



Transcript provided by kaisernetwork.org, a free service of the Kaiser Family Foundation¹
(Tip: Click on the binocular icon to search this document)

**How to Cost-Effectively Manage the Care of HIV-Infected
Individuals
TT2CANN (Title II Community AIDS National Network) and
CommGeniX LLC
August 26, 2008**

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

[START RECORDING]

GARY ROSE, J.D.: My name's Gary Rose. I'm the Board chair of the Title II Community AIDS National Network and we're meeting tonight to talk about HIV medical care, how to provide it, who provides it, how to do it cost effectively.

I was asked to host this session because I have a sort of reputation as being a fanatic about access to care. I'm a single-minded PWA. And what do we mean by access in 2008? I would argue that you can't even fake providing access without a minimal menu of things.

The first is an HIV experienced primary care provider wherever you live. The second thing is a fairly open formulary of drugs, and that includes antiretrovirals, co-infections, side effect drugs, opportunistic infection drugs, mental health substance abuse, all of those things. The third thing is HIV educated OB/GYN care. The fourth thing is HIV educated mental health and substance abuse care. And then, finally, access to catastrophic services when they're necessary. Okay, that's the bundle that I would argue without those things, you're not really providing HIV care.

The two other very important requirements are the care has to be affordable to the patient. What does that mean? I would argue you that all care for patients up to 300-percent of the federal poverty level should just come and

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

then there should be a sliding scale up to wherever we can afford.

The last thing, and this is something we haven't been talking about, and I think, I'm hoping Dr. Sagg will talk about it, the care that we get needs to be adequately reimbursed, otherwise, it's all an empty promise. What's happening now, it's becoming nearly impossible to find an experienced HIV care provider, even if you have private insurance.

We're too expensive to take care of at the rates people are being paid. My doctor of 20 years went out of business. It then took me two years to find an experienced HIV provider. They can't afford to take more than a third of their practice, maybe, of HIV patients because we just aren't, we cost them too much money.

And that's private insurance. Most of the doctors I know are no longer accepting either Medicare or Medicaid patients. So that's a problem. So, we're going to start with an overview of our topic and the overview is going to be provided by one of my favorite doctors, Michael Sagg of the University of Alabama at Birmingham.

Dr. Sagg, for those of you who don't know him, is a multiple threat. He runs one of the best AIDS clinics in the country and one of the places that it's hardest to do that,

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

Birmingham, Alabama. He's one of the best HIV clinicians, I mean, I've talked to his patients, I've talked to his colleagues, people like this guy.

His clinic and his clinical research, he's also an important clinical researcher, reaches people that aren't easy to reach. They're difficult to treat, they're expensive to treat and having data, the fourth thing he's a threat on, having a complete data set on this clinical population is a gift. And he's been determined to collect this data since as long as I've known him.

The fifth thing is, when he's not busy with those things, you know, when he has a couple of minutes of spare time, he's one of the most effective advocates for care for people with HIV that I know. So I'd like you all to welcome Dr. Michael Sagg. [Applause]

MICHAEL SAGG, M.D.: Thank you very much. It's a joy, but also a privilege and an honor to be with you here today. And I'm not going to try to give you indigestion, although that may happen, not from the food, but maybe from my message. As the day goes on, and all I know how to do is tell you the truth. And so there's some good news in the truth and there's some challenging news in the truth and I'm afraid there's also some bad news in the truth. And hopefully in the panel we can start discussing how to convert the bad news

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

into good news over the next couple of years. And the only way we can do that is by working together.

So here's the story. Any questions? [Laughter] Okay, so this is the beginning. So these are the companies that have provided the funding for this meeting. I think it speaks for itself. And so what I want to talk to you about in this good news, bad news, sort of like *The Good, the Bad, and the Ugly*, if you remember that movie with Clint Eastwood one of the spaghetti westerns, the policy of opt-out testing, who will take care of the newly diagnosed patients. That's the question.

So let's look at some of the epidemiology. In this country, right now, among those who are aged 18 to 49, about 0.5-percent of our total population of that age group are infected, 0.7-percent of all men, 0.2-percent of all women. Two percent of the population of African Americans living in the United States today in that age group, are infected with HIV. And I would also propose that for all of these individuals, whichever group we're looking at, most of them, or a lot of them don't know their HIV status.

0.3-percent of Mexican Americans, and it's actually, relatively speaking, disproportionately not affecting Caucasians. Now this may be a little bit, well you can read it pretty well better there than on that slide, so this is

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

the good news. In the early '80s most people died within three or four years and those of us who have been at this a while remember those days and are glad that we aren't dealing with that anymore.

And more recently and I'll show you some updated numbers here in a few minutes, but that the actual number of deaths after a diagnosis of AIDS has gotten much, much better and a lot of that is because of the drugs and I've just color-coded them here. The nucleosides and white and the non-nukes and sort of yellow and the protease inhibitors are in gold, but you can see that there's a nice progression of new drugs. T20 is a fusion inhibitor, some new PIs and that the conclude the Maraviroc, Raltegravin and Etravirine together, those are four new drugs that came out at once.

And what's different in this whole story is two major things from a clinical perspective. In this era we tended to just use the next new drug sequentially, as it came out. We didn't know any better, but what we were doing was breeding resistance. By the time this era came around, we'd figured it out, that we weren't supposed to do that anymore. We were supposed to use at least two, perhaps three active new drugs. And that's changed the whole paradigm clinically of what we're not only able to do, but what we always do now, in the management of our patients.

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

So let me give you just examples, I'm not trying to pick on one drug or another, they all basically show you the same things. And that is there's a study design where you take a patient who's got multi-drug resistance, and you do the best you can concocting a regimen based on resistance testing, by pulling what's available, and that creates what's called an optimized background regimen.

And then in these new studies what would happen is that you added in a blinded way their placebo, one of the new drugs, in this case once a day or twice a day. And again, you don't have to be a statistician, you could be across the street at the Marriott and can tell that there's a difference between this and this, significant difference.

So this is the optimized background alone, read the ability to do what we could do before these new drugs came along, and this is simply adding a new drug to the regimen, it made a huge difference.

If you looked at the Raltegravir data, it's exactly the same. Same story, Raltegravir optimized background in blue, placebo remarkably similar. But that's not the news of those studies, in my opinion.

The new is here. What I'm showing you, if you look across the bottom, this is the number of active drugs in the

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

optimized background regimen, so here's no active drugs,
except for the new drug or not, one active drug, too.

So let's just take an example. In this setting the
optimized background had one new drug, one active drug and
nothing else; 9-percent got less than 50. If you had the one
active drug plus, in this case, Maraviroc at either dose,
look at that huge difference of going from one, in essence,
to two. Then here are two of the active drugs of the older
version, plus another, and you see, now you have three in
essence here. And here, we actually have three in the older
group, and now four, in essence, here. So if that doesn't
scream at you, that you need at least two, and preferable
three, active drugs, I don't know what will.

And based on that, we've been able to really
revolutionize the treatment of patients. We've done from
taking patients who were on death's door and converting them
to a relatively normal life span. And that's remarkable,
because now the goal of every regimen is to get people less
than 50 copies.

In our clinic, as Gary introduced, in Birmingham,
Alabama, a year and a half ago, out of our whole population,
40-percent of patients were less than 50 copies. This month,
66-percent of our whole population are less than 50 copies.

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

That's progress. [Applause] Thank you. That's happening all over the country and that's all good news.

