Interviewee: **Linda-Gail Bekker**

Interviewer: **Lebone Malele**

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LEBONE MALELE(LM): So as I've mentioned before we are going to recreate the history of HIV/AIDS in South Africa and how we as a country have actually gone through a certain series of events and over and above that the triumphs and challenges. So start off by you telling us your background within the area.

LINDA GAIL-BEKKER (LGB): So I'm a medical doctor, I'm a specialist by profession in adult medicine with an interest in infectious diseases and more recently I am the Deputy Director of the Desmond Tutu HIV Centre so I spend most of my time doing research, most of it Health Service research in HIV, tuberculosis and related infections and diseases based at the University of Cape Town.

LM: And when was the first time you heard about it?

LGB: So yes my profession takes me to the sort of HIV and it really was a turning point in my career in that I left medical school and internship believing that I wanted to be a geriatrician actually, so I was intent, I had been trained under JP Mering, I had read his book and I was determined to be a very good geriatrician and went up to, did my internship in McCord Zulu Hospital and for reasons that are many ended up at Eshowe Provincial Hospital doing my sort of bush doctoring as it were. Whilst at Eshowe Provincial Hospital I started to just kind of count heads so numbers of people turning up with HIV related problems and going through our HIV Clinic which we kind of cobbled together, we were a bunch of medical officers finding our way there were no specialists in our hospital that were full-time, there were some part-time specialists, and started to literally count heads and recognise that this thing was turning out to be a really big problem. I remember our first case we sent by ambulance to, we knew of these two people in Durban by the name of Karim who knew something about HIV and so we sent one of our patients by ambulance and I remember the driver of the ambulance put himself in one of these white sort of you know alien type suits to transport this poor individual who I'm sure was more frightened that anybody else to Durban to meet with Slim Karim and the team in Durban. But we as Medical Officers you know really were trying to understand what was happening and had this overwhelming sense that people were dying and we didn't know why. We knew that it was related to the infection but didn't really know causation of death and I to a fault, I am inherently curious, but I also need to know the why in everything you know, the mechanism, and so actually as a result of that wrote to Professor Benita here who was the Head of Medicine to say I need to come back and become a specialist in medicine so that I

can understand why these people are dying and do something about them dying, so that was my journey back to Cape Town.

I specialised in medicine after four years in Eshowe Provincial, I remember that during that time I literally as I say counted heads and had done some statistics and so on and I found myself in Robin Wood's Unit at Somerset and he of course had been to Stanford and really engaged with the very early HIV epidemic in the heart of San Francisco so was, and this was at the Somerset Hospital here at the Waterfront, the new Somerset Hospital, he had come back as a consultant, I arrived, so this was 1992, I had been at Eshowe from '88 to '92 so that was the time when the epidemic was really beginning to break and I guess Kwa-Zulu was hit very hard at that stage. Here the epidemic was different, Robin Wood was working at Somerset Hospital and the Clinic had been, it was really one of the first HIV Clinics I believe in the country run by Frank Spratlin at the new Somerset Hospital in Green Point in Cape Town and Frank was a haemophiliac and I think that is what drove his particular interest but at that stage the epidemic was very much again white man's epidemic much as Robin had experienced in San Francisco and so it was the sort of Sea Point, Green Point you know group of young men also grappling with this new infection that was seeming to target gay men and Robin's in fact tragedy Frank Spratlin was killed in a car accident and died and Robin took over the new Somerset HIV Clinic at that stage. And so there were a group of us who I was a new Registrar and a few other interested people who started to work at the Clinic and in fact we have some staff members who were in that original Clinic, so Liz Fielder who I think needs one day when the medals get given out around HIV she's a deserving member, Felicity Cope, these were people who really engaged at the very start of the epidemic and in fact we documented with Carolyn Williamson the change from the Plate B epidemic that was largely gay white men to the Plate C epidemic that is generalized that we all know today, and so we were actually able to show how the numbers of specimens changed from being predominantly Plate B, sub-type B to sub-type C as we know it in southern Africa now. And so I think we had our Clinic on a Wednesday afternoon and after Clinic every Wednesday we would all go across to the Waterfront to the pub there and you know have a pint or two and kind of deal with the fact that our patients mostly died in those days and it was just a matter of time and so we did everything we could to make their lives comfortable to you know cope as best we could but they inevitably, and it was Liz's job, she went through the obituaries every day in the newspaper and it was a case of I wonder who is still alive and of course, more people were coming in the door all the time. During that time we developed a cohort of natural history, so people who had the

infection but clearly we didn't have treatment at that stage and that was called the CTAC cohort and it was an important cohort for if you like becoming the benchmark against which to compare treated people, so the minute we could start treatment we had this historical data of progression to AIDS, the time that people took to die, the kinds of diseases they were getting and a lot of papers were written, we are researchers but a lot of formative research was written in those early days of what the epidemic looked like in the early days.

