reason why?

JM: You know I think, I think retelling the stories of those years doesn't quite convey the kind of level of personal animosity that everybody was being subjected to and the kind of stress that was going on and I think everybody who was part of it actually was subjected to a great deal of stress in spoken or unspoken. Undermining of all the work that the people were doing and I think it was it probably was a quite a lot of personal cost that the people continued that was part of the, was try to push people out of the field I suspect but no I think that it just, it went on for sometime I think that there's just lots of it that has kind of gone under the bridge. I know that you know people were convinced that phones were tapped and it sounds, it really sounds like conspiracy theories on the

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other way round but to the extent that there were some kind of pretty strange things happening around the time and it just seems bazaar to think that, that a bunch of scientists were kind of had become the focus of the Governments communication campaign, the focus of like public enemies you know it was really weird.

LM: So do you think that what was happening in South Africa was exceptional if you actually put in a global context?

JM: Yes so the same group of HIV denialists who were advising Mbeki or if we can call it that certainly had some following in the US but miniscule. They had very little credibility anywhere in the scientific establishment but here they were being lifted up to you know to be equivalent to mainstream scientists. So on the panel that he formed I think there were 25 denialists scientists and 25 mainstream but in fact you know in a global proportion they should have been maybe one denialist to 25 mainstream so they were given weight way beyond their status anywhere else and I think it kind of unprecedented that, that a country facing a huge health problem like this would kind of closed down and move into denial about it and the motivations for that I'm not sure anybody will ever understand. Perhaps President Mbeki will one day explain it but it's really hard to understand how a whole Government got swayed into taking that viewpoint. Was it because they thought they couldn't pay what they thought would be too expensive, I don't know. Was it because it really was seen as a racist thing that these were predominantly white scientists trying to tell them what to do, I don't know. At what point you know by the time we're talking about nearly a third of pregnant women are infected, everybody knows somebody who's died in their family. At what point did the entire Government establishment decide that lemon and olive oil and garlic was going to cure this when they all had kids dying I mean we also know that their relatives were dying, all their relatives were getting treatment you know they had access. What point did this not, did this disconnect? And I think by, you know by about 2003 when Mbeki said he would withdraw from the debate and the Cabinet started to move towards an Anti-retroviral programme but it really wasn't until after Minister Tshabalala-Msimang was out of the post and that anybody could do anything because the barriers were still there all the way through.

LM: All locked in.

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JM: All completely.

LM: Let's go back to the treatment rollout in South Africa, so what would have happened between 2000 to 2004 because by then the Cabinet had, I beg your pardon not the Cabinet however but the drug prices had reduced.

JM: So I think that first off we, I think it's almost impossible to underestimate the, overestimate not sure, underestimate the power of the Durban Conference in moving that forward. By the time people came to Durban in 2000 there were all these arguments about how treatment would never happen in Africa you know the, and they continued around it but it was a cost issue it was a feasibility issue, it was even for some senior American Politicians that African's didn't have watches and wouldn't know how take their drugs I mean every reason in the world was being thrown at it. I think what the Durban Conference did was it changed that mindset and it really did lead to a lot of what happened beyond that so I mean I think that it was a remarkable kind of time and maybe it was remarkable exactly because of what South Africa had been through up till then with the whole denialist issue because it all kind of collided and so what you saw were some limited projects starting to provide treatment, Khayelitsha with MSF. We had funding from, initially from the French Government to put, it sounds crazy now to put 100 people onto treatment in Soweto and it was, there were 2 parts to it, the part of it was for PNTCT programmes and part of it was to put 100 people remembering there were probably only 50 people in the State sector on treatment at that point somewhere to put them on and we, it took us a long time. We eventually got sign off from the Department of Health because it was bilateral kind of money to do it and Manto Tshabalala-Msimang denied vehemently for years that she had ever signed it despite the fact that she had and then she told everybody that I had tricked her into, tricked her into signing it to give poison to her people again so we had started this tiny, tiny pilot and that was about 2000 so we had a little bit of on treatment from that but the rollout only really started going after the 2003 Cabinet decision and into 2004 and then I think the ramp-up or the scale-up of treatment infectors almost entirely dependent on PEPFAR funding beyond that. I think if for all sorts of reasons that we had concerns about PEPFAR under George Bush. I think it's absolutely undeniable that South Africa would not have treatment programmes now had it not been for that influx of PEPFAR funding that came in the years that followed because that really enabled people to start services to work within Government services, to

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get people on treatment, to show it was possible and to assist Government once they did commit to doing it, to assist Government in being able to extend those services.

LM: You know let's look at the enablement that PEPFAR gave to South African society in as much as the Government had in a way over emphasized the cost of rolling out the treatment. How did society themselves then champion the cause of saying 'you know what we'll do this ourselves, we'll get the treatment rolling'?