Still on the good news. Celebrate. Eat. Enjoy. So the keys to success are that really, who wants to take medicine that makes them feel bad? I don't. Having HIV and getting therapy for it is not meant to be a punishment and in my personal case, I tell this story a lot, but I have high blood pressure, at least it didn't used to be until they changed the rules and now I do, you know, 140 over 85, I thought that was pretty good. Then they said, oh you're hypertensive. Well, now what.

So they gave me some drugs to manage that. And the first thing they gave me was one drug and I noticed about two weeks later I started to get this occipital headache. I said I don't like this. I wondered if it's the drug. So guess what? I skipped a couple of days. What happened? My headache went away. Then I took the drug again. Guess what? My headache came back. And I said I don't want to live with this.

So I went to my doctor and said get me off this crap. Put me on something that can work, but I'll feel okay. And he did, and here I am, and my blood pressure's much better, and I'm not sick. That's the way we're managing antiretroviral therapy today. And as an addition to these drugs being sort

of designer drugs that work against resistant virus or to operate the new [inaudible] of action, the pharmaceutical companies and the researchers have learned to find drugs that are better tolerated.

I think that's why we're seeing so much better success at least two fully active drugs. Missed doses equal resistance and that also goes back to number one. If you're taking medicines that make you feel bad, you're going to, by nature, skip doses. And we need to use resistance testing and we need to start therapy early, which is my next point.

So now I'm segueing away from some of the good news to some of the moderate news. These are data from our clinic of patients over the last almost 10 years who started their first antiretroviral regimen. And this is mortality, alive or dead. So this is survival.

If somebody started in this black line here, with a CD4 count less than 50 in the HAART, 50-percent of them are dead at 10 years. If it was between 50 and 200, 25-percent are dead. If they start above 200, much, much better outcome. Now, you don't have to be scientist or a clinician, it's common sense. Based on these data and data's from other cohorts, these data scream that we should not wait until a CD4 count is 200, we should get people on therapy nowadays at 350, maybe 400, 450.

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

But here's the rub. Look at our clinic over that time period from '96 to 2004. Again, median average CD4 count is around 200. For half of our patients, they're showing up too late, bad news. So all you have to do, if you go to Capitol Hill or you go to Clifton Road in Atlanta, is show those last two slides and you've got all you need to say about universal opt-out testing, because there's one exception to this group, showing up with the CD4 count of 200. There's one group of patients over the same time period who when they showed up, their median CD4 count was 420. Who were they? Pregnant women. And why? Because they all got tested. It's not rocket science. It's common sense.

So universal opt-out testing two years ago appropriately gets implemented, but its penetrance is variable. And I was wondering whether we had impact, and if you'd asked me before I gave this lecture, I would say no, we're about the same. But, I like to be data-driven.

So in preparation for this talk I went back and said guys, run some newer numbers for me. And this is what we see in our clinic. Look at this. Something good's happening. We're starting to see patients a little bit earlier. That's good news. But we still need to do better. We still need to do better, because I'd like to see this median be more in the 400 to 500 range where we really might have a decision about

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

treatment. So let's keep up the good work, but I think the policies we've implemented collectively, over the last couple of years, is spot on.

So what's the key point? A lot of patients who are HIV infected in the United States don't know they're infected and universal opt-out testing is needed. How many of those folks are out there? I don't know. I think at a minimum out of the total universe of whatever it will be, 1.5 million people in the United States who are HIV infected, I'm guessing in my neck of the woods, 33 to 50-percent don't know they're status, in my neck of the woods.

Maybe in New York, maybe in other places, it's a little better than that, but the fact is we're not going to know until we start testing more. And even with improved surveillance that unfortunately just got cut back three days ago, because of funding problems, we're seeing that there was 56,000 new cases diagnosed last year. I think that's an under-estimate. I suspect it's closer to 80,000 or maybe 100,000, we just don't know yet.

So, that's mostly the good news story. Now let's get back to what Gary was talking about in the introduction. What about care and cost of care? So in our clinic, we're very fortunate, we have a very nice data collection system. And I

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

like to be motivated and moved by not only my emotion, but I like to be able to back it up with numbers.

So a couple of years ago I wanted to see what the cost of care was. I didn't want to model it. I wanted to actually know what it was. So what I did, with our team, is for one year we tracked every patient who we provided primary care on, for an entire year. We tracked every encounter with the health system, clinic visits, hospitalizations, every procedure, radiology, consultations, lab work, et cetera. And we assumed that every patient had Medicare. And, that their collection rate was 100-percent. And, okay, yeah. But let's say it is. It makes my point even stronger.

Everyone had Medicare. Collection rate's 100-percent for everything legally allowable and for medications we used average wholesale price. Now most people get a discount off of that, but you can discount it in your head as you see the data. What did we discover? The overall cost of all patients was \$18,300 per patient, per year.

What was heartening was that that matched pretty precisely what the estimates were from models. Moreover, what made sense if somebody started the year with a CD4 count of less than 50, their cost was pushing \$40,000 a year. And if, conversely, they were greater than 350, their costs were only

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

\$12,000 or \$13,000 a year. It's almost like we made the data up.

But here's the kicker. If we take that overall \$18,300 a year and we break it down to what's driving the cost, we see that antiretroviral medicines are about \$11,000, and non-antiretroviral medicines are about \$4,000, and hospitalizations on average was 7-percent, because not everybody was in the hospital, certainly somebody in costs a lot more, and if you average it out, it's 7-percent.

The diagnostics, the labs, the radiology, that was about 4-percent. Look at the physician reimbursement, that's with 100-percent of patients on Medicare and a collection rate of 100-percent. We would be reimbursed for our thousand patient clinics, \$360 per patient, per year. That's the maximum I could legally collect, if everyone was insured and I collected 100-percent.

So, do the math. For a thousand patient clinic, the maximum I could collect is \$360,000. That's it. So, the point is that with the current reimbursement system, it's not a surprise to me, Gary, that private docs are going out of practice. Who can survive in that environment? Who can make ends meet? You can't.

And so, it's falling more and more and more on the publicly-funded clinics, even for insured patients, to take

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

care of them. And that's not so bad overall. You've got experts there, they're good docs in almost every case, I think. I mean, they're good folks. But they're understaffed, and they're overwhelmed with numbers.

There's a little bit of good news in the story, that if we divided the population from baseline, we started in March of whatever year it was, and we assigned them the CD4 count strata, and if in the course of the first six months they either jump to the higher strata or fell to the lower strata, we did this analysis, which showed us if you take the 50 to 199, if they stayed the same, their cost was about \$24,000 a year. If they got worse, their costs went up. If they got better, their costs went down.

What does that tell us? In essence, antiretroviral therapy, which is about the only thing that makes CD4 counts go up, is cost effective. That's good news. I like it.

But it's still driving between those two medication costs, most of the medications are costing about 75 to 80-percent of overall cost. And that's true and we take that same 50 to 199 group, here they are, stayed the same, got worse, got better. You can see that physician reimbursement doesn't change much. Hospitalization jumps quite a bit when people get worse. But the antiretroviral therapy stays the same, and that makes sense. It's going to cost the same.

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

But look at this, a lot of the driver is the non-antiretroviral medication costs. So no matter which strata you're in, 75 to 80-percent of overall cost of care is medications. And again, you can discount that down if you don't want to use AWP.

