

**Committed to Action:
15 Years of the Ryan White CARE Act - -
9th Annual Clinical Update –
Opening Plenary
Ryan White CARE Act Grantee Meeting
August 28, 2006**

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[START RECORDING]

STEVEN YOUNG, MSPH: Good morning and welcome to Washington, D.C., and the Ryan White CARE Act Technical Assistance Meeting: Committed to Action. This is a notable occasion; we are completing our 15th year. Now I know it's been longer for some of you who have worked on community-based and state efforts to cobble together a caring response long before the federal government got involved.

It's sobering when we consider an epidemic and its history. Do we celebrate this type of anniversary? I honestly don't know but it's fully appropriate and right to acknowledge our collective in fighting that epidemic and learn from each other and that what this meeting is all about.

The photos we just saw capture in some small way the triumphs of our efforts and the difficulty of our mission. I don't know about you but it makes me extremely proud and honored to be part of this program and this remarkable collection of people. I know that Drs. Duke and Parham will be providing some important comments shortly regarding those on the front lines.

Hopefully, you have had a chance to look in your package that you got when you registered. On The Front Lines is the name and title of our new Ryan White CARE Act progress report. If ever someone asks you why we do what we do, look at

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the back, look at the report and I suggest you start with the back cover. Over 2400 of you angels worthy of celebration are here today, so I say let's start this meeting off right and whether you have been in this for one year, 15 years, or longer please give yourself a big round of applause.

[Applause]

Everyone is awake now, right. Even our West Coast colleagues, you with me?

Well, over 15 years ago the idea for this program emerged from someone's living room. It grew from a buddy program. An AIDS service organization being overwhelmed from witnessing people dying alone and doing something about it. And for 15 years, we have quietly and sometimes not so silently done our work and a few of our more voracious grantees came to mind here, you know who you are. Your work has been done in many settings: a doctor's office, a clinic, a case manager's car ride to help a client in need, a storefront drop-in center, in the street, in your office, and in the Park Lawn Building in Rockville, Maryland where we work at IRESSA. But as we convene and reflect this morning, it is also right that we remember those that have gone before us. I would like to ask now that we start this conference with a moment of silence and reflection in remembrance of those that we have lost.

[Silence]

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Thank you.

Moving on I would like to give you some highlights of the coming three and a half days as we meet to learn and share and renew and move forward in meeting the challenges ahead. We have 198 workshops and 14 institutes, which are a series of three workshops scheduled on a whole range of topics like Hepatitis C, using and managing data, a variety of special populations and grantee issues. We have one special one Voices From The Storm and many of you in the room no doubt remember exactly where you were one year ago tomorrow with Hurricane Katrina. I have always been impressed with the running of the trains in Europe but let me tell you our planning group has got this down. This meeting is about to take off and run. To start cloning, divide and conquer, choose your priorities from about 21 concurrent workshops that are going to be on at the same time. We also have a 132 posters and I encourage you to visit the poster session and meet with the authors. We have 47 exhibitors and we are thrilled to see that so many recognize the work that you all do. We have a very special team, an in house team of roving staff reporters who will capture many of the ideas being shared during the workshops, so you don't have to be everywhere. Look for the daily conference newsletter every morning and watch what you say lest you find yourself quoted the next morning.

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I would also as we are getting started like to acknowledge the Kaiser Family Foundation for webcasting this session this morning. They do some great work. And of course you all have a CD that you got in your bag with all the meeting presentations. These will also be posted on the HAB website and as I was going through my bag, I didn't realize all the goodies and resources that we had in there, too numerous to mention but all sort of references on data and state profiles and spins projects, quality, our new target center, and too numerous to mention all of them but dig through your bag, there's lots of goodies in there.

We are going to have four plenary sessions at this meeting, three in addition to this morning. I'd like to highlight the other three. This afternoon's clinical plenary is actually part of the 9th Annual Ryan White Clinical Conference Update. And Dr. Laura Cheever, our deputy associate administrator for the Bureau has been leading that effort from our end along with Dr. Michael Sadd [misspelled?] of the University of Alabama at Birmingham and Dr. Donna Swede of the University of Kansas, School of Medicine, as well as the International AIDS Society USA. So we see it as sort of a meeting within a meeting. And everyone is encouraged to attend that session so please join us this afternoon at 2:30 when we talk about rapid testing and prevention in the care setting.