JM: I think that what PEPFAR enabled groups of organisations like ANOVA like FPD like BroadReach it gave those groups the ability to go in and work with Government. Government had at least on paper a commitment to doing this but no capacity to move either money or staff or anything else and so the PEPFAR partners were able to go in and provide that additional capacity that could get things rolling. They were less constrained by the bureaucracy or the corruption whichever way it worked so if a, you know if a fridge was needed in a clinic that couldn't be bought easily through the system then it could be there the next day. If two nurses were needed to run an Anti-retroviral programme they could be put in place by that partnership so it just enabled things to move fast which would not have been able to happen and still in some of the handover that's trying to happen now the constraints are still there, it's still not easy for Government to move even with a, you know the biggest political will in the world. So I think that it did that and once, once the numbers started to go up, once it wasn't 100 people on treatment but it was 1000 people there and it was 1000 people here and 1000 people there suddenly it, people could see it was possible that people weren't dying from taking the drugs. Another claim the denialists were making was the drugs that killed, that people were within their own families seeing this Lazarus effect of people getting well and able to go to work and doing things and the services could see that they weren't completely overwhelmed. You know some very senior Public Health people argued against Anti-retroviral rollout because they said it will destroy the Health Service, everything will just go into HIV and the Health Service will be destroyed around it and in fact it had the opposite because in fact building the capacity for Anti-retroviral's services has strengthened services, not as much to the good but I think has a good foundation for strengthening other services because people look at a functional Anti-retroviral service and say 'well why isn't diabetes care like that, why isn't something like that'. I think, I also think that it enabled medical and civil society parts of the whole to work together. So I think that the

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civil society movement that pushed for treatment was absolutely essential. Without that it wouldn't have mattered how much money came in but I think that the combination of the sciences of a civil society and then the ability to have funding to do something Government was not able to move fast on actually all came together to enable that scale-up.

LM: What are the moments that made you sad and also the moment that made you happy during that friction moments of trying to actually get the ARV's rolled out not only in Khayelitsha but to see that are countrywide?

JM: I think the sadness comes from people from whom it was too late. Women who we started out our PMTCT clinics with who died along the way you know because the treatment just wasn't there for them and really understanding what that means. I think there's some degree and sadness in or maybe that, maybe a sense of failure that we just were never able to get our view through. It's kind of 'was that our fault did we do that wrong, did we create some of this but by not being able to explain it' I don't think it's true but sometimes you; you kind of have those doubts. I remember being called before a meeting of what was then called MILMEC it was the Minister of Health plus the Provincial MEC's of Health to discuss Nervirapine and being absolutely mauled by Manto Tshabalala-Msimang in this meeting, wouldn't let me talk, told me to go and sit down because I was distracting her with my white hair it became a quote that we've used quite often but the, and then you know absolutely vehemently attacking everybody who was anything on this and the sadness was that people sat around that room and didn't say a word. The Provincial MEC's were so terrified that they'd come afterwards and say 'oh sorry about that' but nobody would question it. Its sadness that the political process had got to that stage where nobody would question when they were so out of touch with what people were actually were thinking around HIV and experiencing, I think that was sad. I think the highlights of the fact that it has sorted itself out to some extent that we now have programmes that work. The Soweto Programme that I was talking about that we started in 2002 across the whole of Soweto. At that point we had about 25% of children born to HIV positive mothers who were infected and this year we have 1% so you know seeing it, seeing something come from the very, of the beginning of the first identified cases through to trying to understand what was going on to understanding transmission to understanding how to stop transmission and developing a service that actually is doing that is clearly very, very satisfying and I think the Anti-retroviral

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services are showing the same thing. We now have, when in 2001 or 2000 when we were arguing about this 100, getting drugs for 100 people and Soweto now has something like 60,000 people on Anti-retroviral so its, sometimes we don't stop to take stock enough of, you know we're so busy moving on and moving on that sometimes it's good to look back and see the successes and I think that that really is remarkable and those are being mirrored in various other places across the country.

LM: You know I'm still trying to understand why there would have been such a stronghold to other political leaders by just 2 people, 2 key people. What do you think was going, was there really a democracy concerned that were in a so called New South Africa while the democracy was in the political leadership?

JM: I think people were afraid to talk, number 1. I think they were, they were really controlled by the Mbeki Administration and I you have to, you have to look, you probably have to look beyond HIV to really understand it because I suspect the same thing was happening in other fields. HIV just became the flashpoint for so much but I think there was a much more centralized approach to control that was developing within those years under Mbeki and that I don't know if we'll ever know but I think it was starting to be quite a ruthless Government that if you, you either agreed or you were sidelined very fast. I think there are lots of lessons in there and I think the other lesson is that if civil society doesn't object then you get the Government that you deserve and HIV is, HIV is where, HIV is where civil society objected. Had it not been for the continued mobilisation of civil society which backed up the science I don't think we would have got anywhere. Nobody really cared what a handful of scientists did, they did care that TAC was able to get thousands of people out and marching and successfully keep it on everybody's agenda. So you need both and you know we complain often about Government as South Africans about any aspect of Government but we don't often do very much about it and I think that the lesson from HIV is that you also have to do something you can't just complain.

LM: Are there any other stories that stand out in your memory right now that you'd like to share with us for future generations to remember that you know what…

JM: Ooh no I don't think any of those stories should be told. No I think that…

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are the good bits those are the juicy bits.

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