So, here's where we are. In reality, most appropriations in the last 10 years from Capitol Hill to the Ryan White Program, has been for provision of medications. Most, if not all, of the increases in Ryan White CARE Act go into ADAP. Care dollars are targeted through redistribution of other medicines or other activities. So in other words, for my Title Part C clinic we've been flat-funded for the last eight years. And in fact, in the last two years we've had a 2.5-percent cut for Part C.

In that same time period over eight years, our patient population has doubled, maybe more. I don't need to say a whole lot more. So what are the policy implications? The provision of antiretroviral and other essential medications is important and essential. Not a question. We should fund ADAP. I don't have a problem with that. But the reality check is the operating budget for our 1600 patients at our clinic right now is \$2.1 million.

We collect, if we're lucky, \$500,000 a year from third party. Most of that's for infusion therapy, for the

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

real sick. Our Title III money or Part C money is \$508. Last year it was \$492, went down, flat-funded for 9 years, despite 100-percent patient increase. How are we going to do this? How are we going to make ends meet with a \$1.1 million deficit every year?

Now, I went to Congress personally over the last two years. Tried not to whine, just saying, hey look at the data. I don't have to get emotional here. Rational people can look at this and see there's a problem. So in our particular clinic's case, there was an increased appropriation to Part B that is funneled to the clinics now, that gives me and our clinic some relief, as well as other clinics in Alabama.

I'm grateful for that, but it doesn't solve the problem. It may shut me up, or maybe that was the intent, but I'm not just speaking for me. I'm speaking, hopefully, for all providers, when I'm talking about this. And frankly, between you and me, Part B, I'm grateful for the dollars, but that's not the right way to fund clinics.

It should be through the Part C program. Why? Because the States can do whatever they want with the dollars and if they choose next year that they have another problem that's maybe they're not getting enough to keep the waiting list off of ADAP, they're going to put the money back into ADAP, because that's what their primary mission is for Part B. And

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

I'm going to be left in a deficit worse than I had before. So Part B isn't the answer. It's got to be Part C. Especially for the rural clinics.

So what are the points? Mortality is much higher when patients are diagnosed late. The majority are diagnosed late, except for pregnant women. Many patients in the United States don't know they're infected. Universal opt-out testing is needed and with more universal opt-out testing, I predict, for our clinic, we're going to see a 25 to 50-percent increase in our patient volume.

Who's going to take care of these folks? Who's going to do it? Our clinic's at capacity with existing funding. I mean, we've already doubled our whole patient population with flat-funding going down. Either we were very inefficient 10 years ago or very overwhelmed today. I think we're pretty darn efficient. And I think we're pretty overwhelmed. And I really worry about the next two to three years, if we're going to be able to maintain our mission of what we're about.

Let me say it another way, in a poetic way. My opinion, we've got a very diseased health care delivery system. It's fragmented, it's not reliable for everyone, 47 million people don't have health insurance. And so we create this patchwork quilt of programs to support the patients who are falling through the cracks of the system.

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

So what is the safety net? To me, it's very simple. The safety net of our diseased health care delivery system is made up solely of the fabric of health care providers who give a damn. And if they weren't there, God help us.

[Applause] God help us. I see it every day. I work with these folks and guess what, when one of them resigns, I worry, because I can't replace them.

I've had an open nurse position for the last eight months. I can't fill it. Nobody wants to go to an ambulatory care job where you get to work at 7:30 in the morning and you go home at 9:00 at night. It's the truth. We're well understaffed, where those people are woefully underpaid, and even though I have funding for that position, I can't get them to do it.

So the policy implications, as I said before, we need to fund ADAP. I'm not against that. The pharmaceutical companies have done a great job working with researchers, both internal and outside, to create up to now 30 medications, depending on how you count them, when in 1986 we have none.

Triumph, expensive triumph. Pharmaceutical companies should be paid for what they produce. We live in a capitalistic society, that's how we've chosen to live our lives, that's the right system. They should be paid for what

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

they produce. No doubt about it. But, providers need to be paid for what they do. And heretofore, the pharmaceutical companies, because they have the organization, because they have the money, have created a very effective lobby. Happy for them.

But for us, the providers, we've got bupkis, except over-work and not enough time. How can we organize and spend our time leaving clinics to go to Capitol Hill? I tried to do it. But we need to do more of it.

So we dramatically need to increase funding for the clinic capacity, Title III Part C, whatever you want to call it, and provide incentives somehow for younger docs to do this. What's heartening, I run a division of infectious disease now, we have a lot of applicants to our program. But when I carefully dissect why they're coming to Birmingham, they want to work in Lusaka.

Fifty to 70-percent of our new applicants for ID Fellowship, they want to work in Lusaka. I'm happy about that on a lot of levels. We've got a great program there, enrolled 180,000 patients into care in the PEPFAR Program since 2004. Mind-blowing. Big difference. They want to be a part of that, just like I wanted to be a part of the AIDS epidemic in 1980, because I felt compelled to do something.

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

But the young doctors today, the United States epidemic is old news. They don't want to do this. They don't get paid well for it, and it's not as sexy. Seriously, it's sexy in a career sort of sense. You know what I mean.

So, the President's advisory committee on HIV and AIDS has said every American who need HIV treatment and care should have access to it. Check. People who are HIV positive need essential medications. Check. Without drugs providing care it is difficult to impossible. Check. But, without qualified HIV care providers and clinics, the HIV drugs mean nothing. [Applause] It's a fact. Nothing.

And to the pharmaceutical companies, they agree with this, because they don't want their drugs to be used wrong. For them, the best thing that can happen is somebody goes on a regimen, the viral load goes less than 50, the patient tolerates the drug, and that individual is on the same drugs, just like hypertensive drugs, for the next 40 years. That's good for the company.

What's bad for the company is that a patient goes on the wrong regimen develops resistance, and they only stay on their drug for six months. We're in this together. This is not an us versus them. This is about us, with us, speaking for us, to make a difference. That's what my message is today.

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

I wrote a commentary on this in the *Clinical Infectious Diseases* about a year and a half ago. It said which policy to adapt, waiting lists or waiting lines. It's an unfair conundrum. We shouldn't be fighting over the embarrassment of having waiting lists on our ADAP program versus waiting lines in our clinic. It shouldn't be intention with one another, but it is. We've got to overcome that, we've got to get beyond it and do the right thing.

So we asked a question of providers, about a year and a half ago. And we got another survey from the HIV in May that's just been finished with us, 70-percent response rate. That shows you how passionate these providers are to get help.

We asked the question, how would your clinic handle an influx of newly diagnosed patients. They'd answer, there's enough staff to handle more, there's a need for additional staff, there needs to be additional providers, the infrastructure will be overwhelmed. You can guess what the majority answer was. Most people said, over 50-percent, that they would be overwhelmed, with just a 10-percent increase in new patients over the next year.

We are approaching a crisis. We're in a crisis. We've been in it for a little while now. And the only way out of it is to work together, and to make it happen.

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

So I want to thank the group of people in our clinic who every day commit themselves to what's going on, not just with patient care, but also with data. Whining doesn't work. Data works. And that's we're committed to doing. We want to change policy. We want to make the place better. We want everyone to have access to care with HIV. We want to reduce transmission to zero and I would propose that the way we do that is in an ideal setting every person with HIV in the United States knows their status.