In order to access treatment which we were very aware of, and now we are talking the early '90's, we became aware that we needed to experiment with these antiretrovirals as well and so Robin who had established a lot of links with the first world after his Fellowship at Stanford and in Tom Higgins Lab in California managed to access some drug companies and we started to do some clinical drug trials with antiretrovirals and it was our way of getting people on to antiretrovirals, so we actually over that type 400 or 500 people who would otherwise have died but thanks to getting on to an antiretroviral clinical trial actually you know survived and we had a party for some of them that are still around all these years later and you know of course their contemporaries largely have passed on. But there were battles even then, the Ethics Committees were very unsure about whether it was okay to do antiretroviral drug trials because the feeling was we'll never be able to afford this medication in South Africa and therefore we shouldn't even do the clinical research and you know therein lies the lesson in its own right because I think if we had followed those nay sayers we would have been set back many years, as it was we started to bring the drugs in the form of clinical drug trials. It gave us leverage to say to the drug companies you can't only run this drug trial for two years you've got to provide compassionate use and so we were able to leverage care for ongoing and it created a level of expertise, at least amongst the clinic drug trialists and the academicians around antiretroviral usage which was very important because it enabled some of the activism that needed to happen. First of all we could show these people live so much longer, these people can take antiretrovirals, we can you know Catherine wrote that seminal paper of it is feasible, at that time then the Nazios the envoy, poor guy you know he'll never live this down but he made some daft comment somewhere, he was the American envoy to Africa somewhere and he made the comment that, I forget the details of where he was but anyway I remember his name very well and he made the comment that Africans will never be able to take antiretrovirals because they don't know the time and of course we were outraged and set about to prove him totally wrong and of course we had this cohort treatment where we could show not only were our patients taking treatment exceptionally well but they were doing it

better than anywhere reported in the first world literature, so people recognized that death was there and these drugs were my saviour and I had to do everything I could to take these treatments well and they did so superbly. So Catherine Oral who is our sort of adherence guru in the organisation showed beautifully how not only was the virus suppressed but it was suppressed over a great deal of time and that work is continuing. And we've seen those consistently good results over a period of time, you know we've seen that Africans take this treatment brilliantly well you know, they stay on their regimens, they really do adhere. So those were the early days and so you know as I say about 400 to 500 people started antiretrovirals in that way and so that was a new era of clinical research if you like we were able to show well look at this wonderful miracle the Lazarus effect of these antiretrovirals, look how they change people's lives even when you start at CD4's that are you know hardly there, hardly above single figures, people recover and they do get back to where they were. The next sort of story after that for us was that a group of these folk whose lives had been changed and they recognized the value of it came to us and said well our lives have been changed we want to help other people and so we said okay well let's see what we can do around that and you know we introduced this concept of the therapeutic counsellor, the person who lives with the virus themselves but makes sure that other people do so effectively because they have had this great experience and so the Sizampela counsellors were born and they were a group at that stage of six women and of course it grew over time and we managed to get a grant to pay them money, we really felt they should not do it for nothing and they should have a dignified job and call it a job and give it a career path and so the Sizampela counsellors, I taught them everything I knew about antiretrovirals and my whole thing was it's not enough to know this blue pill must go with this pink pill you've got to know this is called Nevirapine, it is a non-nuclearside reverse transcriptase inhibitor, it works at this place in the life-cycle and literally taught these, some of them you know had never gone to tertiary education but they learnt and they grasped and they got it and they in turn helped others to take their treatment. And what we recognized at that time was that treatment should not be given out at tertiary hospitals only and academic centres, this was going to be a big problem and there was no doubt that you know rightly or wrongly the numbers were increasing, this was a huge prevalent problem and we needed to move treatment out into the community. I must also say that at this stage we had become very strong allies with the Treatment Action Campaign and with other organisations that were really promoting antiretrovirals and so we set out in 2001 to look for money to put treatment into Gugulethu, I had worked with the local community there to bring prevention of mother to child to Gugs and Khayelitsha of course had got it going with Médicins San Frontierès and we were very keen that we should also establish

