

**Access to HIV Care:  
Do We Need a New Model?  
Title II Community AIDS National Network  
August 30, 2006**

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**GENE COPELLO, PhD:** My name is Gene Copello. I am the executive director of the AIDS Institute and on behalf of the AIDS Institute and the Title II Community AIDS National Network, I would like to welcome you this evening to our forum entitled "Access to HIV Care: Do We Need a New Model?"

When Bill Arnold and I started thinking about this workshop - oh, I guess about a year ago - and thinking about the title that we came up with, I really started thinking about the question: Do we need a new model? And at first, I thought, that is a really explosive question. We have the CARE Act. We have Medicaid. We have Medicare Part D. We have these systems in place, but do we need a new model to ensure access for everyone?

But then, the more I thought about it, I realized it really isn't that significant of a question. For those of us who have been involved in the AIDS movement for five, 10, 15, 20, or more years, we know that the AIDS movement has been part of an evolution, part of a direction going forward, improving services, making life better for people living with HIV and AIDS, thinking through new ways to prevent infection, et cetera. Some of the very best minds and most compassionate hearts that I know have been involved in this work.

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So, it really isn't a strange question. In fact, yes, we should always be looking for new and better models of HIV care so that we can ensure access for everyone. It is really what the heart of the AIDS movement is about. We bring together research, practice, advocacy, academia, and from that we improve upon what we know. We improve technology. We improve prevention. We improve human rights for people living with HIV and AIDS, and I think that over the last few years, we have come to realize that whether we are in Kampala or Hong Kong or in Bronx in New York or Huntsville, Alabama, or wherever, access to HIV care is a problem. In some locations, it has improved. In others, it has gotten worse, but the whole concept of access is critical to the future of our being able to clarify what good services are all about.

This evening marks the beginning of a new partnership between three organizations: the AIDS Institute, the National Association of People with AIDS, and the Title II Community AIDS National Network. Our three organizations are going to be doing a series of events over the next year or more on access to care issues and we really hope that you join our partnership and provide feedback to us as we move forward with these events and provide them in different public settings, because we really want to raise the awareness of access and what access means, what it can mean, how we need

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to improve it, and how we need to break down the barriers that prevent true access to truly good services.

So, having said that, again, thanks for your time this evening. I am going to ask two of my colleagues, Bill Arnold and Frank Oldham, to give us some introductory comments as well. First, Bill Arnold, who is the executive director of the Title II Community AIDS National Network, and he will be followed by Frank Oldham, the executive director of the National Association of People with AIDS. Bill.

**WILLIAM ARNOLD:** Thank you, thank you, thank you to everybody who has taken time out of their schedule to be here tonight and I second everything, obviously, that Gene said. And the presenters and the people that we have on the panel tonight are designed to raise specific pieces around specific parts of the problem. Everybody in this room knows that people with HIV do not have universal access and those of us who have been in this work for a long time really can't rest until we can get to the point where we can say that everyone should have and, in fact, does have universal access.

So the start of this combined organizational AIDS service organization or NGO effort, however you want to think of it, is to repeatedly here, over the next 12 or 24 months, to keep raising these issues until such time as whatever has to happen has happened so that the individual issues have been addressed and addressed successfully.

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Every presenter here tonight has a particular part of the problem that they are going to deal with and one which you may not think of very often that we have made our volunteer, Bryan J.R. Jackson, the young man in the middle there, available because while he is 15 right now, eventually he will be 16, 17, 18, and as he goes into adulthood, what happens to his access to HIV meds? But that is one of the points. Everybody else has significant points. They will be familiar to some of us and some of them you may not have thought of, but this is the beginning of a long conversation you are going to be hearing from NAPWA, the National Association of People with AIDS, the AIDS Institute, and [inaudible] can for some time on these issues until everybody is so sick of hearing about them hopefully, we will have actually successfully addressed them. Thanks very much.

Frank?

[Applause]

**FRANK OLDHAM:** Thanks, Bill. I will introduce [ph] Frank Oldham, Jr., executive director very proudly of the National Association of People with AIDS. I have been positive for over a decade and a half and I am still here.

[Applause]

You know, the issue of access to care is critical to all of us. We must never forget that nearly 500,000 African-Americans and Latinos have died from AIDS since the

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beginning, 250,000 gay men have died from AIDS since the beginning, and NAPWA is the voice for 1 million Americans living with HIV and AIDS. We have, thanks to our partners in the pharmaceutical industry as well as our partners in the medical industry, new hope with the combination therapies and new treatments. That is why our three organizations have come together and our conference, the conference that we usually have, a signature conference for NAPWA, has been staying alive.

I had a meeting when I first arrived in Washington with Bill and Gene, and we talked about what has happened, what has changed, it used to be that people would become ill with AIDS, you would go to a hospice and then to a memorial service, but now there is new hope. But people must have access to that new hope and that is why we have polled our conference in these brochures here, I hope you will attend, in New Orleans in this partnership "Staying Alive: Access Matters." With access, we can save lives in America and not be faced a decade later with another 1 million Americans dead from AIDS. Thank you very much.

[Applause]

**GENE COPELLO, PhD:** Thank you, Frank. We are going to move into our panel now, and as we all have said, the panel we have tonight is distinguished. Each person brings a particular perspective to the area of access, and we are

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going to begin with Dr. Michael Saag, who is at the University of Alabama in Birmingham.

**MICHAEL SAAG, MD:** Well, thank you very much. It is a pleasure to be here. I am going to speak to you for about 10 minutes on some converging vectors that are leading in my opinion to an emerging crisis in health care delivery for HIV.

Now, we use the word "crisis" a lot in our daily lives, perhaps, but when I am using the word crisis, I am meaning it in the sense of patients not being able to get access to care. And what I am going to share with you are data, a lot of it from our clinic, the 1917 Clinic at UAB in Birmingham that we have been able to follow all of our patients since 1988 through these electronic systems, but the data that come out from this paint a picture that is really quite concerning to the point of being frightening if we start to project into the future. So let me dig in with you.

This didn't project as well as I would like. You can see four lines on this curve, the colors got converted when I brought it to this computer, but I think you get the picture. The top two lines, this is a Kaplan-Meier survival curve, people alive after eight to 10 years at our clinic in the HAART era, this is post-1996, and if you look at the top two lines, those are individuals with CD4 counts when they started HAART therapy above 200, it was above 200 and above

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350, the middle line going down towards the bottom is someone who started with HAART therapy with a CD4 count between 50 and 200 and the bottom line is somebody who started HAART therapy with a CD4 count less than 50. You can see that the eight-year survival of someone who started HAART therapy with a CD4 count less than 50 is around 50-percent, meaning half of them have died, even in today's era. If you look at someone who started HAART with a CD4 count between 50 and 200, 25-percent to 30-percent have died within eight years. So, only those people who are starting with CD4 counts above 200 are gaining the genuine benefit of what I hope is a lifelong, a normal life expectancy, from antiretroviral medications.

The slide that unfortunately didn't transfer shows you in our clinic, I will just describe it for you, the median CD4 count of somebody showing up to our clinic in Alabama over the last decade. The median CD4 count of someone showing up with a new AIDS diagnosis in our clinic is 150 on average; three-quarters of our newly diagnosed patients have less than 200 CD4 cells. Take those facts, add them to this picture, and it is not very pretty. There is one exception to people showing up with low CD4 counts, pregnant women. Why? Because pregnant women, for the last several years, have had opt-out universal testing. Their median CD4 count on arrival to our clinic newly diagnosed is

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400. The take home point in my opinion is that we need opt out universal testing now. We needed it five years ago.

[Applause] I agree that there are caveats to this. One, you have to ensure counseling is done. You don't just test and release them and say oh, guess what? And you also have to assure access to care. Those are moral imperatives so with those two assumptions being done, we can save lives with early opt out testing. That is point number one. Let me move on to some other points.

We were also able in our clinic, over the last several years, to calculate the genuine cost of care, not a model but an actual, what are our expenditures annually? Sorry, you can go to the next one. So, opt-out testing, let's go to the next picture. So what we did is we for a year's period of time captured every encounter with our health system, be it for a clinic visit, hospitalization, or a referral for radiology, laboratory, and for all their medications based on antiretroviral and non-antiretroviral medications. As you look at the circled area here on the left hand side, you can see that the overall cost of care at the bottom is around \$18,640 per year. That matches very nicely with modeled estimates. You will also see, still focusing on that total column, that people that have CD4 counts less than 50 cost \$36,000 roughly a year and those who have CD4 counts of 350 over the course of the years are about

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\$13,000. In other words - hit the button for me please - patients with CD4 counts less than 50 cost 2.6 times more of health care dollars than with those of CD4 counts greater than 350; again, arguing for the points of universal opt-out testing and finding people earlier. It not only saves lives, it will be less expensive in the long haul. Next slide.