Every person with HIV in the United States is on therapy. Every patient in the United States who knows their status and is on therapy, has less than 50 copies. And I would propose if that happens, transmission approaches zero. Treatment is prevention. [Applause] And we need to start now. Thank you for your attention. I think we'll move on to the panel. [Applause]

GARY ROSE, J.D.: There are cards on your table for questions. We've received some questions already, but I could use some more. Please write a question on the card, raise the card and somebody will come around and pick them up. They're on the table. They're also on your table and on the table in the back.

TT2CANN (Title II Community AIDS National Network) and CommGenIX
LLC
8/26/08

Dr. Sagg, I think you know why we love him. I want to introduce the rest of the members of our panel. And it's a great panel.

One note, we had a substitution. Mayor Ron Dellums of Oakland was supposed to be here. His mother has died; so our thoughts and our prayers and with him. Dr. Shannon Hader is now the AIDS Director for Washington, D.C. As we all know, that's a really dangerous position. [Laughter] People don't survive that position long. I've been doing AIDS in Washington since about '89, people just don't survive. And she volunteered for this position. Dr. Hader. [Applause]

Our next panel member is Tom Liberti. I think you all know Tom Liberti. He's the HIV AIDS Director for the State of Florida. [Applause] I didn't know this. Tom has been doing public health in Florida since 1974. God, that's determination. [Applause]

Final member is Archbishop Joyce Turner Keller. She has been a minister for 38 years. And now she got her Doctor of Theology and she was working as bishop and now she is an archbishop. She is also a fierce, fierce advocate. [Applause]

Okay, so what we have, in case you didn't notice, is we have someone responsible for major HIV urban epidemic, someone with a large HIV state epidemic under their control, an HIV consumer from a hard-hit southern state that doesn't

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

have any funding, and one of the most articulate Part C representatives. So we have the right group.

I want to ask, since we heard from Mike a little bit about the system he has to deal with. I would like to go through our panel members and ask them for just a brief description of their own system. Tom, would you start?

THOMAS LIBERTI: I'm Tom Liberti from the great state of Florida. A state that's been hard hit by HIV for 27 years. We have over 150,000 reported HIV and AIDS cases in our state. We have 11,000 people on ADAP as of today. We test over 330,000 tests in our state each year. And the Ryan White Care Act brings in \$210 million.

I could go on with statistics in my state, but as Gary has mentioned, and Dr. Sagg has articulated so well, we have one of those complex, convoluted at times, patchwork systems that takes care of, on any given day, between 75,000 and 100,000 HIV and AIDS patients in our care and treatment. We have 125,000 plus people who are infected in our state. I believe we actually have a fairly high rate of people who know they're HIV status because of the aggressive testing program that we've had for many, many years.

We have the highest number of tests, as I mentioned, 330,000 tests done just last year, in 2007, and that was an all-time record, with 90,000 of those tests being done as

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC

8/26/08

rapid testing. You want me to just stop there? We have a diverse state. We are in two time zones. One of our cities is 90 miles from Havana, Cuba. So the challenges of providing HIV care in a state as diverse as Florida is an everyday occurrence.

At a later point I want to make some comments about Dr. Sagg's presentation and the challenge we have of meeting the demand. This issue of meeting the demand since routine testing has been approved in 2006 is a huge issue for this country, and has been elevated at a high level and we don't have the response from the federal government that we need.

GARY ROSE, J.D.: Dr. Hader.

SHANNON HADER, M.D., M.P.H.: Sure. So how many folks here are from D.C.? Show of hands, anyone? Wow. So you all might be shocked when I give you my little description here. Here in D.C. you might have seen in some of our headlines, we have what we're calling a modern epidemic, modern in both this year's scope of our epidemic and also its complexity.

So we have the highest AIDS rates and HIV rates in the country, here in D.C. When you take our rate based on folks that have already been diagnosed and are known to be living with HIV, our rates are twice as high as New York City, and four times as high as Detroit.

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

When you take those rates and project them, and say well what about the folks we don't know who are living with HIV that actually gives us an estimate that between 3 and 5-percent of our overall adult population here in the District, is already living with HIV. So these rates are higher than Ethiopia. These are on par with Uganda.

These are seriously not okay. And then when we take it a little bit further and say well what's really going on. And this is where the complexity comes in. When we look at our newly reported cases of HIV, about 40-percent are related to heterosexual transmission, about 25-percent are still occurring among men who have sex with men, we have about 15 to 18-percent related to injection drug use.

So, essentially, we've got plenty of ongoing transmission in every risk group that you can imagine, which means we've sort of got to do it all. We can't just focus on one group, one people, one transmission mode. We've got to cover everything. And I think importantly, we also, when we're looking at our data, finding a few more sort of surprising or shocking things.

So most people that hear our information and they say, heterosexual epidemic, really. Is that really going on now? That can't really be going on, right. And we started looking at what was going on and we find that probably among

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

our new heterosexual epidemic, probably at least 50-percent of folks don't know they're HIV infected and a lot of this is because they don't fit traditional risk profiles.

And we compare, sort of based on behavior, folks who are HIV positive and HIV negative, and we find out, you know what? There's not a whole lot of different, because a lot of those who are getting infected do not have extreme sort of XXX rates of risk behaviors, they have very normative, very average risk, but they're in this XXX risk environment where we've got so much HIV going around, that essentially if you're having unprotected sex and you don't know your partner's status, you might be exposed.

And systematically, we haven't prepared for that in the United States. That's not the messages that have been getting out. So, we're grappling with this very complex epidemic and we're grappling as well with the systems that weren't built to take care of this epidemic. We look forward to sharing more information.

GARY ROSE, J.D.: Joyce, from the consumer eye view, can you talk about the systems you need to deal with?

ARCHBISHOP JOYCE TURNER KELLER: Wow. Well, from the system in Louisiana, what we are facing are health care constraints. We have fragmented funding from the state as well as our local government, our cities. Then we have the

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

issues of transportation, especially if you're in a rural area, even if adequate care is provided, if it's not accessible, you still have no care.

We're dealing with, since Hurricane Katrina, which was an issue before, we have a housing issue. There are a lot of people who are homeless. And we know that there's a direct correlation between homelessness, HIV and substance use. One of the problems that we are facing and we have to admit that there's flat-funding from HRSA and with flat-funding from HRSA, we have an increase in the number of people who are diagnosed positive, but from the CDC we're getting more money for testing, but less money for treatment.

So what do you do with the people that become infected, and once they're tested they know their status, what are they going to do? And this is the health care constraint because one of the things we're still facing in the state of Louisiana across the board is that we do not have enough knowledgeable professional HIV treaters.

We have doctors who are willing to see you, but they really don't know, they're not specialists. They don't know what med to give you. For a period of time, I was on just fusion. Just fusion because the person who put me on fusion did not know that another med should have been added to that,

TT2CANN (Title II Community AIDS National Network) and CommGenIX
LLC
8/26/08

as you were talking about eight, that's right, [laughter] I went to him for a while, until I started reading.

Another problem that we're having in the state of Louisiana is that a lot of people are asking why are people falling out of care. Some people are falling out of care due to disrespect, whether we want to admit that as an issue or not.

As a positive woman I can say that. That's why I have my own company, due to disrespect, attitude and discrimination. [Applause] That's an issue that we face as positive people. A lot of people are falling out of care and having problems assessing care because of confidentiality. Somebody who knows somebody is working in that office and that person who wants to retain that anonymity cannot do that because they're afraid that their status will get out. And once that gets out, there could be an issue of domestic violence. Recently in Baton Rouge, just the last two days, we've had three women murdered. We don't know the reason behind that.