PMTCT here and in those days it was single dose AZT, that was in '99/2000 and of course all our women went to Khayelitsha you know people will vote with their feet, so they heard about this thing could save their babies and they went, so we thought no we need to bring PMTCT to Gugulethu. So we got on a plane and we flew to England to see if we could get some money to do this because in those days you know you kind of had to make it happen in order to lead Government along to get this thing and we, even in those days, because even in those days remember PMTCT people were dragging their heels, we had all those cartoons of you know our politicians are messing around while Rome's burning and so even though they were Health Ministers who subsequently have had good report cards in those days there was reticence around life-saving interventions like PMTCT and of course Nkosazana Zuma and other Health Ministers of the day. So anyway we managed to get a small grant of about £500,000 that was from a woman called Katie Hannon, it was given by a charity called Crusade and the only requirement was that the Clinic should be named after Katie Hannon so we said that's fine, we can live with that, we'll call it the Hannon Crusade Centre and by that stage actually Fareed Abdullah must be given some credit in this part of the world had decided that PMTCT would be rolled out in the Province, so actually Gugulethu had got AZT and so we thought no well then we should do treatment, it's not fair now that only women are getting treated we should treat the family. And so we decided this would be a family based Clinic, children, women, men would get treatment there and it would be a dedicated antiretroviral centre and of course everybody said to us nobody will come, it will be a white elephant you know no one will step into a building that is only for ARV's and you know today we have had 10,000 people go through those doors and we have never found that there hasn't been a queue up and down the road so...

You know when the need is there people come. So we started in those dark days with 150 treatment places and you know a community of 500,000 on our doorstep with even in those days an antenatal care prevalence rate of a good 25 to 28 percent so you can do the math of what the demand was but what we could offer and so they were days of rationing, I remember we sat in the clinic and you would say you can have treatment but you can't, you can't, you can't you know we made these decisions about who had more right to life than other people because you know that's what we had to do and South African doctors have learnt over the years to ration, we ration kidneys, we ration hearts, we ration blood transfusion and in those days we rationed the antiretrovirals and they were tough decisions but again there are people that

are alive today who were the very first people who started antiretrovirals. I remember they were called NY1, 2, 3, 4, 5 and we now are on NY10,000 and something and patients know that they actually refer to themselves as I'm NY39 because we wanted to keep things as anonymous as possible and everyone who comes into the Hannon Crusade signs a consent to be evaluated, so again it's been a very important Clinic for us to follow the natural history, or not the natural history but the history of treatment, what treatment is done and how it's evolved, the lessons we've learnt. So this was 2001 and Catherine and I sat down and we wrote the Antiretroviral Protocol for the Western Cape, for Hannon Crusade first of all and that become the protocol for the Western Cape and the protocol for the Western Cape eventually became the Antiretroviral Protocol for the country. So that was, so we were very, very, very early in those days getting that going and yes as I say we added treatment places piece by piece, we got five from Karyn Moshal who is now an ex-South African doctor in London that she gave from her personal you know finances, Pangea gave us 25 places and then we wrote a grant to the Global Fund and then we really, then it was much easier because then they really wanted us to get people on to treatment and we worked very hard to do that and you know we have averaged 16 to 18 new initiates every month ever since. So it's a busy Clinic, the Sizampela counsellors came home, that was their place and they ran therapeutic counselling from there and they really have been the cornerstone and just an extraordinary group of motivated people who live with the virus themselves but believe that you know this commodity is as we know miraculous and it must be shared in the widest sense and so that's where Hannon Crusade, we've written more than 100 papers looking at TB co-infection, cryptococcosis, the impact of antivirals, the switching patterns, a number of different very important policy changing ideas that I think have come out of that Clinic, so I think there's the power of putting you know, I say I'm not sure we fulfil them, but you know we are academics sort of research minded individuals next to a service entity to say what are the lessons we can learn as we do this and I think that has been incredibly powerful, we've learnt lots of