What you will focus on in the center section is the difference in cost predominantly is driven by medications. No matter which CD4 count strata someone is in, 70- to 80-percent of their overall cost is medication costs. Antiretroviral costs, if you look at that column, are relatively constant, ranging between \$9 and \$12,000 dollars a year. The difference in cost between a CD4 count greater than 350 and a CD4 count less than 50 is almost solely due to non-antiretroviral medications. Hospitalizations as you can see go from about \$1,400 to about \$8,300, but that is dwarfed by the \$1,800 to \$14,000 costs in non-antiretroviral medications. Hit the button, please.

So the increased expenditures for patients with more advanced disease are largely due to non-ARV medications and hospitalizations. Next. This is the scary part for me as a provider, if we assume, which we did, every patient had Medicare, and we assumed that every legal charge we generated was paid in full, 100-percent full reimbursement. Our average reimbursement per patient per year legally is \$359 per

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patient per year. That is a fact. For our 1,000 plus patients, the maximum we can get reimbursed is \$350,000 dollars. That covers physicians, nurses, rent, utilities, social workers, you name it. How are we supposed to survive? How many of you, I'll just take a show of hands, how many of you have noticed private practice HIV doctors going out of business? You will not, clear prediction, it's easy, is that you won't see many private practice docs doing HIV care five years from now. It will all be in publicly funded clinics because someone can't make it unless they are lying and cheating as an HIV care provider with the reimbursement, and this expands to primary care in general but HIV is particularly hit. Hit the button again, please.

So, expenditures for physician clinic costs are less than 2-percent of the annual expenditures, total expenditures, for health care for an HIV patient. Next slide. Now, there are some good news, there is some good data in this, and I am afraid I don't have a pointer but if you sort of focus on what we were able to do is ask the question if somebody's CD4 count improved or got worse in the course of that year's period of time, we divided the year in half and it started off say at the 50 to 199, if you will focus on that second set of columns, if they stayed the same they were in the red bar, so roughly about 23,000 a year. If they got worse and dropped to less than 50, their costs

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jumped to about \$37,000 a year. However, if their CD4 counts improved and went to the next highest group, their total cost dropped to about \$19,000 a year. Well, the only way I can see people getting a CD4 count increase is through antiretroviral medications and so that is clear benefit of ARV therapy. Next slide.

You will see that most of the change in costs is that second column which is the non-antiretroviral costs which I have already shown you and hospitalizations, but again, those hospitalization costs are dwarfed by the cost of medicines. Next.

So we if segue to what has been happening in this city and then across the nation over the last four years, there has been mostly flat funding of the Ryan White CARE Act. What increases have happened, as you will see from the second bullet, over the last four years, all increases have gone to Title II and almost every one of those dollars went to fund ADAP. The majority of the \$70 million new dollars in the current integration of the Ryan White appropriation for this year is targeted for Title II. CARE dollars, in the current reauthorization and as far as I can see all new appropriations, we're being told or I am being told that the pie is fixed and so if there is going to be increased payment for services, don't count on new monies. It has got to be a redistribution.

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Now, I am going to pick up on what was said earlier about the change in what has happened in the epidemic. Fortunately, we have come a very long way from hospice and hand holding, watching people die, to actually helping people live, get back to work, be productive, and actually live in my opinion a normal life span. So therefore, the services that are needed are quite different today than when the Ryan White CARE Act was first authorized. We need to have the Ryan White CARE Act reconfigured to support these new needs and that is going to mean some tough choices for everyone. But I have to say that, what good are medications if there are no providers to provide care? This is tough business. This is hard to do well. It is easy to mess up. You need educated, well-versed practitioners seeing these patients and if they aren't there the medications are just going to be misused and we are going to have a health care crisis of resistant virus like you can't imagine. Next slide.

So the policy implication so far is that the provision of antiretroviral medications has been the primary focus. Why is that? Well, it is because there has been no voice for the CARE providers. Almost all the voice on Capital Hill has come from lobbying efforts appropriately from pharma saying, we are providing medicines, we would like to get paid for it. There has been nobody from a CARE provider standing up down the street on Capitol Hill saying

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we are providing service, we would like to get paid for that. Moreover, not only do we have to ask for that, we have to advocate, write grants, to pay for the services we are providing. I don't see many attorneys doing that. I don't see many other doctors doing that, but we do that and despite writing grants and despite getting information out there to persons and other places, our funding has been flat funded for the last seven years. Next slide.

So here is our reality check. I am giving you a full exposure of me and our clinic. Here are the data. Our operating budget for the last year and almost every year there before is about \$2.1 million dollars a year. Our third-party payment, which I have already alluded to, is \$500,000. Most of that is from reimbursement for medication administration, very little of it as you saw was for actual care provided. The Title III monies that we get have been \$508,000 a year. We have been flat funded for seven years. We got a 2.5-percent cut last year and we have a 60-percent increase in patient volume over the last five years. Now, there has been salary increases and there have been new lab tests that we have to pay for, but despite all this, we run an annual deficit of \$1.1 million dollars. Who can run a business of any sort with that kind of deficit? How are we supposed to survive? These are facts. Those of you who are

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at clinics, how many of you are running a deficit right now?

Okay, next slide.

So the key points, mortality is much higher when patients are diagnosed late. I've already said that. The majority of people who are newly diagnosed are coming in late, except for pregnant women. Many, if not most, people HIV infected in the United States don't know they are infected right now. How do I know that? Because they are showing up late, so that is the tip of the iceberg. The rest of the patients who are infected are just out there but they don't know it and they are not in care. Next.

Universal opt-out testing is needed. Next. With more universal testing, I predict that our clinic will have 50-percent increase in patient volume over the next year to year and a half, so the obvious pregnant question in the room is, who is going to take care of these folks? Where are the doctors going to come from? Who is it going to be? You can tell we are at capacity. We are beyond capacity. I haven't been able to hire a new FTE or a nurse in seven years. Where are the patients going to get care? So let's go back to our two assumptions of universal opt out testing, counseling and access to care. Counseling and access to care. Can we deliver on access to care? Next.

This is from Laurie Dill, who works in Montgomery. I will quote. She is the medical director resigned from MAO in

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June of '06. "I will be the acting medical director while we recruit and hire a new medical director. We are currently actively looking to fill two positions, a full time medical director, and a part time physician to see patients mainly in our rural satellite clinics. As you know, Montgomery AIDS Outreach is a Ryan White-funded agency. We currently have myself and two nurse practitioners as provider staffs. We have full time clinics in Montgomery and Dothan and hold one or twice a month clinics in six other satellite clinics. We follow 1,000 patients over a 23-county area of South Central Alabama. Anybody want the job?" Anybody? Next.

Policy implications, provision of antiretroviral therapy and other essential medications are important. They are essential but we need a dramatic increase in funding to increase clinic capacity. That has to come from Title III. Why? Title I monies go to coalitions, local, politics, local politics, you can't rely on that. Title II goes to the state, state politics, you can't rely on that. Title III monies go right to the clinic. That is the most sure way to get dollars for care. Unequivocally, that is where the money is needed. How many increases have been in Title III funding from Congress in the last seven years? Virtually zero. That is why we are all flat funded. Next.

So the provision of medications from the Presidential AIDS Commission, every American who needs HIV treatment and

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care should have access, absolutely. People who are HIV-positive need essential medications, absolutely. Without drugs providing care is difficult to impossible, true, but add to that without qualified care providers in clinics, HIV drugs mean nothing and that is a fact, so what we have to do if the pie is indeed fixed, what do we want? Waiting lists or waiting lines? Thank you very much.

[Applause]

**GENE COPELLO, PhD:** Thank you, Michael. Our next speaker is Dr. David Holtgrave from Johns Hopkins University.

**DAVID HOLTGRAVE, PhD:** Good evening. Thank you very much, Gene and Bill and Frank, for inviting me to be part of this panel. It is a real honor and what I would like to talk about tonight is a very different model in keeping with the title and drawing upon the Institute of Medicine's report that was commissioned by Congress in the 2000 Ryan White Reauthorization language, and we can go to the next slide already.

The Congressional language in 2000 commissioned the Institute of Medicine to do a report to examine the feasibility of creating a publically funded system of care that was to be accessible, equitable, cost effective, and of high quality, comprehensive, and easily negotiable. And the panel was also charged with looking at changes, possible

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changes to Medicaid, and also to examine the cost of any proposal that the panel would make.

Some additional things that the Institute of Medicine was asked to consider were changes in the epidemic, in the increasing need for support services, very much an emphasis on considering state to state variability with regard to access to publicly funded care, and also disparities, racial, ethnic, geographic, and other disparities with regard to optimal treatment regimens.