Then there's some cultural competency. There's another reason people are falling out of treatment, because there are language barriers. That's what we are facing in the state of Louisiana. We're dealing with issues that nobody wants to talk about because they say that I'm always creating

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

slag [misspelled?] Well, the reason I want to make you uncomfortable is because if I make you uncomfortable and angry enough, then we can implement change. But no change will take place until somebody's uncomfortable in the place that they are, because silence proves what? Acceptance.

I am not accepting the fact that we, in the state of Louisiana, are not getting adequate funding, adequate care and we need adequate treatment and I'm with Dr. Sagg about actually paying people enough money to take care of me because I think I matter. And I think every other person living with HIV and AIDS does matter.

So we're going to try, I will go to Washington for you, [applause] I will stand up, [applause] I will speak before Congress [applause] I will not lie because I'm a 501C3, so [laughter] I will remind, some people would say it's blackmail, I call it negotiation, I would remind those people that want my vote, that I want something for it in return.

And I will hold my vote hostage, and will ask the people in the state of Louisiana to hold their vote hostage and I ask you to hold that vote hostage until we get on the table what we need for our providers, and our clinics, and those people living with HIV and AIDS. Thank you. [Applause]

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

GARY ROSE, J.D.: Okay. So eight years of flat-funding. We have probably 40-percent more HIV positive people in the country, around there than we had counted before. The testing programs are going to be effective. It's taking some time to put all that together. So we're going to have this engorgement of new patients. Where are they going to be taken care of? We're going to pretend we're in a Disney movie, and you each get two wishes. What are the two policy solutions that you would propose to make this mess work? Dr. Hader.

SHANNON HADER, M.D., M.P.H.: Oh gosh, I can go first. Two wishes, I thought it wasn't going to be policy; I was going to wish for a real cure. Since we're short of the actual, let's make them realistic wishes. I think I have two main wishes in terms of really a request for the feds. And I'm an ex-fed, so maybe you can only be like most critical of your own family kind of thing. Number one is actually not what people might think. I'm not just going to ask just for more money. I would actually ask for coordination and meaningful accountability.

So, for me, as a small jurisdiction, you know we're a little small town here, 600,000 people I'm responsible for our HIV, STD and TB programming, as well as hepatitis, and about 85-percent of my core budget is my formula-base, non-competitive federal grants. This is the money that comes from

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

our taxes and goes to the states and the jurisdictions to help support our core programs.

Well, just for that annual regular ongoing core programming, I have 12 separate core applications on five separate fiscal years, all with completely different reporting requirements, evaluation requirements, planning requirements, and documentation that goes in multiple times a year, none of which actually coordinates with each other to make one comprehensive plan.

That's a waste of not only my staff's time or energy but it causes massive trickle down fragmentation on all these levels of care we're talking about, and guess what? We've figured out how to do it differently for other programs because guess what? PEPFAR has one time a year where these plans come in and they go a go or no go and let the funding get out there and do the comprehensive programming that is supposed to get done all over the world. That's wish number one, a little bit of coordination and sane accountability.

And then I think wish number two and I'm probably going to make some enemies eventually on this one but I've been here ten and a half months and I'm staying, so [laughter]. Wish number two is I really think we have to get rid of again from the federal level this trickle down complacency.

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

I really think our federal HHS and other groups are sending the message that we're okay and we're not. This is not okay. When our federal leading agency announces brand new HIV estimates that are 50-percent higher than we've ever talked about before, and the main talking point is not, it was not okay at \$40,000, it's not anymore okay even less okay at \$60,000, and instead their talking point is, isn't this great? We have a great new technology. [Laughter] We can measure. That is not okay. That's not the leadership I need. [Applause]

Likewise when I go to a presentation yesterday where the topic was from our HRSA counterparts, well how do we project what that growing need based on the counseling and testing policies is going to be for care and treatment? And there's a presentation that highlights all the core assumptions that can go into calculating what your increase and new diagnosis is going to be and what that means for care and that's it.

And a question from the audience comes up and says well, but what's the punch line? What's the number? What does this mean? And the response from our HRSA leadership is well, that would take a lot of work to calculate that. [Laughter] That would take a whole lot of time and some really sophisticated people and I said so what, I'm supposed to do

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

this in D.C. and Tom's supposed to do this in Florida, and then we're all supposed to get together and compare notes and have everybody tell us we're wrong?

Where is our federal leadership, giving us the data, the accountability and the projections that says you know what, this is what we're going to need so trickle down complacency is just not working because certainly at our jurisdictional levels things are not okay and we know that they can have solutions and we can do better and we can make a difference. [Applause]

THOMAS LIBERTI: I want to be very blunt [laughter] about the first thing and that is money, okay, and I just want to revisit what Dr. Sagg said, the dilemma that he described in primary care in the United States in his clinic and others was totally predictable and absolutely understandable and presented to the federal government in a number of venues.

When the CDC and others talked about a policy about routine testing to find new infections and the AIDS community and the public health community said we are in favor of this policy, the next sentence was where is the money to take care of the patients? Myself, and I know I can't see through the light but I know Dr. Sweet is here, we're both members of the CDC HRSA Advisory Committee, an appointed group, and we asked that question.

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

Furthermore we said we want you to calculate how many new infections would be found in the testing policy and we want you to give us a cost, and they did, and then we want the federal government and it wasn't a bank buster. It wasn't a bank buster. It was the money that we need to take care of patients. You can't have every clinic in the United States go from 300 patients to 600 patients, from 1,000 patients to 2,000 and not increase the funding for doctors, nurses, laboratory and everything else but drugs. It's not an economic understanding. [Applause]

And that's part, we saw it work with ADAP and as Dr. Sagg and others have said, we are thankful about that and appreciative of the fact that we have almost adequate ADAP dollars around the United States but we don't have any flexibility, which is my second wish, is that if I have excess ADAP dollars in my state, I can't use them for primary care. I can't help the clinic in Ft. Lauderdale or help the clinic in Miami that's calling me saying I need another doctor.

So, it is not that complicated to come up with the unmet need in the United States based on the number of new patients that would be found through routine testing, calculate a cost, do everything to increase the Care Act or whatever mechanism if the powers to be, if the congress or others do not

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

want to send the money through the Care Act anymore, \$2 billion is too much, then they've got to come up with another system.

If it's medicaid, ETHA, or whatever, but it's common sense that the more people that we find through aggressive testing programs, through rapid testing technology, and we want to put them into a medical home, you've got to cough up the primary care dollars.

MICHAEL SAGG, M.D.: Okay my first movie comes from Dream Works. [Laughter] Because it's actually achievable and that is I'm thinking beyond HIV, I'm thinking we need universal health care in the United States. [Applause] And what that means is a radical transformation of what we're already doing in a fragmented way. When you ask the average person on the street do you think there should be government provided health care, they say hell no. And then you say should I get rid of your medicare, they say hell no [laughter] and I say what the hell is that? [Laughter] So, that's number one, and how we pay for it I have ideas if you want to go into it.

The second is coming because it's almost laughable, I'll say comes from Monty Python, and I view that what we need to do as a society is eliminate for profit health insurance companies. [Applause] Now this is radical that nobody works for government could say but think about it for just a moment.