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Tomorrow a very special plenary where we recognize our heroes in the traditional midday awards ceremony. And Thursday we are going to close by talking about health disparities something we work on a daily basis. And we will hear from Assistant Secretary of Health, Dr. Admiral John Agwunobi. Finally, the planning committee has taken great pains to make sure you stay refreshed during that arguous schedule with breaks and informal networking time. We have a vespid room available to those living with AIDS who might need it and also if you need assistance, go to our Help Desk, outside the ballroom if you need assistance. And please look at your agendas, there is a lot going on. We have exhibitor time today that ends at 2 and that will give you time to get back here for the clinical plenary. I especially encourage everyone to come to tonight's evening networking forum. We hope to see everyone there.

The evaluators in the room will be glad to know we haven't forgotten about one last thing. So it is last and that's evaluation. Two years ago, you let us know what you thought of our 2004 meeting and we heard you in planning this year's meeting. And you will notice some changes, a streamline continuing education process and more workshops, specifically on topics you suggested. We need that feedback again so if you could please take a few minutes later in the week, fill out the

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evaluation form. I need to let you know that we will be holding all future notice of grant awards until we receive your evaluation form. We cleared that through grants management. Just kidding but we do have something for you as an incentive, we have a little gift to give you, but you only get this if you fill out an evaluation form. So please do so towards the end of the week.

With those highlights for the meeting and its schedule, let's get started. I would like to introduce our first speaker, Dr. Betty Duke who has been leading HRSA since 2001. She brings significant expertise and experience to HRSA having served as a career senior executive under five HHS secretaries. And that is pretty remarkable when you consider how things change decade to decade and from one administration to the next. Dr. Duke has worked within HRSA on some important initiatives to help make our agency more efficient, things internal that you may not be aware of. This has included an improved grant making and grantee assessment process, which is now handled under a central office as well as coordinated internal communications, legislative, and procurement budget function.

Dr. Duke also created the HRSA Scholars Program, I know we have a few scholars in the room, started in 2001 to attract talented new employees to HRSA after viewing forecasts and many experienced employees would soon be eligible for retirement.

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Now Dr. Duke I want to let you know that there are some of us who have a few years left. But it is encouraging to know that early this year we counted up a 168 scholars who have completed rotations through the agency and has assumed full time positions. And over time will aspire to higher levels. in addition to the Bureau and the CARE Act, a big program effort of Dr. Duke's at HRSA has been the President's Health Center Initiative to expand the number and funding for the nation's safety net system of health centers, roughly 900 new or expanded sites in 2001. Bioterrorism, hospital preparedness, and health information technology are other efforts that she is leading. Also an acclaimed professor as well as an experienced administrator, ladies and gentlemen, please welcome this morning Dr. Betty Duke.

[Applause]

ELIZABETH DUKE PH.D.: Good morning. I am so happy to see all of you today or at least try to see you. I know you're out there. It's a wonderful morning when we can all get up, see that sun shining, recognizing that we have good work to do. a good life is one with good work in my definition. And so, we know we have a good life because we have a lot of good work to do here.

It's been a real pleasure to see some many friends that I've over these years and I welcome all of you as well as new

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friends that we will get to know during this session. The work you do is really extraordinary. The commitment and energy you bring to your work is - I'm a dwarf. Thank you very much. Steve is a lot bigger than I am. Thank you. - What you do is really important work. Our world is a better world because you choose to get up every morning, put on your shoes, and go to work to make life better for your fellow human beings. I feel very lucky to be part of this community and I thank you so very much for allowing me to be part of it and for being part of it yourselves.

We have 15 years and I thought, I thought that Steve hit the right note. It's hard to know whether you celebrate such an occasion and I think we do. I think we celebrate everything good in life. And this is a good thing we are doing. So let's celebrate it. Let's celebrate the fact that together we make a difference. And there is a definition of the good life that says you get up, you put on your shoes, and you go to work and make a difference and that's what you do. So, I thank you for that. I thank you for that personally and I thank you from a grateful nation.

We drift together in these events because we have an opportunity to learn from each other, to share, to set goals, and then to work hard to achieve them. We also get together to rededicate ourselves for the vital work we do together. And we

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also gather to remind ourselves in the midst of the suffering that we struggle to ease that good works are still present in this very challenging world we're part of. Good works are found every day in the communities you're part of because of the programs you run.