lessons from that so yes. During that time of course we did meet the denialist years so Durban 2000 was you know paradigm changing. We had recognised antivirals, we'd been using them in our cohorts but very much recognised that antivirals needed to be available and we needed universal access. So we were certainly there at Durban 2000 and that was critical. We have always had this very interesting relationship with the activists which I think is unique around the world where you know in other parts of the world the activists and the academicians often don't see eye to eye but here we took the Health Minister to Court, we took the Government to Court around this issue and we took the pharmaceutical companies to Court around you know the competition, pricing and so on, so we've played a role on both sides and driven all the time by equity, justice and access for all, so that has been the driving piece. And then recognition that is this wonderful tool that medical science has given us that really it's a no-brainer to get it into Africans and begin to save lives so you know I think we've been sad that we've in many ways as a country led from behind if you like, have come from behind when in fact in many ways our thinking as an organisation, and I know there are a number of organisations in the country, that have forged ahead regardless and I think that has been our strategy, put your head down, get under the radar and do what you have to do anyway kind of thing and be activists when the time is right, choose your battles but otherwise do what you can under the circumstances and I think we achieved a lot even in those days of you know just getting on with the job. I must say in the Western Cape we've been lucky in that we've had compared to I think other Provinces where there perhaps has been tougher denialist environment, I think we have often had a blind eye turned or you know people have allowed things to happen that perhaps hasn't been national policy when it was particularly problematic so in some ways perhaps our battle hasn't been quite as ferocious but I must say that I think you know the science has driven the activism in many ways and the need to move the thing forward. So that brings me to the point where treatment becomes accessible, you know and obviously we continued to look for new ways to improve on this, so Hannon

Crusade still exists and now is a very nice partnership between the Province, the Foundation, the Desmond Tutu HIV Foundation and you know the community I guess at large and it's funded largely by the South African Government which I think is terrific you know, it's a triumph, we've arrived at that point where correctly the South African people are providing care for their own and we continue to evaluate and monitor and guide. So we are part of the national move now to try and integrate tuberculosis care into antiretrovirals and antiretroviral care into tuberculosis treatment but also to ask what are some of the lessons we can learn from HIV, you know we've made some huge public health inroads, what can we take across to other areas of public health and so some of the things we've tested subsequently have been perhaps we should take the services to the man in the community or the woman in the community, so we like many others I know have taken mobile HIV public health screening into the community, we are now also looking for some effective ways to prevent HIV and so that's become you know another new passion has been well treatment is one thing but how do we turn the tap off and prevent this problem and so you know I think it is a very new interesting era that South Africa finds itself in where we really can if we play this properly we can actually make a significant global contribution and be kind of ahead of the pack in this regard of actually bringing some of these answers to fruition. If you like I guess cashing in on the tragedy of our burden of disease because we do have an enormous burden of disease so we become you know an important part of the world to test some of the new modalities, so we are trying to make a significant contribution in that regard as well.

LM: That's good, sorry let's go back to the AIDS 2000 Conference, so you say it was a part of action, what are the challenges that you were experiencing before the conference?

LGB: Well I think you know I've said it before in some ways you know we were fighting the ideology of the day more than we were fighting the virus, in fact we knew that there were tools that could fight the virus and so we knew what had to be done in that regard but what we didn't know was how to fight the politics and the leadership of the day which made no sense to any of us. I mean I think it was one of the most frequently asked questions I was asked at any time whenever I went anywhere in the world was why does your President think the way he does and you know where does that come from and it was a very difficult, I mean today I'm not sure I know what the answer to that is it made very little sense to any of us and yet this overwhelming frustration and fury I suppose that people were needlessly dying when in fact that could have looked different. Countries with so far fewer resources were actually appearing to do better than what we were doing you know again despite us having expertise and understanding and resources. So yes I think that frustration was extraordinary, it was an absolute you know brainwave, Mark Wynberg was the Chair of the IES in 2000, a wonderful man, visionary, and he I believe was quite instrumental in saying this needed to happen in Durban in South Africa and so it came to Durban in 2000 and you know these conferences are, people think they just happen where they happen but the IES group decides quite strategically where the conferences should happen and I am very honoured at the moment to be on the Council so I have watched the process recently, I mean some of it is about who has the biggest Conference Centre you know and clearly your own organisation has played a role in Durban 2000 and thereafter but you know I think this was absolutely correct that it happened in 2000 in Durban and the reason was that antiretrovirals were blowing up, you know we had had the conference four years before in Vancouver I think it was which really showed this is the miracle of antivirals look what it can do to change the natural history of the individual but the south was incredibly quiet, there was very little going and in those days if you remember treatment was R3,000 a month, I mean it was exorbitant, the only way we could access it was to put people on to antiretroviral drug trials and you know that was unacceptable.