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

I want you to think in your mind about one single solitary contribution that a for profit health care company makes to society outside of its dividends for its shareholders because it sure doesn't help me and it sure doesn't help my patients because what we've done, for example prior authorization, we have been inundated in the midst of all, I didn't go into this in my talk, that's why I'm using this opportunity, we've been inundated in the last four or five years with more and more prior authorization and medicare Part D has been a disaster for us.

Why? Because the private health insurance companies create plans, everyone different from the other, and I don't know what my patient's on and I write a prescription, let's say I write seven, they go to the pharmacy, four of them are on the plan, great, three of them get rejected. What happens? Those patients come back to the clinic and say get my medicines and I say is it my job to assure that you get your medicines? I do it because we're that fabric again. I do it because I don't want to see them go without, so we timed it and it got.

This year at IDSA it got this year, we have a presentation that we did a time and motion study for an entire year, actually two years, of what it costs our providers to do prior authorization. Answer? When we have, back it up, we have an EMR that makes getting access to medicines easy. This

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

is as good as it will get, 23 minutes per prescription, 23 minutes, that translates when we calculate the cost of the personnel, one-third for one prescription, one-third of their clinic allowable reimbursement for one prescription.

So if they had three prescriptions the entire cost of reimbursement disappears in the time our provider spends getting medicines through a system that does nothing for patients, so what do we do? Mutual based insurance companies where the provider, sorry where the patient is also the share holder. If the provider and the patient, sorry if the patient is also the shareholder then if they do a good job as a company the dividend goes back to the person who benefits, lower cost, more benefits, simple Monty Python. Not going to happen, but that's what we need.

ARCHBISHOP JOYCE TURNER KELLER: Okay, my first wish, that if I could do anything to change policy, I would like to have one of our representatives from Congress and one from the House come and spend a weekend with me after I'm given new meds and they have to wipe the sweat from my forehead, count the times that I run to the bathroom for diarrhea, and wash the dishes that I probably will go. And I hate using paper plates so I'm constantly using dishes when I know I don't have time to wash them.

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

But the big mess I make, I'd like to have them clean it up [laughter] and sell them one weekend of my living with HIV and AIDS and seeing the side effects of the meds that I'm dealing with, have them to baby sit the 13 grand kids that I have, and then tell me that I don't need the medicines that I get to offset the side effects of the meds that I'm taking.

I would like if it was my wish and I could change policy, I would love to have health care, my health care, decided by my physician and not by my insurance company. I would like to know that for the next med that my body needs is in the formulary and there are no restrictions, no limits on my health care or any person who's living with any chronic illness.

If there was anything I could do to implement policy, I would demand that they be sentenced a weekend to live with me and my grand kids. That's what I would do [laughter]. And believe it or not, they would be on the phone before that second day [laughter] calling, trying to set up a session to sign any bill that I would put on the table.

That's what I would do to implement change because see, nobody is going to tell me that there is nobody on the hill that's living with HIV/AIDS. They either know somebody who's living with it or someone has died from it in their family and I would like to see the complacency disappear.

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

If I could change a policy, that is the policy that I would ask to be implemented, that they be sentenced to spend one weekend with an HIV positive mother, grandmother, or any person that's living with this disease and see what it's like and know that we're not asking for a handout, we're only asking for a hand up. We're asking them to save our lives and that is not an impossible thing to do so I might send a petition out asking some of you to sign it to see can we get someone to spend a weekend with me and see what life is like.

GARY ROSE, J.D.: So Joyce I would amend your request and just say while they're living with you for that weekend that they should also take your medicines to see what they feel like.

ARCHBISHOP JOYCE TURNER KELLER: Oh I would love that.
[Laughter] [Applause]

GARY ROSE, J.D.: They may never get out of the bathroom. [Laughter] I've gotten a couple of questions on testing so I'm going to put them together. How is routine HIV testing going in your jurisdiction? Do you think it's effective? What needs to be done? What doesn't need to be done? And secondly who is paying for it?

SHANNON HADER, M.D., M.P.H.: Alright, first again. So I think routine testing in the District of Columbia is going well, but we still have a long ways to go. So we're in a very

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

adventitious place in that we have no sort of policy
restrictions to full across the board routine opt-out testing.

And then we're also in this environment at ISCRIBE
where our rates are so high and HIV is the number one cause of
premature death of our citizens across the jurisdiction that
when I can tell that story to providers it becomes a very
compelling this is about you and your clients, so that's an
advantage, but that said it still takes a long ways to go from
policy to full implementation.

We have some wonderful leading organizations, at least
two that have modeled and gotten to scale on full routine E.R.
testing and that's G.W. and Howard University Hospital. We
have two labor and deliveries that are in full routine opt-out
testing, two more coming on board, and three more to go,
because we have a huge peroneal transmission problem.

And we are working with primary care providers to
really do the true implementation of when people show up, give
them a routine opt-out test, but we know that's not all
happening yet. When we use a lot of different surveys that we
ask, whether it's people who are getting testing, whether it's
behavioral surveys, really three-quarters of the people who are
newly being diagnosed with HIV had at least one contact with a
health care system in the past 12 months and they were not
diagnosed with HIV.

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

So it's not that people are out there not being touched by the system, they're not getting the services they need. And so we are really trying to change the dynamic within the health care system to say you know we don't have to do this much to convince you to use the new troponin test for heart attack screening when they came out, because why was that? Because there was no way you were sending someone back out of your ear onto the street having a heart attack that you would then be responsible for.

So you sort of say well, you know, maybe your new best friend is risk management. If you're having problems getting routine opt-out testing implemented in your organization, you got to start thinking that if I was one of these patients that we see a lot of in D.C. showing up in a hospital setting with cryptococcal meningitis that's going to leave me hurt if not dead and I'd had any contact with any health care provider in the last 12 months and they haven't documented that I had refused an HIV test, you know what I would do?

I would sue, sue, sue, sue, sue, because that's what happens with heart attacks, that's what happened with [inaudible], and that's what gets our standard of care for people who can't demand it up to the level it needs to be so we're going pretty well but we've got a long ways to go. I think we're ahead of a lot of folks. Who is paying for it?

TT2CANN (Title II Community AIDS National Network) and CommGenix
LLC
8/26/08

We're paying from the public health system, we're paying for some of the start up models, people to develop the best practices, help train other health care settings, other practitioners and get it going.

But we truly believe the bulk of this testing should be covered in the health care system, just like all these other routine tests we do, go to the doctor, you don't have to beg to get on the scale right, you don't have to beg to say please doctor, let me get weighed today when I come in so you can screen me for obesity. You don't have to beg to get your blood pressure tested. You don't have to beg to get your diabetes tested. You shouldn't have to beg to get an HIV test. It should be something that certainly in D.C. you're getting when you walk through the door.

THOMAS LIBERTI: Yes just from a large state perspective, we of course from a public health standpoint embraced both routine testing and expanded rapid testing, we kind of combined them in our thinking in our state because we really, really believe that knowing one's status is so fundamentally important and I think I got a little bit of good news and a little bit of bad news.

When before routine testing really was launched and rapid testing, we all knew that there were two major barriers for expanded testing and I say the law meaning all the

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

different consent laws around the United States, in a variety of different, 50 different varieties in the funding and my short report card is that in the time that we've launched both rapid testing and expanded HIV, excuse me, expanded routine testing, the law part has not been the barrier, it's been the money.

And so we expanded to emergency rooms, excuse me, emergency departments, jails, community health centers, passed a law that it's opt-out for pregnant women, substance abuse and in all the places that the staff went down and trained and expanded, we don't have a law that requires written informed consent already so that was off the books.