I know several of you saw on ABC's news special last week on AIDS in Black America. And I think sometimes in that program, they skipped over some of the good works that are actually happening and maybe they don't know about the good works, but my communications staff and I are going to make sure they learn. We know that you serve over a half million people with HIV/AIDS every year. And we know that more than half of those people, 52-percent of them are African American. And we know that another 25-percent of them are Hispanic. And we know that a third of them are women. We know that you go where the disease is. You follow that disease, you make a difference. We are making a difference and I thank you from the bottom of my heart. And we will try to make sure that America knows that we're there, that you're there and that we are making a difference.

Today as the film clip showed you at the beginning, we all remember an Indiana teenager who really still inspires us today. I know it caught me off guard. My gosh, I was a lot younger and to see him on that screen really touched my heart

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and I know it did yours. He set us an example. He set us an example of tolerance and determination and he tried to bring out the best in his fellow man. And I'm going to say man because he may have been a young man but he was quite a strong man. Of course, he helped to lay the foundation for the program that we work on together today.

We are very, very proud to have Ryan's mother Jeanne White-Ginder here with us today. Jeanne is right here at the first table [Applause]. I would you to recognize her. She is in with us for every meeting. [Applause] Thank you Jeanne. [Applause] It's such a pleasure to be able to share the event with Jeanne and to have her recognized through all of you that Ryan's legacy lives on.

I want to take another moment of your time just to recognize some very special people that I have the pleasure of working with every day. That's our HIV/AIDS Bureau at HRSA lead by associate administrator Deborah Parham and the deputy associate administrator Laura Cheever. I am very proud of our HAB staff and I would like you to help me recognize all of them here this morning. Please stand and let us recognize you. Please. [Applause] All of you. [Applause] Thank you all so very much.

You know it's hard in a big, big building like the Park Lawn Building to literally get around and say thank you personally

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to everybody every day but it is my pleasure to work with you and I take encouragement and inspiration of each and every one of you.

Deborah will be talking after I finish this morning. She is going to talk very specifically about the many successes under the CARE act and I'm going to talk today about some other topics of some themes that we're using in HRSA to try to make life better including NRH HIV/AIDS program. So, I'm going to talk about the vital role of health information technology in improving the delivery of healthcare. I'll talk about some of the Spins grantees who have really made some significant advances in those programs. I'm also going to talk about the best way for health professionals to volunteer for emergency services. I'll talk about the gains we've made in improving HIV/AIDS care along the US/Mexico border. I'll talk about our commitment to oral health and also about our budget request, also about reauthorization.

Starting with health information technology, I was specifically reminded of it because in the green room this morning I was checking my e-mail - you know, we're all addicted to those stupid little blackberry things and you go anywhere and your doggone beeper, you know getting vibrated or you're getting beeped or driven nuts by them. But also you are so addicted you can't leave the stupid things behind - so here I

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am in the green room and I'm checking my blackberry. And my blackberry is telling of the progress of Ernesto. That's our next hurricane and so far he seems be moderating a bit. But of course it brought back some pretty bad memories because it was just as you remember, just a year ago tomorrow that Hurricane Katrina hit the Gulf Coast and her buddy, Rita, came along just a few days later. And in that, we really saw some of the best of America as well as some of the worse of America.

Some of the best of America was actually right here in our HIV/AIDS program when 15 states and the District of Columbia really rose to the occasion and served over 1500 evacuees from the Gulf Coast. People running those state's Adapt programs did whatever they had to do to serve those evacuees. They made emergency enrollments, they wrote prescriptions, they honored prescriptions written elsewhere, they worked with pharmaceutical companies to get, obtain donated medications. The assistance was absolutely critical because we would not allow those patients to have a gap in drug treatment which could possibly spiral a downward spiral in their well being. Ultimately we had a job to do and we did it.

I want you to recognize that was really extraordinary. Because you know everyone says you know bureaucracy set in and we can't do anything extraordinary. We can't be flexible. Well, we were flexible. We were flexible in the face of some very

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tough realities. Those realities were that that our evacuees came to us with absolutely nothing. They came with no medical papers, no prescriptions, no evidence of their current treatment, no way to verify their treatment except by going through initial screenings under the most chaotic of circumstances. And yet, our grantees rose to the occasion. They conveyed the kind of commitment and the kind of service that all of us can take faith that there is goodness in humanity and that life can be better because of what we do.