Now the Institute of Medicine panel worked for about two and a half years, and we had to interpret that charge a little bit and some of the interpretations we made were that we were to focus on low income individuals living with HIV. We were to focus on the public sector rather than the private sector, and there were no constraints on funding and service delivery. In other words, we didn't start with the assumption that there was a fixed amount to the pie but rather we should look at what was needed in terms of care and services and we assumed that we must consider Medicaid, that was a requirement of our exercises charged by Congress.

On the next slide, you see a summary of the interpretation of our charge which was to challenge, to set out a forward looking vision of HIV care that meets the needs and makes the most of opportunities presented by this decade of the HIV epidemic. On the next slide, we see some

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contextual factors that we considered, things like the current status of the epidemic, the importance of HAART and other therapies, the fact that adherence to HAART was essential, and also that the federal investment in HIV was already substantial, not enough but already substantial and the question was how could that perhaps better be utilized as well, so the next slide we see some of our methodology, we reviewed very carefully the literature and tried very hard to look at all the data that was available around care and treatment services. We held public meetings, listened to persons living with HIV and service provision organizations, we listened to advocates, we had a very broad liaison panel and other providers that we talked to directly, AIDS providers across the country.

And also on the next slide you'll see that we considered the costs and health effects and all of the recommendations that we made and did a cost effectiveness analysis that I will mention very briefly in just a moment.

So on the next slide we see some of the conclusions. Now this is the middle of my talk set of conclusions, not the end of my talk set of conclusions. This was after we considered all the data, what really did we think we were faced with in terms of challenges? Well, we thought there were significant disparities in assuring access to standard of care cross geographic and community populations, that the

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federal state partnership for financing HIV care was not responsive to the national epidemic overall and that under current financing networks, many HIV persons living with HIV may go without care or have limited access to care and that lack of access to HAART was indeed poor quality care and there are other details I could go into that I won't tonight.

On the next slide, you then see the primary goal of our analysis was to find a system that would achieve the end, to improve the quality and duration of life of persons living with HIV. And on the next slide we have some secondary objectives to ensure early and continuous access to care, to promote the delivery of high quality services, to keep administrative costs low, and to ensure accountability. On the next slide, you see a review of the different financing options that we looked at. We considered that would happen if we simply expanded the Ryan White CARE Act? We also considered several changes to Medicare and Medicaid and I won't, again for the interest of time, go into detail on all of them.

Then we looked at block grants to states. Could there be a new kind of block grant constructed that would achieve the end we wanted? Finally, we considered a federal entitlement program that would be state administered but still a federally funded entitlement program for HIV care, and if you are interested in further detail on any of those,

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the report is finally out in hardback, a couple of years after it became available online, but all the details are there as well.

So how did we judge these different options? What criteria did we use? On the next slide, I have listed those criteria. The first was we wanted to make sure that whatever we recommended meant uniform eligibility rules, that it had a benefit package that met the standard of clinical care for HIV, that it provided adequate provider reimbursement to address some of the issues that Mike Saag talked about a few minutes ago, that there would be an adequate financing mechanism to support provision of care, and also an accountability and evaluation system so finally now I get to the recommendations from the Institute of Medicine. The recommendation was essentially this, that there should be a federal entitlement program for all persons living with HIV under 250-percent of the federal poverty level with a sliding scale buy-in above that and for convenience or lack of a better term, we called this program the HIV Comprehensive Care Program, or HIV CCP for short. So if you see that abbreviation in this talk, I am really just referring to our overall recommendation that there be a federal entitlement program for persons living with HIV under 250-percent of the federal poverty level and that each individual would be

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entitled to a uniform federally defined benefits package reflecting the standards of care.

And on the next slide you see what we recommended should be included in this entitlement program. I will get in a moment to the fact that Ryan White would still wrap around, the Ryan White Program would still wrap around this central entitlement program if it were ever adopted, but in the central entitlement piece, that HAART and other medications should be an entitlement, obstetric and reproductive health services, treatment for mental health and substance abuse issues, case management, HIV prevention, and primary and necessary speciality services.

On the next slide, we see the recommendations that we thought it would be important that providers be reimbursed, at least at the Medicare levels, to increase participation of experienced providers, that the federal government should be a prudent purchaser of drugs to be able to reduce the overall costs and increase purchasing power, and that a program should test the use of centers of excellence to provide delivery of care. And on the next slide, a very important recommendation was that this kind of entitlement program could be coordinated with a refocused Ryan White CARE Act. So, for instance, not everyone who would be living with HIV might have the documentation necessary to get a federal entitlement program, so the Ryan White CARE Act could provide

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services in that case. There may be other issues with access to getting into services, increasing knowledge about how to get these services, and other kinds of transportation and other axillary or ancillary services that could wrap around this entitlement program so there would still be a need for the Ryan White CARE Act, but maybe refocused in a different way.

On the next slide, we see, well, what does this program do? What would it cost? What would it achieve? We think that actually even though it would increase the federal expenditure in HIV, it would relieve substantially the state expenditures on HIV care. We thought that, our estimates were that in the U.S. there were about 233,000 people aware that they were living with HIV who were not getting access to HAART as they needed and we thought that this program as recommended would get about 60,000 such persons into a program that would provide access to HAART. Not everyone would maybe avail themselves of this program, so it is not going to be everyone who needs it, but could be at least just under 60,000.

So what else would this program do? Our estimates were after a lot of analyses that it would reduce premature deaths among those receiving care from about 35,000 over 10 years to about 15,000, a decrease of 56-percent of mortality, it would increase the number of quality adjusted life years

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saved by almost 130,000 and prevent about 3200 new HIV infections over the 10-year period that we analyzed and would actually be cost saving in terms of the prevented infections.

On the next slide, we see that the incremental costs of providing HAART to just under 60,000 additional persons would be about \$2.65 billion, but I want to say it in a slightly different way. We think that this program would increase the federal expenditures on HIV care by about \$2.6 billion in the first year but it would decrease the state expenditures by about \$1.1 billion and it would avert other kinds of medical care costs like emergency room visits and so on by about 800 million, meaning that the entire system would have to increase by just under 600 million a year. That is, an increase of about 7- or 8-percent to the entire system. So I think that if someone says well, this Institute of Medicine panel is just really out there calling for federal entitlement program, it is only really calling for about 7- or 8-percent more of a national investment in HIV care in the U.S. in order to do everything that we are talking about here. And I think that kind of single-digit increase is certainly in the realm of reasonableness.

Now, in terms of on the next slide, we asked the question in the analysis, is this cost effective? We actually found that when we looked at both the preventive benefits as well as the increases in longevity and quality of

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life of persons living with HIV, that the cost per year of lives saved would be just about \$43,000 dollars and when we compare that to what we spend on kidney dialysis and other kinds of surgeries and other investments that we routinely make in medicine and public health, we find this is a very good buy and would easily be considered cost effective by general standards. Also, we found that if we look at other kinds of cost offsets, there is a lot of money to be saved if antiretrovirals were purchased at the federal ceiling price. That may be a way to offset some of this cost as well, so again, probably in relatively academic fashion, it took us an entire book to say that we think that there is great evidence for providing HIV care to persons living with HIV in the U.S. and that we think the evidence suggested should be a federal entitlement program, especially for persons below 250-percent of the federal poverty level.

And we can go to one more slide. If you are interested in the report, again, you can buy the book but I think a much easier way to do it is to get it for free, to go the National Academy Press' Web site. It is there, you can print it out and also view it and read it online. I will stop there and again say thank you for including me in this panel this evening.

[Applause]

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**GENE COPELLO, PhD:** Thank you, David. Our next speaker is Jeffery Crowley from Georgetown University.

**JEFFERY CROWLEY, MPH:** Good evening. Do you have some slides for me? I think they are called P2CAN-DINNER. While he is doing that, I have to say I had to laugh. I was told I had 10 minutes to talk about Medicaid and Medicare changes. Bill Arnold knows that I could probably talk for two hours about Medicaid and then turn to Medicare, so I guess you are lucky that I only have 10 minutes but it is going to be sort of a big-picture overview. I mean, I think what they really want is as you all might be aware, Congress has made some changes recently to both of these programs. And just to give people really a sense of what does this mean for people with HIV/AIDS and also what does it mean for the Ryan White Program, just to step back further, let me just talk about sort of what we mean when we talk about Medicaid, Medicare and Ryan White.

So Medicaid is the largest health care program in the country. We spend between, the partnership between the federal government and the states, states voluntarily choose to participate and if they follow federal rules, the federal government matches what they spend. Collectively they spend about \$350 billion dollars a year on Medicaid, so there are about 54 or so million Americans. To qualify, you have to fit in a certain category and also have a low income so the

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main categories are children and families, people with disabilities which is the main category where people with AIDS qualify, and seniors.