However, we are supplying the test kit and we are supplying and I'm worried, we had a consultation with CDC about this recently if, the \$64,000 question for me is if we pull out the money some day, will those places continue to do that level of testing if the insurance company doesn't pay, if medicaid or medicare or even that was written recently, the federal government's insurance carrier doesn't pay for routine testing and I'm seriously worried that they'll stop and so we have to. I think we're making progress on reducing barriers of informed consent. We now have in the countrywide we have to reduce the barriers of the funding and I think we'll be on our way.

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

MICHAEL SAGG, M.D.: Moral imperative is about all of you so far, I'd like to move to Florida [laughter] and the state pays for itself. Less of a policy issue, more of a political problem I think. As long as I've been doing this work for 20 years, 25 years, the process is, data comes out from a city or a state or nationally, the numbers of African Americans who are infected is shockingly high.

You get about two new cycles of shockingly high, gone, done, nobody talks about it. Next time, you get exactly the same reaction over and over again, every time it's released there's no historical memory that we've seen this happening the whole time. It's getting worse, how do we deal with it? What do we have to do just generally to impress, how can we break this, how can we break this pattern? Joyce?

ARCHBISHOP JOYCE TURNER KELLER: How do you break the pattern? You go back and you undo the Tuskegee Study. Bottom line, a lot of African Americans are still, I mean are still in that mode where they feel like guinea pigs. There are some who still believe that AIDS is manufactured and placed into our neighborhoods. We're talking about cultural competency where the people want to address that or not it's something that happens.

I'm certified to do HIV counseling and testing and there are times when I talk to people, when I'm doing outreach

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

and I will offer them an HIV AIDS test and I get them to understand that I was tested. I first disclose that I'm positive and I said if it can happen to me, it can happen to anybody.

A lot of African Americans feel like if you're coming into my area based on my zip code that is racial profiling because I don't see you in other areas where there are Mercedes Benz or Cadillacs or BMW's, or Town Cars parked in those areas. I don't see you knocking on anybody's door on a Saturday morning, then why are you in my neighborhood?

How do we erase this? Continue to do what it is I do. As an advocate I go into the churches and I talk about being positive. I go on our college campuses, into our classrooms, and I talk about being positive and the need for African Americans to be proactive in their health care. But then the other issue becomes even when the numbers are as high as they are, the other question I'm being asked is where are the numbers from the other areas.

And what I'm getting is that I had someone tell me well if you look for the number, if you look for the problem in a particular neighborhood, that's where you're going to find it, but where are you, you know, we don't see, this summer, I'll put it this way, I worked with children during the summer. I

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

went into the Hispanic areas, the Latino community, and I
picked up children that were Latino.

I went into the areas where there were children that
were Vietnamese and Asian and my question to them was, one of
the young ladies that I had was from Vietnam and she just lost
her sister to AIDS and I wanted to know who's testing in this
community, she said I haven't seen anybody, so African
Americans, it's not an excuse, it's a fact, a feeling that AIDS
has become a "Black thing" and they don't want to be
responsible for this "Black thing".

Because when you look at the new data that has just
come out, data that has just come out, it's addressing gays and
African Americans and they're like well who else is responsible
for this? So African American men definitely have to go there,
a feeling like they're getting a bad rap because they're seeing
the biracial children in our communities, they're seeing the
biracial children in our schools and in our churches and they
are saying the numbers are high in our communities due to
heterosexual contact.

But it's not only African American men that are
sleeping with African American women. And they feel like
they're getting a bad rap and you talk about the numbers,
African American women are testing positive but not every

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

African American woman that is testing positive is infected by
an African American male.

And we've tried to figure out where those numbers are
coming from, but we have to also look at the fact that every
African American man that is diagnosed positive is not
diagnosed positive by an African American woman. I guess the
one thing we need to do is you talk about how do we erase it,
when you come in and give an African American or any other
person a test, we ask when was the last time you had sex, we
ask what was the gender of that person, but nobody's asking
what is the ethnicity of that person?

I think that if that question was there and maybe to
some people it may not feel like that much but it's much to me
and I say that because when I became infected with HIV it was
not from an African American male. It was from a white rapist
so those numbers need to be put out there. We need to add
that. The CDC needs to add that. Let's see if that will make
a difference because any step is a necessary step and we don't
know what the impact will be and you can't say it won't work
because nobody has decided to try it.

SHANNON HADER, M.D., M.P.H.: Yes, I mean certainly in
D.C. we see a lot of racial health disparities. We are a
predominantly Black city. We are a population 55-perceten Black
so it's interesting because a lot of the conversations you hear

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

about cultural competency and other jurisdictions, this is our jurisdiction, this is our world, period.

With that, we have 80-percent of new infections are among our African Americans and here in D.C. it really is mostly African American. Some areas it's mostly new African immigrants, but this is our D.C. folks that have been here for a long time and I think there are two things that we really need to impact locally.

For us one thing has really been risk perception and when we finally released, you know, these data that I just told you about, we just released them in December. This was the first AIDS data for D.C. in five years and the first HIV data ever, so even on the front lines people knew the rates were bad.

They didn't know how bad really and we didn't have all these details to talk about, who is getting infected, and we found out that it's not just one neighborhood or other, we have high rates across the city and we have every risk group and every race getting infected. So the biggest thing though is when we launched this data, folks still had a very strong perception that HIV is just only a gay white man's disease and maybe a little of those injection drug users and that was about it.

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

And I can't tell you how many just press conferences I had where the journalists oftentimes sort of my age, middle age, beautiful African American, educated women who would just keep asking but why is that, why are people getting infected here and sort of tell me why it's not me? And I finally had to come out and say it's sex, it's called sex [laughter]. That's it. That's why people are getting infected.

What they'll want is actually breaking through that risk perception and that gets into, I think number two, when we're talking about, it's called sex when we've got this much HIV going around, you don't have to do a lot to get it. And I would like to build on what you mentioned, this is where it becomes about relationships and social networks, you can't describe it just as racial profiling or ethnicity's or where you live and but we haven't always had the information or shared enough detailed, smart information that really makes sense to people.

We just finished with CDC, one of the national health HIV behavioral survey modules on heterosexuals. And this was called a high risk heterosexual study. But we were really lucky because the methods for us were defined as, well high risk was we're going to get away from saying you as an individual are high risk, how many sex partners did you have, and instead high risk was defined as, you had the double whammy

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

of living in a geographic area that had the highest HIV rates in the city and the highest poverty rates so we're going to look at vulnerable heterosexuals.

And we completed the study and we found I think really important things that we started to share and we look forward to sharing more broadly, which is our average participant was, I think it was 1,000 people, our average participant was 30 years old, which reflects our epidemic, we don't have a young person's epidemic. We have nearly as many new diagnoses in people over 50 as in under 30. So it's the 30's and 40's people are getting infected here in D.C.

We asked all the regular questions the person one okay, last time she had sex did you use a condom? And 80-percent of folks said no, didn't use a condom. Okay well live in D.C., not using a condom, not a good thing, okay. But then we asked the obvious question, said well out of you folks, how many folks are in a regular committed relationship? And 70-percent said yes I'm in a regular committed relationship and said okay, regular committed relationship, not using condoms, sort of going hand in hand, almost any place in the world but ya'll live in D.C.