But it also taught us something. It taught us that the development of health information strategies was absolutely essential for our safety net providers. This is an absolute commitment of mine. We have been working on developing a strategy for HIT across HRSA because we realize that the need for electronic medical records is something that if we can achieve that we will never find ourselves in that situation again where evacuees are literally at the mercy of faith. And we will make a difference with our HIT commitment.

The HIT commitment is also a commitment of Secretary Levitt's. His view is that the value of information and technology can not only improve the quality of healthcare in the management of disease but it can lead to better informed health decisions by individual, it can prevent errors, and it can reduce costs and improve quality at the same time.

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Secretary Levitt is in charge of the Office of the National Coordinator, which is commitment to producing an electronic medical record within ten years across the entire economy.

We followed suit this year and in HRSA, we created our first Office of Health Information Technology this year, headed by Cheryl Casnoff [misspelled?]. She is making a difference for us by leading us and giving information through us to our grantees about ways to proceed so that we don't all reinvent the wheel and spend money and time in a useless fashion. We believe that working together we can make that dream come true. And part of it, you all are already ahead on because in 2002, we launched six Spins grants. You know special projects of national and regional significant. These projects addressed the use of HIT in our program here but we believe that they can make a difference across the entire HRSA program and really through the medical economy at large.

I'll illustrate with just a few of those. We have two projects at Cornell and at Johns Hopkins that measures the effectiveness of audio computer assisted self-interviews. These are designed to improve the communication between providers and patients. The goal is that medication adherence will be increased and the quality of life improved. That's a really worthwhile goal and one where the commitment of relatively

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little resource produces outcomes well beyond what we could hope for really.

The other four projects involve the use of decision support systems. Those included the electronic medical records I talked about a moment ago and interactive Internet database development. One of those four projects is at Louisiana State University. That's implementing electronic tracking and reporting system for outpatient clinics that aid of the public hospitals. And here physicians and nurses and other providers use the system to access laboratory and diagnostic and medication data. This system was instrumental in managing and retrieving patient records after Katrina. So there is a real immediate payoff on that investment.

Dr. Michael Kaiser of LSU's project director is with us today. he played a pivotal role in coordinating the care for the patients in the wake of Katrina and Rita. He continues to coordinate that recovery effort in the public hospitals and that system is the fourth largest public hospital system in the country. We are very proud of him. Take a little pride of maturity or maternity, I'm not sure which because he is one of us. Michael headed our CARE Act Title 4 program before he went to Louisiana. He is one of the, along with six others, outstanding HIV/AIDS providers who will be honored at our award

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ceremony tomorrow so I hope you will recognize him and give him a round of special applause at that time.

Another thing I would like to tell you about is a program that has the worse acronym in government. You know in the government any program gets a name, then it gets the name shortened to some kind of an abbreviation, that acronym then becomes a noun and the worse part of federal service is they actually make acronyms into verbs, drives you nuts. Well this is truly the worse one, it's called ESCARVIB [misspelled?]. ESCARVIB is the Emergency System for Advanced Registration of Voluntary Health Professionals - I don't even see why they call it ESCARVIB - but what it is is something really worthwhile and it goes to what I said over the years, is that good people work in our programs and they want to reach out and help in emergencies. And in an emergency, there are issues around credentialing and those, you know nitty, gritty of the service world.

What we've done at the, really the request of the Congress is we've set up a program that allows for advanced registration. Through that advanced registration when you choose to volunteer your state already has cleared all of the necessity credentials, licensing, and malpractice coverage issues so that you can literally go to the emergency and serve to the fullest of your capacity. This system is run with

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federal support at the state level. So the best way you can volunteer to help in emergencies is to get with your ESCARVIB rep in your state, register with them, and then be part of the state response when you go into an emergency. If you don't know who your ESCARVIB is in your state, ask your project officer in HAB to point you in the right direction, and we can help facilitate that for you.

The reason this is so important is you know there is chaos in an emergency. You remember that from our pictures of Katrina last year. This way the volunteer system is organized. The interest of the recipients as well as the interest of the volunteers are well protected. The states will know whose coming to help them, what skills are coming so that they can ensure that the skills get put into the right places where they're needed so that those who volunteer actually practice to the fullest extent possible. We are very pleased to say that we have 13 states fully up and running on ESCARVIB and seven are just about up and running.