Medicare is also a big program. It is the second biggest source of HIV/AIDS care after Medicaid. It serves about 40 million people and it is really seniors and working people that became disabled. So if you are under 65, you worked, you paid into the Social Security system, then you develop AIDS and become disabled, you can qualify. It is fully a federal state program and it is not too much smaller than Medicaid, you know, maybe in the \$325 billion-dollar range.

So, Ryan White, I think some people are surprised to understand, it is the third largest source of HIV/AIDS care and really the purpose of Ryan White is to be a gap-filler. It is to really fill in for the gaps left by these much larger programs so when we think about the role of Ryan White and what we wanted to do, one big stretch is to really make sure that those gaps are as small as possible or that these larger programs are doing as much as they can and also as David mentioned, the concept of entitlement. Both Medicaid and Medicare are entitlement programs and one of the things that means is that creates some rights for people. If you meet the requirements, you have an AIDS diagnosis so you are considered disabled, have a low enough income, you are

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guaranteed Medicaid coverage. It doesn't matter if more people showed up or if they are spending more money. It is an open-ended commitment. So unlike Ryan White, where we have to depend on Congress each year, it is open-ended so there are some features about that program.

Now before I give you my talk because I'm going to be really fast, let me tell you what my take home messages are. The first is that the country really does face some pretty significant health policy challenges. The CARE Act, I heard people talking about this at the All Titles Meeting, being called the safety net of the safety net, it really is directly implicated by the resolution or really non-resolution of these major policy changes so it is something we really need to pay attention to. The challenges we face as a country, though, and even the challenges in Medicaid and Medicare, are not necessarily what you might think they are or certainly not what our politicians or policy makers tell us they are. I think they are often quite different. Recent changes have been made, as I alluded to, and I'll talk about briefly to both Medicaid and Medicare, but they haven't really addressed the real problems.

So, in this environment, what should we be doing? I think the HIV community needs to recognize that a lot of these broader health policy changes, our politicians aren't saying, you know, we don't like people with AIDS anymore so

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let's do this to hurt them. They are really not even focusing on it, which is a good thing, but these changes have big impact on people with HIV/AIDS. So part of our job means to help policymakers, members of Congress, understand what is the HIV impact of some of these changes. And so lately, I think we just all need to be engaged in all these things and we need a good defense which I think we have been doing a pretty good job. But we also need a good offense, you know, because times will change and when we get a better environment we have got to know what we want to ask for. Next slide please.

So where are we in 2006 with the National Health Policy debate? I'll just make a couple of observations. First of all, there is just a broad split among political parties and stakeholders and what our goals and approaches are. I mean, there just isn't consensus. Are we really trying to get to universal health coverage? Should we focus on public initiatives like expanding Medicaid or, as David mentioned, new initiatives, or do we really need to just promote private health insurance? Should we increase revenues to pay for some of these new things? So there is just not agreement on what we should be doing. There is already significant concern about cost of what we have already promised people through the entitlement programs as I

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mentioned, Medicare, how much that is going to cost in the future; Medicaid; Social Security, etc.

Just yesterday, the Census Bureau - they annually release new data, which came out yesterday - there have been significant increases in the number of insured Americans and there is increasing poverty. Since 2000, 6.8 million more Americans have become uninsured and 5.4 million more Americans are living in poverty. In this wealthy country, it should shame us that more than 12-percent of our population is living in poverty. Almost 47 million Americans are uninsured, so we have some pretty big programs here and then the last observation I will make is that we are seeing increasing wealth disparities. In 2005, for every wealthy family that received a tax cut due to the tax cuts that were enacted in 2001 and 2003, there are 116 new Americans that became uninsured. You know, we have some really significant challenges. Next slide, please.

The next thing I would like to say is that when we talk about Medicaid or Ryan White, we always hear what a budget mess we are in. We just have no money at the federal level. This slide is from the Center on Budget, and what I wanted to show is from 2001, it's just a couple of years old, to 2005, we went from projections of record surpluses to record deficits. In 2001, when they were talking on some of these tax cuts, Alan Greenspan, the chairman of the Federal

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Reserve, said, you know, we have to cut taxes because he was worried that the surpluses were going to be so big they would destroy our economy. So five years later, we have this record deficit and we are told it is the problems of Ryan White, it is Medicaid, it is all these things. Well, let's look at what caused this change.

If you look at this pie, there is a big red wedge. It's roughly half of it. What has caused the change? Tax cuts, 48-percent; increases in defense and homeland security spending, in national spending, 37-percent. So it's really these two wedges of the pie at the top, there are entitlement spending 8-percent, that is where we have increases in Medicaid, Medicare, Social Security, and then the domestic discretionary programs except homeland security. So Ryan White, National Parks, everything, else, so those two wedges are only responsible for 15-percent of the change, but whenever we have a budget discussion, nobody is talking about cutting defense spending, nobody will acknowledge that we should maybe not extend these tax cuts, oh, but we have to do something about Medicaid being out of control. It is a real distortion of what the facts are. Could I have the next slide?

If any of you in this room have heard me talk about Medicaid, you have heard me say I think part of the things that we need to do is we need to reject the framings of the

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issues and I always talk about this, Medicaid is the boogeyman. I think that our politicians and people, they talk about Medicaid in a way because they are trying to create the idea that there is just something wrong with it and we need some radical change. If they had this belief that oh, maybe it works mostly well but would you make some minor changes? That would lead us in one path but they don't want to go there. They want to enact fundamental change so they tell us that it's broken, they tell us it is out of control, they tell us it is crowding out what we spend at the state level for everything else, and that it is unsustainable.

And I think, you know, if I had my two hours I could refute every one of those things. I do acknowledge that we have some challenges but I think these are false statements. So what I would say is that the challenges we have are bigger than Medicaid and they are bigger than Medicare. What are some of the challenges we face as a country? How we control health costs, you know, they are rising across all pairs, faster than inflation. It is not that the private sector is doing a great job and Medicaid is failing. This is a problem everywhere. In fact, Medicaid is doing better than the private sector. Financing access to new medical technology, you know, one of the things we do right in this country is we invest a lot in biomedical research. We can develop new

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drugs, new procedures, techniques, faster than we have come up with a reasonable method to pay for them, so do we do any smart technology assessment to decide when it is smart to make national investments in these things? No, we just really say oh, there is a tendency to say oh, if you are wealthy enough you can get it but then we will squeeze on programs like Medicaid to help low-income people. You know, we really need to figure out how we are going to establish a national system to finance long-term services, to take pressure off Medicaid; 42-percent of what states spend on their Medicaid programs is for Medicare beneficiaries and probably this is because Medicare just doesn't cover an adequate benefits for people, [inaudible] as people disabilities and much of this is things for like nursing home care or people that, they may live at home but they may need help getting out of bed, help resting, going to the bathroom, very basic things but yet we don't have any national systems. So Medicaid wasn't designed to be our national long-term care system, but only because we have failed elsewhere and Medicaid is the only thing there, it has taken on this role. Again, Medicaid hasn't failed here. And then we also have some demographic changes, the baby boomers are getting older, we have more people that are going to need access to public health care.

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So, recently I mentioned we made some changes in the Medicaid context. We have passed what is called the Deficit Reduction Act or the DRA, and let me just give you some reactions from the beneficiary community of what that meant. This is a law that was signed by the president in February. It is called the Deficit Reduction Act, but it is unfortunate in that it actually increases the deficit. It saves money but the company tax cuts that is moving sort of as a package actually if we [inaudible] all of them we are going to increase the deficit. So again, it is this wealth transfer where we are giving back to wealthy Americans and making cuts from lower-income people. It is full of non-solutions. We certainly have made lots of policy changes but it didn't resolve any of those fundamental health challenges that I described. It is an unnecessary harm and I say that because you know the Senate bill, even if they agreed, if Congress agreed they were going to save a certain amount of money in the budget process, the Senate bill passed a package that would have gotten the same level of savings but would have done it all without making any changes that would have hurt Medicaid beneficiaries. But at the end of the day, powerful interest won, so when they reduced the savings that they were going to get from drug companies and managed care companies, the money has to come from somewhere. So, who do they turn to? They turn to the [inaudible] from Medicare beneficiaries

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but I would have to say at the end of the day it could have been much worse. So the fact that, I'm sure many people in this room, in the HIV community and the broader community worked really hard, we really did a good job.

So what are some of these changes? I am going to very quickly just gloss over them but new rules that allow premiums to be charged for Medicaid beneficiaries, for people about 150-percent of poverty, new rules for cost sharing, so it says that we can charge people more cost sharing and for people above poverty, if they can't pay their cost sharing they can be denied services. So previously, before this law was enacted, they could charge up to \$3 dollars for an item or service. If you go to the doctor they could charge you \$3 dollars, up to \$3 dollars per prescription, but the rule has always been if you couldn't afford to pay it, you still got your drug, you still got your service.