And you know you heard talk like this will never get to the third world, it's never going to be affordable you know, and in fact given the burden of our disease that was just irrational thought I mean it was wrong, clearly we needed to drive the price down it was just a matter of time but I think Durban 2000 became the catalyst, it brought the north to the south and they suddenly you know woke up and had to face themselves in the mirror and actually ask themselves can we live with ourselves knowing this you know, this is just not okay and it was a great time for Zapiro and other people to showcase you know the whole thing and make a meal of it and yes we had Thabo Mbeki to deal with and he barely turned up and really did continue his denialist stand but Nkosi Johnson was there you know who really was again wonderfully courageous but also absolutely key in the whole game you know, the cog in the wheel as it were, things aligned very importantly and so Nkosi's comments and really giving a face to African AIDS I think was absolutely critical at that time. And you know how do you describe it other than you just felt the paradigm shift, people's minds just suddenly were opened you know and there was just...

LM resistance…

LBG: Exactly, so you know I'm not sure all these years later...

LM: And Tshabalala?

LGB: And her she is passed but I don't know that we've changed Thabo Mbeki's mind in all of this, I don't know, I don't know if it's possible to do with somebody who is that closed to the whole thing but in terms of the very importantly our peers to the north of us I think that's where the mind shift really particularly changed and that was very key. And then obviously after that I think there was a lot of behind the scenes stuff that went on to try and drive drug prices down, but practically even then it took two, three, four years for us really to see the impact of that and again you know the Harvard paper that attributes those deaths to Thabo Mbeki and he will one day have to deal with that and live with that and I

don't know how he feels about that, maybe he denies even today that he's responsible for the deaths that occurred at that time, I'm not sure he can fully take the blame because I think it took the world, the global world, a long time to drive the prices down to a point where access started to actually happen. But yes you know political will is a very powerful thing and a very important ingredient. Having said that I don't think it completely stopped us getting some of the way which I think speaks to civil society's ability, and no country knows it better than this country, the power of the person on the street you know how when there's common will and a common goal we actually can still achieve a lot you know. So you know the lesson not only on the antiretroviral but we drove down the price of amphotericin, we drove down the price of fluconazole, in fact we got free, the work that MSF and TAC did in that regard ach man we actually had fluconazole given to us for free for many years as a result of the efforts there with the Pfizer free drug campaign. But amphotericin the price came down after a Court case around competitive pricing so you know there are significant victories that have happened and again you know if there is one lesson I would tell my children and their children it's you know at our peril do we say this will never happen because of some negative thing, we can actually change this if we believe...

Hard enough you know and if we fight the strategic battles in the correct way and ja fight is a difficult word in South Africa because we often think it's all about violence but I think we were very strategic we used the Courts when we needed, we toi-toi'ed when we needed, we used satirists when we needed and we used conferences in a very strategic way as well. And then of course the generic companies were also very key in that whole process, and then eventually, you know I think the normative agencies had their minds changed, so once UNAIDS got it and once WHO got in then I think you know we had the Three by Five Campaign and a number of other good initiatives that I think really did start to wind up access and get access flowing which I think has been very important.

LM: Do you think that the so-called new Government then had undermined the role that HIV or the impact that HIV/AIDS had on our society and they had not prioritised it well enough?