But that's okay; let's ask a few more questions. And said so that person you had sex with last, do you know their HIV status, 50-percent of the folks said no, I have no idea.

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

But you're not using condoms, saying you live in D.C., not sounding good.

Then we asked the final question. I think is really, this is why talking about relationships is going to be really important because are the tough conversations. And we said okay, those of you in this regular committed relationship where you don't know your partner's HIV status, you're not using condoms, do you think your partner's stepping out on you? Do you think your partner has another sex partner now at the same time, 45-percent of the men and 55-percent of the women said yes, I'm pretty sure that my partner has another sex partner right now, too, but I don't know their HIV status, I'm not using condoms, and I live in D.C.

And I think that's not a story we've been willing to talk about a whole lot, but that's the kind of reality that people need to know, again the average number of sex partners in the last year of everybody in the study was two, 30-percent of the people had one sex partner in the last year.

We're not talking about what the traditional high risk, high, you know, partner reduction, duh, duh, duh, we're talking about a generalized epidemic that has to really come down to how do we talk about the things that mean something day to day in most of our lives?

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

GARY ROSE, J.D.: We have time for one more full panel question and I'm going to pick a doozy because somebody sent it up here. If we look at the total amount of federal funding being spent on HIV/AIDS, that includes Ryan White, medicare, medicaid, V.A. money, how do you think that compares to the actual cost of treating the people with HIV in this country? Is it simply a matter of more resources or is it a matter of the way those resources are allocated? You start.

MICHAEL SAGG, M.D.: Okay I've got a pretty strong opinion about that, I always want to look internally at ourselves first and I would go to do that analysis I'd go look at a capitated answer. I can tell you from our clinic, we probably are running somewhere between \$1,500 and \$2,000 per patient per year, not including medications, just our cost of delivering care.

So if you want to figure in the medications I've already told you it's \$18,300 per patient, but just for the clinic part of it and I'll leave the medications aside because that's a whole different topic, but just for providing care, \$1,500 to \$2,000 would get you a lot.

Right now from Ryan White Part C we get \$330 per patient per year so we're woefully underpaid but I will tell you that one place to look and this is woefully politically incorrect, but I've already went to killing for profit health

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

insurance so I'm on a roll, Part D, Part D, we need to look at it. We had our biggest success in stopping perinatal transmission in this country.

In my state which isn't the most wealthiest state in the union, I can count on one hand the number of transmissions that have occurred among women and prenatal care to their babies and they were all more or less accidents for different reasons, one or the other, so why is it that the Part D clinic in our city has been flat funded like me for the last 10 years?

So, the answer is well, we're providing care to the exposed but not infected. Good. That's regular pediatrics and for the mom's, well no they need to be in the adult clinic, thank you very much, because I don't think the pediatricians are trained to take care of a 30 year old, so I'm all about combining our resources.

But before I go to Capital Hill with a straight face and demand and bang my hand on the table, we need more resources, we need to look at what we're spending and I would advocate a capitated system, maybe modified by the stage of care, CD4 count, and we also need to look at what type of discounts ADAP's are giving and that type of thing and once we clean up our own act, then we can ask for more resources.

THOMAS LIBERTI: Well, again, I think there is a lot of money in the system. The federal government spends over \$10

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

billion on HIV in the United States and 90 plus percent is in care and treatment and that little sliver is in prevention. So the balance of what we spend it on, the other part that I think, the mix of I talked to an AIDS clinic one time that said they have to manage 31 sources of funding to run their clinic.

There's something wrong with that picture. The amount of administrative paperwork, I met with the Department of Corrections last week in the governor's office in my own state and compared AIDS prices for drugs and it was a disgrace. We get a great price because of the ADAP task force and ADAP and the Department of Corrections doesn't.

And they're spending over \$20 million on AIDS drugs to take care of 4,000 patients in the Florida prison system, 90,000 inmates, 4,000 infections, and not enough money for HIV care, treatment and drugs. It could be major savings in that the care could be better, more physicians could be hired, in this particular case the pharmaceutical price was lower inside an institution.

There's so many rules and regulations that a community health center can do this but a hospital can't do that and a G.L. can do this and so you know we don't have time for that kind of overhaul but I think the way Dr. Sagg said it was that you know some capitated way, some way to realign the big pool and make the playing field a little bit more level, we could

obviously squeeze out more in what we, that's already there and then determine what the unmet need is.

SHANNON HADER, M.D., M.P.H.: Yes I would agree with the two step approach which is I suspect that a lot of our monies being spent right now have variable efficiency and effectiveness but part of my suspicion is because we really can't tell the good story of what's being bought for the bucks out there across the board. We don't have consistent basis level data that help us make that argument.

And I always think the best argument for major increases of new monies are to be able to show what you are and you aren't buying already but in terms of functionality of it, I really, you know, I have this analogy that I always sort of come back to, which is I don't know if any of you have ever renovated an old house but I used to have this little 1918 bungalow down in Georgia that essentially you come in to a house before it's been renovated, you start figuring out what are you going to do, what does it look like and you say oh that's a cute little computer nook, you see that little indent there in the wall and that'll be great and then you start with some of these old houses you start into it and do your first hammering and you realize oh my gosh, that's a whole layer of wall board that comes out and there's another wall and that's paneling and there's another wall and oh my gosh, there's 12

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

foot box foot ceilings that were down to here because during the depression you know they lowered the ceilings to save heating costs.

And suddenly you've done knocking down all these walls and you find out you have this whole like bedroom with three windows that you've been paying property taxes on all the time because you've got that square footage under there but you haven't been able to use it for what it was intended for. And I sort of feel like at this point I know this is sort of like not acceptable in this meeting, but I feel like the Ryan White Care Act is sort of like that.

Over the last 18 years we've added another layer of walls and then we've brought the ceilings down and then we've added another paneling over here and suddenly we're boxed in to this whole set of rules and regulations and things that made sense at the time and were the easiest next little tweak to do and it's sort of time to clear it all out and go back to the basic intention of what these monies were for, which was what's the most rational and complete system of care that we can possibly support and how do we get there? [Applause] And then we can build on the extra room.

THOMAS LIBERTI: I'm going to take moderator's privilege and answer that question myself. A couple of years ago to a resounding silence the IOM put out a report about

TT2CANN (Title II Community AIDS National Network) and CommGeniX
LLC
8/26/08

managing care for HIV and they said that the only way to do this, because the system as currently constituted is such a mess, is to have a whole new fresh system built and they explained what was involved including the things I talked about before and they were assuming it was every patient up to 250-percent of federal poverty and they gave the patient numbers.

And what we did at TT2CANN was we looked at the patient numbers that they were presuming would be taken care of under this system and we looked at every system that was currently paying for care, we only took a percentage of their payments for HIV and discovered that every system that's currently paying for care under a concentrated system would save money, every single one of them, big money, 50-percent of state medicaid payments for HIV.

So I think the answer is going to be we have to think about this. If we don't think about this as a whole, we are not going to solve it. It has to be a complete idea and on that note, I want to thank everybody for coming. I'm having trouble here. Thank you.

Please stop by the exhibit tables before you leave.
[Applause] Fill out your evaluation forms and thank you once again to our funders. Good night.

GARY ROSE, J.D.: Good discussion.

THOMAS LIBERTI: Oh yes, people were asking for Dr. Sagg's slides. They will be available through the Kaiser Webcast of this meeting, okay? Thanks again.

[END RECORDING]