Now, for people above poverty, they could say no, sorry, you can't pay, you don't get it. Flexible benefits, we hear about this so-called idea that again a private market is better so we are going to give people benchmark plans, we are going to give people Medicaid beneficiaries private health plans that look more like what state employees get, the only problem with this is Medicaid beneficiaries aren't like state employees. Many of them are already in Medicaid because they couldn't get the benefits they needed from

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private insurance. You know, it is just not an appropriate thing. I would say here that another challenge we have is that Congress tried to protect a lot of people, it tried to protect people with disabilities, dual eligibles, a lot of the groups where people with AIDS become eligible for Medicaid, about the way it is being implemented says that states can put everybody in as long as people have a right to jump out. But do people with AIDS know that they have a right to get out? No, so we need to watch this.

New documentation requirements, you know we are having an immigration debate and maybe a spillover of this is that Congress said we want to make sure nobody on Medicaid is a non-citizen. And what they did is they put in these new requirements to document this, but they may have been thinking about undocumented people that shouldn't be getting Medicaid. They didn't really focus on the fact that this is creating a huge burden for states and U.S. citizens that could lose their coverage just because they don't have all the stringent proof that they are now requiring. They also made lots of changes with long-term services, which I don't have two hours so I will skip over. [Laughter]

So, what are some of the key things in what we are seeing both in Medicaid and also say much of the supplies to some of the Medicare changes we have seen? Personal responsibility. There is this idea that if we give consumers

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choices that we are going to save money and so we are going to give them choices and plans, increase premiums and cost sharing, and behavior modifications through incentives. If you remember, Medicare Part D, initially when this was first being implemented, we wanted to make sure people had a choice of at least two plans, then we were faced with the nightmare of realizing many people had 35 to 40 plans, you know, is that choice really going to save us money or make the system work better? I think it is questionable.

Tailored benefits, it is one of these terms that just sounds so lovely. We don't want to hurt anybody. We just want to make sure we only give benefits to people that truly need them so we are going to say if you fall into one group, maybe you have mental retardation and you get this set of benefits. If you fall into this other group, if you are a poor child you get this set of benefits, you know. And what it really does is it takes winners and losers, it politicizes the process of determining who gets medical benefits, so really, this could come down to who has the best lobbyists. U.N. You know it's very troubling. Increased role of private marketplace, you know, increased control of the private for profit plans to determine benefits packages. We have seen this both in Medicare Part D and increasingly in Medicaid. It is very troubling. All the research evidence and it is extensive is that private coverage is more

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expensive and less efficient than public coverage so why are we shifting all our public health coverage to the private sector? Increasing spending predictability, states and the federal government are trying to say we don't want this open ended promise. We want to just know how much we are going to spend but that could just mean by giving states that certainty, people that need coverage could lose it.

And then, lastly, it is a real difficult environment both because there is confusion about what is going on, there is limited public information, and there is loss of really state legislators getting involved in a lot of these changes. Can I have the next slide?

So, what do we need? Two more slides, the first thing I think we need is we need a good defensive, and I think we have been doing a fairly good job, but I would say we can't just pick the federal level, we can't say oh, we are going to focus on D.C. or the state level, we really have got to do both. HIV community leadership is important but we can't win this alone. We really need to be actively engaged in broad-based coalition. We need to make the case that this new flexibility I just talked about doesn't solve any of the real problems. And I think many of you know this intuitively but you know, charging people more cost sharing or denying them services they need because they can't pay the cost sharing because we decided we are not going to cover that is

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not going to solve the fundamental problems of the health system. Hassling people so that if they can't prove they are citizens, if they don't get Medicaid, is not a solution. And I would say the good news about these changes that I just described is almost all of them except for the citizen documentation and one other I haven't discussed, they are all optional for states. The states don't have to do these bad things. States don't have to charge people more cost sharing. They don't have to move away from the traditional Medicaid benefit package to a private sector plan, so let's not let them.

So, we need to work really hard and as I said at the very beginning, most of these efforts haven't targeted HIV/AIDS, but they have major implications, so when we see people moving to say in a state where are going to expand coverage to people that haven't had it but we are only going to give them two drugs a month. We need to talk to policymakers and say, well, you know two drugs a month doesn't really work for people with HIV/AIDS. You know, or we are going to set a limit on how much money we are going to spend on you, talk to them about what that means, especially if we are setting these limits based on average costs, because often people with HIV are far above average.

Okay, here is my last slide. Things aren't going to be this bad forever. They are going to change and we have

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got to be ready when they do change to make our case for some of the good things we want to see. I want to echo what David said about some of the HIV-specific solutions but there are broader solutions I think we need to be a part of. We need to be really engaged in pushing for universal coverage, long-term care reforms, both because of the right things to do we need them as a nation but also if we are thinking about sustaining the Ryan White program, sustaining Medicaid for people with HIV/AIDS, if we do some of these things it will take some of the pressure off these programs and Medicare, you know, I could redesign the system. We are probably not going to do that, but even if we stick with this Part D [laughter] system we have, maybe one thing that a lot of people are taking about is we need a push for just a federal plan to get your drugs, so [inaudible] have to go out in the private marketplace. Let people do that if they want to, but maybe people should have a right to just get a federal benefit. Just like now in Medicare, people have a right to say oh, I am going to stay in traditional Medicare and just get my benefits through Medicare, or I could choose to get a Medicare advantage plan and I will go enroll in a private plan.

Maybe we need to just give people that option to have a federal benefit that is administered by the federal government and not a private plan that is trying to make a

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profit. In Medicaid, I think we need to do a number of things but, you know, one of the things I have come to the conclusion working both with HIV groups and disability groups is sometimes we spend five or 10 years getting Congress to do new things and give states new flexibility and say a new option to do this. And I am sick and tired of doing things so five states do great things when 45 don't. I think we need to raise the bar for everybody so I think we need to think about pushing for mandatory eligibility and there are different ways we could do this. All people below the poverty in this country, you know, let's just cover everybody, or if that is not feasible, let's cover all people with disabilities and longtime seniors up to the poverty level. How could you argue that someone who has met a strict standard for being severely disabled, they have an AIDS diagnosis, and yet they have \$700 in income a month as too rich to get any help? It doesn't make sense, so maybe we just need to require all the states to do this.

And the last piece of this is we have this concept of medically needy coverage, this is the idea that if you have too much income, if they take into account the fact that many people have high medical expenses they could spend down by subtracting what they spend, not all states do this. In some states, guaranteed coverage for Medicaid is for a person with disability, has income of \$605 a month, and if you had \$620

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you could be too rich and it doesn't matter if you had \$100,000 dollars of health costs a year, there is nothing you could do to get Medicaid. That is just not right. The other problem is about 37 states allow people to spend down, but in some cases they allow them to spend down so much, it is ridiculous. In Louisiana, you have to spend down so that you only have \$100 dollars left in which you buy all your food, you pay for your rent and housing. That is crazy, and is Medicaid, they are called medically needy programs or spend up programs, these were created when we were really trying to get people into nursing homes and in the nursing home where they pay for your rent, your food, and everything, that is a different thing than we are talking about now.

So we also need to create mandatory medically needy coverage but also have a reasonable level so people could, if we want them to live at their homes they could afford to pay rent, buy food, take care of their homes, and that kind of thing. So, I know I have said a lot but I will stop and thank you for inviting me.

[Applause]

**GENE COPELLO, PhD:** Thanks, Jeff. Our next speaker is Bryan Jackson, who is a volunteer with Title II Community National Organization and Brian is from Missouri, who is visiting us here in D.C. and as Bill said earlier, he is a

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person living with HIV and I heard him speak before and it is really an honor to have him back here in Washington. Bryan?

[Applause]

**BRYAN JACKSON:** Ladies and gentlemen, hi, ladies and gentlemen. I am Bryan Jackson. Those are two I's, I can see there are a lot of mistakes everywhere tonight. Anyway I am 15 years old and I was HIV-positive since I was 5. I am here due to complications of HIV. Because I didn't fit in the usual profile of these testings for HIV, I have been tested for a number of diseases, even ones that only are just in other countries before they realized I had HIV. America is number one. Can someone inform me what that means and who says it, allowing people to die, even though preventions are available to make a number one when it comes to moral, ethic or common sense. In 1996, I lay dying in a hospital bed. In a matter of two months, I go from being playful, happy, energetic to a bloated, [inaudible] vomiting [inaudible]. My mother struggled to carry me to numerous appointments, begging them and praying for doctors to find out the reason why I am on deathbed. But since I wasn't at risk for HIV, I wasn't tested for it, until May 24, months after I had become severely ill, that my mom and my doctor both asked for me to be tested for HIV. The results were devastating. I was diagnosed with full-blown AIDS with a number of other AIDS-related infections. My family was told that I was going to

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not live long. Doctors said six months at the most, and according to the medical journals then, people died within three months.