LGB: Yes you know those first four years obviously are very important years in all of our memories as fairly warm and fuzzy as they were the Nelson Mandela era and few of us want to say anything negative about those years you know but I think it is a gap in intervention you know I think maybe we just didn't realize just how bad it was going to be or maybe we had so many other things to focus on, maybe we took our eye off the ball because we were so relieved we didn't have a blood bath and we were able to reconcile and move forward, but I think we took our eye off HIV as a priority without doubt and we lost a lot of ground in those first four years. You know it's interesting I mean I've obviously had a lot to do with North America and the United States you know I've heard the criticism leveled at Bill Clinton as well that he has done much more for HIV and AIDS post his term in office, or couple of terms in office than during his terms in office and in fact there are even those people who would say George W Bush in his PEPFAR programme achieved much more during his time in office than what William Clinton did and we are all you know obviously very fond of him and what he did at the time but you know maybe, and our politicians clearly need to also be advised by advisors but I'm not sure that Nelson Mandela actually felt the urgency to the extent that perhaps he did once he was so impacted in his own family and that was after his term in office. Then we went into the Mbeki era thereafter and then that really not only you know was a gap it moved us backwards which I think was huge. And you know as I say I really think there was a sense of we had to fight the virus but that was not so bad as trying to fight the politics of the day you know and the sense of spinning one's wheels because you just didn't feel like you were swimming in the same direction and moving forward. And you know the more recent years have been extraordinary just because I think there's a new found energy and a sense of we're in this together and we can actually make a difference, there are problems you know we have the biggest treatment programme

in the world, that is a huge challenge, but because we're in it together I think the problems become more achievable, more surmountable in many ways.

LM: Because you know you mentioned earlier on that inasmuch as civil society independent organisations were able to get treatment rolling what do you think happened that delayed the Government from nationalising the treatment plan, because you guys were very successful here in Cape Town but it took a while nationally.

LGB: Well I think what happens you know the GSB will give you this thing of how you have your earlier doctors you know and then you have your, you have your entrepreneurs and I think we're there, the innovators you know the people who think of the idea first and never ask why not you know or ask why, you always say why not you know, they've got it in the first world we'll get it here we must do it, so you've got the innovators and then you've got the earlier doctors who pick up on this and will go but you need a certain critical mass of that the dipping point before it becomes something that everybody goes for. And I think that's the missing ingredient we had is that you need Government will and the push especially in a public health intervention for something to really gather momentum to go forward. So you had pockets of innovators and earlier doctors who were saying come on guys let's do this and agitating and you know even prepared to go to Court or take civil action or whatever to do this but enough critical mass to take it to the next level was in the hands of Government or some other large programme and I think to a certain extent this is where the President's Emergency Fund kind of filled the gap for a bit, tragically in some ways in our history, that we had to have another organisation come in and their mandate, I was not a recipient of PEPFAR funding but what I watched from the side was their mandate was use any organisation except Government you know so go for civil society to roll this out you know, go with faith based, now that may have been in the Republican thinking I don't know but you know use faith based organisations, I watched the Catholic Bishops roll out antivirals in the most extraordinary

way. So you know it's interesting how when there's a vacuum nature will fill it and in this case it did get filled but it needed resources and once the resources were there then civil society could really pick up on it but I think now rightfully the balances are being fixed and the Government is taking ownership and I think it's right, it will be a tricky time as we sort that out over the next while and hopefully you know the programme won't experience too many speed wobbles but this is now starting to sort itself out I think.

LM: Anything else that you would like to share?

LGB: I am trying to think.

LM: Let's take it from now we have moved from the AIDS 2000 Conference and also the treatment that the Centre is able to roll out and also having taken the Government to High Court with regards to making nevirapine available let's move to 2004 when the Government actually launched their treatment programme, so what role did you guys play in that?

LGB: Well I think you know as I mentioned we very proudly wrote the Protocol which was adopted nationally and subsequently I think we have really contributed to policy inasmuch as we've understood the burden of TB and antiretroviral clinics in our HIV community, we've written a ton of peer review publication and policy type documents around how to do this better you know or what the pitfalls are and what to watch out for and how to do this right, so we've taken I guess quite an academic role in that regard and because we are fundamentally researchers we did not see ourselves as what I've affectionately termed the juggernaut service providers you know that were then PEPFAR funded so the Right to Care, the FDP, the ANOVA groups that really then moved into these large scale organisations that scaled treatment up, I think our philosophy, our mission is really to focus on the how and so we've continued I think with quite a lot of integrity to just keep plugging away at that understanding the burden of HIV and TB interaction at the individual, at the cohort and at the community level, so a lot of work around

understanding the role that HIV plays in the TB epidemic and vice versa. And then as I say you know perhaps starting to have a little bit more focus on prevention which I think is the next era that South Africa must move into, we have a treatment programme and the treatment programme has to be maintained and we will move into another era where we will have this aging population on antiretrovirals and that provides another whole set of challenges and so innovation and continued understanding of how we deal with an ever increasing pool of patients on antiretrovirals must go on but somewhere somehow someone has to turn the taps off and I think that is around looking for innovative prevention methodologies. And again I think the scale of our problem and the generalisability of it if you like or the generalised nature of it I think has set back prevention because you know we kind of have this notion of one size fits all you just go out there with an A B C message and clearly people must just change their behaviour you know, it didn't work in San Francisco it's not going to work here to my mind. I think we do need to come...