Yet by the grace of God and the power of prayer and medications, I stand before you today as a miracle, wanting to tell my story and bring hope to many and knowledge to all. My family and I feared for my life when I was diagnosed with full-blown AIDS. Now today, 10 years, that fear is reborn. Not because I have AIDS, but because some of our politicians' views of those with HIV and AIDS. According to the Ryan White CARE Act, when I become an adult male with HIV, my life, not to be worth as much as a child or a woman, and I am not worthy of being helped. I might lose my HIV health care, my life savings medication, or even my home. Understand today the Ryan White CARE Act can not cover all those infected now. HIV, both HIV and AIDS, yet that number keeps increasing every day and the government refuses to stop [inaudible] when it has the means.

So I ask, who is going to help me? In turning their backs, by not completely funding the necessary care of medication for those infected and affected by HIV, those are the leaders who are allowing people to suffer. Even when they support fully funding Ryan White, how to present the level, what it really means is we are choosing to harm millions of people with HIV and AIDS by not providing them

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all with care and medication through available, therefore they are choosing who lives and who dies. They are choosing genocide for some.

A question about those controlling funding for HIV and AIDS: Did you help me buy a ticket on the HIV plan to life or simply get the [inaudible] for entire fight, may day, may day, this is [inaudible], the fluid light is low, HIV-positive people are plunging near their deaths today. Yes, someone who has HIV is placed on his or her deathbed every day because the people voted into office are not seeing what is going on in reality. Does all of this mean that I may lose my meds? I actually prefer to stay alive. More than 215,000 people who are HIV-positive in America today, they know that they are HIV-positive and they are not on ARVs. I don't know if I want to join that group. South Carolina recently started ADAP waiting list. Do you think I want to join that list? Straight up. ADAP has at least 310 people on that waiting list in five states today. I don't really want to join that list. ADAP in five states are expected to cut back on drugs, the liability and other access in this coming year.

I worry about my state, which could be next, but the faith in God tells me to stay strong, pray, believe, be [inaudible] and my heart tells me to bring hope to the world. So I stand here today, I thank God for my life and pray high

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of hope in your hearts and a strong of wisdom and morality in the minds of those in government. As I say, HIV for me stands for "Hope is Vital" so I stand strong and pass it on. Thanks.

[Applause]

**GENE COPELLO, PhD:** Thank you, Bryan. Our final speaker tonight, before we go into questions and answers, is Jeanne White, who really doesn't need an introduction. I think we all know who Jeanne is and of course the mother of Ryan White, who the CARE Act is named after. We are blessed at the AIDS Institute in that Jeanne is one of our board members and she has brought her love and her joy and her hope to our institution as she has to so many others. So please join me in welcoming Jeanne White.

[Applause]

**JEANNE WHITE-GINDER:** Good evening. I am glad to see everybody here today. As a former member of the AIDS Institute, I am just happy to see everybody and am glad that you are here. I am also glad that most of you are attending the conference, which is 2,400 people. It is the largest Ryan White conference that's ever been, and I am just very excited to see so many faces.

You know, it is so important that people be able to access care. When Ryan was first diagnosed with AIDS in 1984, he was one of the first children and first hemophiliacs

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to come down with AIDS. They told me he would only probably live three to six months. He had a T-cell count of 25. There were no drugs, but believe me, we prayed with every drug that came on the news, we tried to dig into, so to speak, and try to learn everything we could about that drug and then there would be another drug and then there would be another drug. There was no drug for Ryan.

When he turned 16 years old, we were finally able to get him on AZT and that was very, very hard. Ryan was very underweight and there had been no trials on AZT for kids under 16 so it was very hard and yes, I saw a big improvement, just on the AZT, but I think finally the AZT ended up probably destroying his life because it affected his liver. But at the same time those drugs were so important when there was nothing.

There is no care, there are no services, there is nobody to talk to, and we had a few AIDS organizations that was our only hope and they were telling us what was working, what wasn't working, it was a community-based, by talking to each other on the telephone, doctors talking to other infectious disease doctors, but it was a hit-and-miss of whether you made it or not. Ryan was in the hospital two months one time and he coughed and vomited everything he ate. He had two diabetic seizures. He was blind twice. We thought he would never leave the hospital. He was down to 58

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pounds and they kept experimenting with drugs. They would give him five drugs, antibiotics, they would switch in five days and try to give him something else, and then they were just experimenting, just trying anything, anything at all that might work.

Finally, nobody knows why, but he stopped coughing and vomiting, he finally left the hospital. Later on, they found out he had a real rare form of whooping cough and somehow one of those drugs had just started to work.

I'll tell you, I know of the dreams that people have of licking this disease because I had them for my own son. You pray that somehow, some way, there is going to be something out there. We have that something out there now. We have the drugs and treatment for people. The sad thing is the service organizations, they need to be paid. I mean, you guys need to get paid, but we also need to be able to see that people get their meds and their drugs and have access to care and treatment. That is so very important that people are not left lingering, or not knowing what to do.

If we can focus on education and ensure people what there is to do and what there is for them, if they are diagnosed, maybe it won't be so hard for people to try to go and get tested. It's just so important that we get people in to get tested but yes, it is so important that we be able to treat them at the same time.

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I remember in 1990 when we first started the CARE Act, it was hard. It was me, the gay community, and Leslie [Inaudible]. David Miller here, we had a conversation earlier, and I had the privilege of meeting a guy in a restaurant just a couple of nights ago. He came up to me and he said, you know what? I was with you in 1990 in front of the White House when we did the White House march on Washington and I just couldn't believe that. I thought oh, here is another one that is still alive, because so many of our friends are not alive, so many people that worked so hard on this AIDS epidemic, they are no longer here, but I have had the privilege of meeting a few of them that are still.

I don't know what it is going to take for all of us to raise our voices again to get more money, we have to have more money, we have to be able to treat the patients that you have, we have to ensure people have quality lives, it is just, we have to do it. If we have to form another act, if we have to shout and we have to visit our congressmen, we have to do it. Somehow I think, maybe you weren't in that first fight when you are fighting for your lives, the fight for the patients lives and fight for your own security in your own jobs, fight by getting out and speaking and seeing how important it is that we not give up on this fight, that we continue to try to get more money because it is the lives of our people. Thank you.

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[Applause]

**GENE COPELLO, PhD:** Thank you, Jeanne. We are going to open up to discussion now, but before I do that, I did want to acknowledge TIVATECH for helping to provide tonight's program.

[Applause]

So I guess maybe what we will do is start with the panel, see if there are any particular comments you wanted to make after listening to each other and then we can move on to the audience. Any comments? Frank?

**FRANK OLDHAM:** I think that, you know, we have heard a lot about the history, we have heard about where we are right now, and we have also heard about what has to be done nationally and partnership, and I think the partnership is with partners in government as well as the pharmaceutical industry, the medicine, and people living with HIV and AIDS, and advocacy. We need a reverse of advocacy, but with all of us as partners, because of the way the epidemic has changed. No longer as people dying as we said in hospices but to access care, if they don't access care, we will still have a repeat symbolically of Hurricane Katrina.

**GENE COPELLO, PhD:** Michael?

**MICHAEL SAAG, MD:** Last night, we had a similar meeting among some Ryan White care providers. My conclusion at the end of that, there were two options. One option is

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that funding stays flat for all AIDS, kind of like it has been for the last, most of the last several years, in which case we are forced to negotiate among ourselves for how the pie is sliced. And a quick sidebar comment to that and the reason why I made the last line I did about waiting lists versus waiting lines is that Alabama, for example, has had waiting lists for the ADAP program since its inception, yet at our clinic and in almost every clinic that I know of in the state of Alabama and not a single patient has gone without medications. And that is on the back of pharmaceutical industry providing compassionate used drug and social workers filling out countless applications and advocating for the patients to make sure they got their medicines. So waiting lists do not equal lack of access, it is just a different kind of access. It's a more painful kind of access but it is not lack of access, at least in the reality that we have seen so far.

The second possibility is that we increase funding on the national level and that way, in this partnership, we can find ways to find a happy medium between care delivery and provision of drugs. But I have to say that I have to add a third choice to this right now, and that is perhaps a new model of care that perhaps is an entitlement approach. I mean, I loved the IOM report when I first, I was actually one of the reviewers for it, and I thought wow, this is really

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innovative and cool. And the next thought was it has no chance because the political will just wasn't there and not at least in the Congress that I saw at that time was there any, could we ever get discussion, but maybe it is time to do that.