LM: I think we have done that because someone says...

LGB: Well it was you know so what actually went down there and I'm not sure even as a researcher that I have a good understanding of what the turning point was there, is it a bringing together of the right ingredients of interventions at the right time in the epidemic so you know the epidemic's...

LM: The mindset of society.

LGB: That's right yes, you have an epidemic and you know maybe it's the kind of people who were hearing the message at that time and again a critical mass piece. We haven't seen evidence of it in a big way but I do think we are now, you know maybe again we could have gone at that to see well how could we emulate that but on the other hand I think we now have opportunities to say are there prevention packages that are very specific to population, so I am a great believer in population specific prevention

packages, you know when you say if you are a pre-pubescent adolescent what are your needs versus a commercial sex worker who has been in the business for three, four, five years and might need a very different package compared to a gay man who hasn't outed himself and is living in a township where having sex with other men is very culturally stigmatised you know so those are the kinds of responses now that I think we have a growing menu of modalities and I think we have an opportunity and this is where you know I would feel that we could change our legacy of being early adopters rather than waiting for everybody else to show us including Malawi, Botswana, Swaziland, countries around us with fewer resources to show us how to do it before we do it you know. So I do feel you know and it's tough being a politician in this country because it's hard to do the right thing, I mean you know I'm very aware that Dr Motsoaledi was an early adopter on the whole gene expert thing and he rushed out and bought all these gene experts and I know he's been given some criticism around it, people are now going was it the right thing to do and it was such an expensive commodity did he do it too much too soon, you know that's one way of looking at it, on the other hand I'm like wow this is just so refreshing!

LM: We have gone from based on what they believe...

LGB: Of course, of course and you know who knows, I think he'll be partially right at the end of the day and he'll be partially wrong and we would have learnt a lot you know it's better than spending money on arms and submarines we don't need so I think we will have to work our way around something like that and you might argue that maybe with more consultation etcetera we might have done it somewhat differently but again from where I come this is a very different thing to criticize a Health Minister when I think what we have had to criticize a Health Minister for in the past so you know it's refreshing at many levels.

LM: Okay would you think that Government was not open minded enough to accept advice from experts?

LGB: Definitely, definitely.

LM: If you look at how the denialist era started in South Africa, Thabo Mbeki with the dissidents they just said HIV does not cause AIDS.

LGB: Yes absolutely so you know I think I am not a politician, I don't try to be a politician but I would imagine a key ingredient of a politician is choosing your advisors very carefully and discerning who you are going to listen to for advice and who you are not and that clearly was a very serious error of judgement and to this day I don't know if anyone really understands why he chose some people from North California versus a slew of academics in country who were dealing with the problem everyday you know, who had got it, who understood it and so yes I think we do, maybe there's another lesson for our grandchildren in all of this is that we tend, you know can anything good come out of the people at home, well you know actually this country I think does in this regard we boast world renowned thinkers and people who have made their mark internationally.

LM: Yes a month ago there was an achievement to say we are getting closer, we are just moving a step closer.

LGB: Yes that's right, having a vaccine you know but there have been thinkers who have some of the first clinical trials for PMCTC were done here you know, we have contributed the first microbicide trial was done here you know I mean I think we did some of the very first antiretroviral clinics in large numbers of people way back in '94 and that was ten years before we had a universal programme for South Africans at large, so that's the flip side if we don't actually pay attention, and in fact it was so much, in

those days that terrible era of denialism it wasn't so much that you were ignored but you were actually blacklisted, so you know you were actually put onto a we don't want...

To speak to those experts because they are activists who are puppets of the first world and the pharmaceutical companies and they aren't two Africans you know so there was this whole sort of notion of the answer can only come out of Africa you know and yet we had a life saving modality that Africans needed regardless you know.

LM: Where it comes from.

LGB: Of course, of course.

LM: Even though some , or example say the garlics, the beetroots help. How did that affect you as a researcher; you know looking at your application because you are thinking do you want to stay in...

LGB: Yes so you know my bread and butter is evidence-based you know, sometimes we have to make decisions on empiric data, we have to say we don't have the evidence of how this will work in this population, we have partial evidence, it works in this population it might therefore work in this population, so we weigh up the evidence every single day of our lives but we always strive for building the best evidence before we make a decision and you suddenly have this person who is deciding your fate and the fate of your country people and it's based on absolute rubbish you know and she's listening to people who not only believe in their own rubbish, so you know I mean the vitamin theory, but actually were making money, so she was being led along by people who were not only wrong in their thinking, and look throughout history we've had people who have believed in what they thought and they would have died for what they believed in what they thought, but this rife we had the rife whole debacle he was actually benefiting financially from his own pedalling of snake oil which you know the fact that, and one

doesn't want to speak ill of the dead but you know she didn't see that I think was beyond belief. I haven't actually even spoken about the whole Virodene I mean you know we had that whole episode of where again because this was a nodality coming out of South Africa we had to push it even though evidence was slim at best you know and really in fact there was more evidence of harm than there was evidence of efficacy. And again there was a sense that that had to be actively laid to rest you know whereas in any other civilised community in the 21st century it wouldn't even have seen the light of day you know and so that whole piece had to be worked through. So I think you know, and I'm very sensitive, I'm an African I'm a fourth generation African you know, I'm very sensitive to the need to recognise that cultural competency and understanding culture and Africa is Africa it's not America, it's not Europe, it's Africa you know so I get that but I think you know to shun life saving medication and evidence in the face of needing to make some philosophical point about providing something from Africa or you know is an injustice to the people of Africa. And I think whilst we can strive to find how we apply these wonderful inventions in the best possible way in Africa that's slightly different to saying it must all be bad because we didn't make it here. So I think we can learn a lot from many different aspects and then also I think own a lot that you know there is good within our country whether it's expertise, understanding, know how, the ability to put stuff in, we are up there with any other country, certainly in the HIV and TB field, in fact I would argue in the TB world we outstrip the rest of the world, we should proudly be pushing that forward and owning that actually if you like almost selling it as an asset or marketing it as an asset to the rest of the world rather than the other and for the first time as I say actually really, well not only the first time but in this era or in this field really move ourselves into front and first position in this regard.

LM: I've got five minutes left so some people mention what we have learned from 1994 to 2004 to be the lost decade, what do you think the lost means?

LGB: Well I think we need to be absolutely blunt and say we lost lives, you know people's mothers, people's fathers, people's children and you know those don't come back, those are gone, buried, dead and that we need to first of all because I think you know I don't know what I would tell somebody who is dealing with living now without somebody they loved as a result of that era. I think we lost in addition credibility as a country which I think was harmful to South Africa and that's a shame because I think we had a level of expertise and an ability to offer that, we had to kind of overcome you know sort of a sense of disbelief in ourselves as a country from our first world contemporaries so I think that was another piece. I think we lost ground clearly, so not only did we lose lives but we could have had a universal access programme a lot sooner, at least four years' earlier if we had leapt on the wagon in 2000 when the paradigm changed we could have, you know there's four years of wasted time there that's a lot of HIV, if you think I am putting on 80 people a month at Gugulethu alone at Hannon Crusade at a national level can you imagine the impact. So you know I think those things you don't put the clock back on them. I also work for the Desmond Tutu HIV Foundation, I have heard the Archbishop Tutu pronounce on this a lot and you know he has been asked do you think Thabo Mbeki needs to go to a Truth and Reconciliation Commission type thing and his answer has been you know these are mistakes that are behind us and he does have, in true Tutu style, he does have a very reconciliatory approach to this and I think in order for our country to move forward and you know make sure this never ever happens again we should do what we are doing now, tell the story, make sure we get it down in history so we do make sure we never do it again, but then I think we need to look forward and actually we have a lot of work to do, we have many lives still to save and actually we need to get on and just do it and that is going to take all of our collective energy, innovation, creativity and I think that's where we need to put our time and our resources now.

LM: Well thank you.

LGB: Okay it's my absolute pleasure.