I am going to finish with just one kind of tribute statement that I think is totally not only underappreciated but just unknown to most people, even involved in health care, and as we talk about the safety net, what is the safety net in this country? I will tell you what it is. The safety net is made up of the fabric of health care providers who give a damn, and that is the bottom line. When people come to my clinic and they can't get medicines, social workers, nurses sit on the phone for Medicare Part D prior authorization into hours, into the wee hours of the night, sometimes every night, because they give a damn. There is nothing in their contract that says you have to stay here and do this, and, in fact, if they were simply working from a business model, they would say, our doors close at five, I'm sorry you don't have your medicines, find a way to get them. That would be a response, but that is not the response, at least at any AIDS clinic I have ever seen, as adopted.

And frankly, I think there is abuse of health care providers of that safety net. I think we are abused out of ignorance, we are abused, we are taken advantage of by a

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system that doesn't recognize what is holding this country's health care delivery together and it is simply health care providers who give a damn and God help us when those folks burn out and leave. I don't know what is going to happen.

**GENE COPPELLO, PhD:** Comments, question, yes Greta?

[Inaudible]

**MICHAEL SAAG, MD:** So the question is, what are the data that support the notion that somebody knowing they are HIV-infected gets into care? I would say that it is a spectrum, for one thing I can tell you someone who doesn't know their status isn't in care. I can guarantee you that. That is 100-percent. At our clinic, among the new referrals which is the best data I have, about two-thirds show up for their first appointment so they are in care. So my answer is about one-third of the patients newly diagnosed don't show up and there are movements at our clinic and other places that are doing a lot of aggressive thinking about how to get that patient in the building and admittedly this is a patchwork. Not every geographic region is the same, but I think as I said earlier, opt-out testing is not a policy that stands alone. It is a policy that is mandated to be associated with counseling and access to care.

And the problem is that, frankly, the people who don't show up have many other problems in almost every sense. And if I had to summarize it in two words, it is substance

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use and mental illness. Those are the two patients, as a rule, who are not showing up for their first appointment. That doesn't mean we should ignore them or give up on them. It means we have to think creatively about how to create techniques and approaches that get them into care.

**GENE COPELLO, PhD:** Did you have a second question?

**MALE SPEAKER:** Well, I think that, as you've heard from Dr. Holtgrave and people up here, we do need a new model in terms of what to do about the people living with HIV and AIDS to have better care. I do think that the thing we have to be careful of - I really consider the AIDS movement to be kind of a vanguard for universal health care because they have raised the bar as far as the quality of care that all people should have in terms of care, housing and supportive services, and it does confront the issue of poverty and a lack of access. So I think that the new model, the concept of an entitlement program that would have quality care for people living with HIV and AIDS is something that must be looked at, it must come about.

**GENE COPELLO, PhD:** Okay, sir? [Inaudible]

**MICHAEL SAAG, MD:** The most important thing he said is he agrees with me 100-percent. [Laughter] The second thing he said was that his social workers and case managers are there with him and his point was that those individuals are part of primary care provision. I couldn't agree with

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you more. I mean, absolutely, and I think most of the definitions of the 75-percent in the current proposed legislation of core medical services includes social workers and other health care professionals who help us do what we do every day. [Inaudible] Ah, yeah, so the point is medical case management maybe needs to be better to find to include what we really mean, which is social workers and folks who are rolling up their sleeves every day and doing all the grunt work to make sure people get their medicines and get their care, absolutely.

**GENE COPELLO, PhD:** That is an excellent point and there are several national organizations that have been trying to really clarify and push that issue with Congress. Hopefully, the final bill will have that clarified. David?

**MALE SPEAKER (DAVID):** [Inaudible] so why don't we do this right now? Next Saturday outside the White House, you, me, and anybody else who wants to come. [Inaudible - laughter] Let's do it right now!

[Applause]

**MALE SPEAKER:** So, you are absolutely right.

**MALE SPEAKER (DAVID):** Can you make it Saturday?

**MALE SPEAKER:** I don't know. I can't make it Saturday but I will do it. But I will tell you that the spirit of last night's meeting for the Title III group reminded me a lot of the early ACT UP day except the

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difference was this time it wasn't the patients who are acting up, it was the providers, and you are going to see that happening.

**MALE SPEAKER (DAVID):** Well, when they made [inaudible] they know they are going to get sued so in reality we could do this again.

**MALE SPEAKER:** We should do it again.

**MALE SPEAKER (DAVID):** [Inaudible] you or Gene or Frank or Gene or the kid there. [Laughter]

**BRYAN JACKSON:** I have to be the kid now?

**MALE SPEAKER (DAVID):** So, let's set the date.

**MALE SPEAKER:** All right.

**GENE COPELLO, PhD:** Other comments, yes, back here, ma'am?

**FEMALE SPEAKER:** [Inaudible]

**GENE COPELLO, PhD:** Is it possible to get copies of your slides?

**MALE SPEAKER:** Sure, I can provide it through the organizations. I will get it to Bill. It is published. This event is being webcast. It will be available and the slides will be available on the Kaiser Family Foundation website shortly and this is a published paper from the April Clinical Infectious Disease, 2006. The full story is there. [Inaudible]

**GENE COPELLO, PhD:** Okay, yes?

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[Inaudible]

**MICHAEL SAAG, MD:** So the question relates to clinical trials and gets back to I think David's point about where is the funding for that and is that a threat to access to care? While anybody who works in human subjects' protection would tell you that you don't want to coerce people into clinical trials by having that be their access to care, whether we want to admit it or not for a lot of patients that is the case. And we protect ourselves all the time against going there, but the fact is that a lot of patients gain access to medication and other services through that route.

Generally speaking, the CARE dollars - not the CARE dollars, sorry, the research dollars for clinical trials has pretty much remained flat funded as well. I think we are all, there is a brilliant slide. It's kind of sobering to see the tax cut slide but the fact is because there is a burgeoning deficit, there are very few programs at the federal level besides defense and homeland security to my knowledge that is being increased in a substantial amount and so therefore all of research. And I will tell you it is more than just clinical trials. That is going to stay flat and that is going to be an issue, but let me tell you something that is underappreciated and that is that the total research infrastructure in this country is in great jeopardy right

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now. What do I mean by that? Investigators who we coddled and nurtured as young investigators to get them into science now can't get funded. They can't get funded. They don't have a job and remember that it is not just science that is being moved forward with these research dollars. Every one of our major university institutions, the engine that drives it is research and with the threat right now that exists to that federal funding is a threat not just to science and to researchers and to indirectly patient care, it is a threat to our major academic institutions.

The quote I like to say is academic institutions are like tropical rainforests. They take decades to develop and weeks to destroy and we are all in jeopardy right now. So there is a lot more at stake here than simply access to care or access to research. On an AIDS-specific level, it is an entire larger picture that is quite sobering to look at right now.

**MALE SPEAKER:** [Inaudible]

**MICHAEL SAAG, MD:** Yeah, so the question is, what about the redistribution of the dollars that exist overseas and the other issues? I don't, I think there is justification on a number of levels to study issues overseas because the magnitude of the problem in most countries besides the United States is so overwhelming and doing this right is essential and I think, what unfortunately is happening not just at this

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meeting but in your question and for all of us is when things get tight, we start being pitted against one another. And I try to avoid as best I can saying that this particular scientific project is more worthy than that because in this case domestic and international research is important and I think actually with the reorganization of the clinical trials units, there will be some efficiencies and that is good news. But what we really need is more funding overall. I would hate to see us have to get to that awful choice of what is better science because to me, what I see going on right now is pretty darn good. Carl?

**MALE SPEAKER (CARL):** [Inaudible]

**GENE COPELLO, PhD:** Yeah, I think just to repeat the question to the issue is around the marketing of these kinds of programs and how do we make sure that there is interest in these programs? And also, how does this compare to other disease areas?

One of the things that we did in the IOM report was look at just the cost per year of lives saved for a number of different disease areas and included one table and even if you completely forgot about any issue of AIDS exceptionalism or anything else and just looked at return on public health investment, the kinds of programs that we are talking about in the IOM report are the kinds of things that have been discussed here tonight compare very well and are a great

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investment of public resources and I think that is one way to do it. I think the other thing important, too, is to make sure that people understand how timely still these issues are and when I used to work at CDC, they didn't like if I took epidemiological statistics and expressed them as an occurrence per minute. If there are 40,000 new infections a year, that means on average about one infection every 13 minutes in the U.S. and that was sort of frowned upon but I think people are smart enough to realize - I don't mean exactly one infection every 13 minutes, we are just showing how urgent the epidemic still is in the United States.

And I think when we think about AIDS-related deaths, we have went from about one AIDS funeral every 15 minutes in the U.S. some years ago to still about one every 33 minutes in the U.S. So since we started tonight, we have buried about four people with HIV in the U.S. And I think that is a statistic that we need to really use as part of continuing to get people to pay attention to this incredible epidemic.

Sir?

**MALE SPEAKER:** [Inaudible]

**MICHAEL SAAG, MD:** Let me ask you, so the question was about the new model Title IV and family-centered care. When you mean family centered care, do you mean where everyone in the family is HIV-infected or one person in the family and the other family members are not HIV-infected?

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**MALE SPEAKER:** [Inaudible]

**MICHAEL SAAG, MD:** Okay, so the question is about delivery of other, I'll call them ancillary services, especially to women for child care that are often provided through Title IV. Again, it depends on if we are to assume a model where we are stuck with flat funding and we have to make really difficult choices and in my triage the number one rule is treat the patient. That means get them the comprehensive care they need as an individual, get them access to drugs, get them access to all the services, be it substance abuse counseling, be it psychological counseling, et cetera. And that is part of in our clinic a Title III model, if you will.

We don't get any Title IV funds but yet we provide a very high level of care without them. And I know all about the Title IV and it is a great system for women and children but the women who are getting infected, newly diagnosed in Alabama today, are coming to see us. They get their pregnancy care, when they become pregnant, with us, and that is the model, at least that we have.

And my point is that a single point of care is more important than a fragmented approach to care so wherever the dollars are, they need to number one focus on care and then if we have dollars left over, then I think we start talking about child care. I would triage transportation above child

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care, frankly, because if a patient can't get to the clinic, we can't provide care and so we are forced unfortunately in the current assumptions that we don't get increased dollars, we are forced to make some really nasty choices. But the bottom line is, for me, keeping that patient not just alive but healthy and productive. And for 54-percent of our patients in our clinic that have less than 50 copies of HIV RNA, I don't talk to them about HIV on their visits. I talk about how their kids are doing. I talk about how their work is going. I talk about not smoking. I talk about normal things, if you will, that any internist would talk to their patients. And those patients are a joy because I know they are not going to die of HIV with any reasonable likelihood compared to the risk of other things and that is the model I am shooting for to start with and then the other things would follow.

**MALE SPEAKER:** [Inaudible]

**MALE SPEAKER:** I think it is really important to be able to talk in great detail in discuss [inaudible] about what the patterns of investment have been. A lot of my work also is in prevention and we have a paper coming out very soon that will talk about the patterns of investment and prevention over the last few years. And when you adjust for inflation, actually, as more and more money has been spent internationally, it is great that the money is spent globally

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but you can actually watch prevention in the U.S., the investment going down over time. And I think that is something that people don't realize and I think in one part it is the sense that well, we have got this epidemic cured or it is not an issue anymore but there is not widespread knowledge about the fact that actually the investment in prevention is going down both in real terms and when we adjust for inflation. And I think we need to get that message out.

In some ways, it goes back for me to the point that Carl made earlier, as we continue to market, if you will, just basic facts about where we are at in the U.S. and one other thing that kind of ties for me to your point and to Carl's point earlier - The Kaiser Family Foundation did a poll not long ago and about 43-percent of people in the U.S., Clinton answered all of the basic questions about how HIV is transmitted and I think we make the assumptions that everyone in the U.S. now knows basic facts about HIV, really understands how it is transmitted and can be prevented, and whether or not there is a cure and if treatments are available.

But actually, the knowledge base is going down in the U.S. and it is actually getting worse, and I think we have to address some of those very fundamental issues about investment, about knowledge, and about attitudes and stigma

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and it must be done and the media has to play a role in that as well, too.

**GENE COPELLO, PhD:** A question over here, yes?

**MALE SPEAKER:** [Inaudible - laughter] what are we laughing about? I agree, next Saturday [inaudible].

**GENE COPELLO, PhD:** Other questions, comments? Yes ma'am?

**FEMALE SPEAKER:** [Inaudible - applause]

**GENE COPELLO, PhD:** Thank you. Other comments, yes ma'am?

**FEMALE SPEAKER:** [Inaudible]

**MALE SPEAKER:** [Laughs] that's true. I think that sounds like a great project right, Bill? I think we could do that.

**WILLIAM ARNOLD:** One of the things we want to do at Staying Alive - Access Matters this year is to come out with platform recommendations as to what needs to happen going forward. You know, we have heard about Act Up. I am a longtime survivor as well. I remember those days. I remember the deaths but what do we do now as the young lady said here, what do we do now going forward? And I think we have to do that with a new partnership and that is why I keep repeating the efficacy organizations, the AIDS service organizations, our partners in the federal government and our

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partners in the pharmaceutical and medical industry, we all need to come together to make this happen so I think –

**FEMALE SPEAKER:** [Inaudible]

**WILLIAM ARNOLD:** And that is how we come out with a unified platform, obviously we need it, there are too many people still dying of AIDS in the United States.

**MALE SPEAKER:** Can I make one comment on that, too, Gene? I think besides the fact sheets too, one of the other kinds of forms that might help is, I'm involved with the Baltimore City AIDS Commission. One of the things we did over the last week was have a candidates forum where everyone who is going to be on the ballot in Baltimore, whether it is for the U.S. Congress or if it is state legislature, were invited to come and answer questions publicly about HIV and where they stood. And we put about seven questions together that people were asked and then the audience could ask questions as well, and there were probably about, I guess, maybe two-thirds or so turnout of all the candidates, about 12 or so came. And they not only then had to answer the questions but do it in a public forum, and I thought it was actually a really useful form of democracy and also a way to get the commitment around HIV issues.

**MALE SPEAKER:** It can also be useful and instructive to visit [www.aidsvote.org](http://www.aidsvote.org) in case you want to know what certain very dissatisfied parts of the HIV/AIDS community

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have in mind with regard to elections, both current and coming. Bob?

**MALE SPEAKER (BOB):** [Inaudible]

**MALE SPEAKER:** I will speak to that. [Laughs] In election year, especially, it needs to get in the evening news. It is as simple as that. Reaction amongst political leadership has to do with what is the media attention that I am going to get asked about and I have to respond to. And there are, you know, there is the ACT UP history of how to get on the evening news, and then there are probably some new ACT UP or ACT UP [Inaudible] or maybe we will have to create even something that we haven't thought of yet. But the end results of the whole thing does have to be unique to be in the evening news, unique to be in the media, it needs to be a public conversation.

[Applause]

Interestingly enough, the congressional black caucus is debating internally right now whether or not they should all publically take an HIV test at their conference I think in September 8<sup>th</sup>, 9<sup>th</sup>, and 10<sup>th</sup>. It would not surprise me at all if the entire congressional black caucus decided to do it. That sort of thing puts you in the evening news and as some of you probably know, Senator [Inaudible] recently was publicly tested for HIV along with his wife on a trip to Africa and it got, I looked through all the press clippings,

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it was in hundreds, not dozens, but hundreds of foreign papers.

**GENE COPELLO, PhD:** Jackie?

**FEMALE SPEAKER (JACKIE):** [Inaudible]

**GENE COPELLO, PhD:** It's a good point. David?

**MALE SPEAKER (DAVID):** [Inaudible] AIDS research center doesn't get the level of funding necessary. At University of Alabama, [inaudible] there are HIV sites that are being closed. There is no national effort to [inaudible]. I've got maybe five years left on these drugs [inaudible] my liver or my kidneys. Look, I've been on them for 10 years. That is too long to be on these drugs. People can't live on these drugs too long. [Inaudible] chronic care model like insulin for diabetes [inaudible]. We have an agenda that [inaudible] if we are not on the evening news [inaudible] some new methodology [inaudible] new methodology is getting national attention. This has to end now and not just in Africa but right here in the United People's Republic of the Bronx. If we don't do that, [inaudible] so we've got to make a decision [inaudible] good old days. [Inaudible] at NYPD. You go out in the street and you demonstrate because it is that or die and I think one of the problems is we don't have enough [inaudible] positive leaders whose lives are on the line. We can't get a proven [inaudible] program through Congress that they [inaudible] because you can't get

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something through [inaudible] of an appropriation. You can't get our providers any. Who are we fooling? [Inaudible] every few months we get together [inaudible]. Who else is going to fight? [Inaudible]

**GENE COPELLO, PhD:** We've got only a couple of minutes left, so [laughter] we are almost to the end here. Are there any other, anyone who hasn't had an opportunity, excuse me, to speak or ask questions or comment they would like to? Yes, ma'am?

**FEMALE SPEAKER:** [Inaudible - applause]

**GENE COPELLO, PhD:** Before we close, just a reminder that the materials will be on the Kaiser Family Foundation website in the next few days probably, right, Bill?

**WILLIAM ARNOLD:** Yes.

**GENE COPELLO, PhD:** Yep, in the next few days and copies of the slides, et cetera, should all be on there, but for some reason you can't access them, just call one of our organizations and we will get you a hard copy of them. Let's give the panel a round of applause. [Applause] And thank -

[END RECORDING]

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