Now having said that you can tell that I am truly a redhead under this bleach, and I'm very impatient that we don't have 50 up and running but we have already a good story to tell you. Last year our ESCARVIB system registered and sent to the Gulf area 8300 health professionals, more than any other system. We processed that many in the very first year of a

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program. That is pretty amazing. So, we are actually better off this year and next year we'll be further. So please be part of that system. We believe that it is a big step forward.

Another issue that has been a real priority of mine has been improving healthcare along the US/Mexico border. If that area were a state and that's that 2200 mile border from California to East Texas, if it were a state it would have the absolute worse health outcome statistics in the entire nation. I believe we can do a better job there and I believe we need to so. Last week I was in Tucson on a border health summit to work with grantees and build some partnerships. We have been that since 2002. We believe we made some progress but we know we can do better and here again, our HRSA Spins grantees have lead the way. We had five five-year projects that ended last year through our grantees along the border. They were charged with finding ways to reduce the barriers to care, to increase early detection of patients along that border, and to ensure access to comprehensive care along the border.

Well, we now looked at the evaluations of those programs and I could take an hour just talking about the findings, but I'll just basically share with you that the evaluations show that we learn that we can do a far better job if we use the community health workers, the primatourers [misspelled?] to engage local residents in a culturally

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confident way to get folks into care and keep them in care. We also found that the huge border area is an issue of distances and that the need for transportation services is incredibly significant for our patients in that area.

We also found that we needed develop better working relationships across the border, because our border is a very poorest border and people come and go across that border, therefore health needs really not to have a border, no barrier.

One of the things we have also been working is improving oral healthcare. That's been a passion of mine in this job from day one. I've said that the way to recognize the difference between the rich and the poor in America is very simple. You just look in their mouths. We can do a far better job. Good oral health is a key to good health overall. And we know the importance of good oral healthcare in HIV. Oral health problems many times are the first symptoms of HIV infection and later they often point to clinical regression. So periodontal disease is a significant problem for us and one that we fight very hard. The access to early and adequate oral healthcare is something we care deeply about in our program.

You know for many years we funded the dental reimbursement program, an innovative approach which ensures that low-income patients will have access to high quality dental healthcare when they need it. This year 16 new Spins

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grantees, part of a five year oral health initiative will be begin testing the very best ways to get oral health services to our HIV positive population. We are going to be putting those grants where there is no oral healthcare or very inadequate oral healthcare, which meet the demand. Those grants will be announced later this week. I'm really proud of this undertaking and I salute my colleagues in HAB for helping make this dream come true. I know that we can make difference.

You will also note that we have similar initiatives in our community health centers and many of them are joint titled two, three, and four with Ryan White so we believe we are going to get some synergy from the Ryan White grantees and the community health center grantees to ensure that we have improving oral healthcare for everyone. By any measure we have made progress in oral health but we know we can do a better job so look to those grants, look to those Spins projects for ways to make a difference in our future.

I want to conclude by sort of a update on where we are in Capitol Hill. You know we sent the President's budget to Capitol Hill for 2007 earlier in the year and that included a \$95 million increase for the CARE Act, if approved - and I hope it will be. That would bring the program to a new high of \$2.2 billion. Of the \$95 million in our proposal \$70 million would go to resolve the problems of state waiting lists for the ADAPT

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program. The other would be life saving medications for the duly diagnosed. We know that the formula in the ADAPT program sometimes is a challenge and so we believe that this \$70 million could help with that waiting problem which has been very significant. The other \$25 million is for outreach. Grants for community and faith based organizations to reach out into the communities around them will provide technical assistance and also money for sub-awards for grassroots organizations. We need to get people into care. It's for them, it's for the community. It is the right thing to do.

We also have a provision in the budget as it sent to the Hill to give the secretary flexibility to meet the needs where they are and that would allow him to transfer five percent of the funding from any title in the CARE Act to another title where it's needed.

Let me give you a sort of old budgeteer and I'm an old budgeteer. When they start telling you, you've work for five secretaries, you start to um, um, um, um, well I've been around a lot long time. I've done a lot of budgets. I like budgets. Budgets are the way you get things done in this country. Money is a proxy for action. 2006 was a really rough year for HRSA. Ten of our programs were totally eliminated in 2006. And seven other of our programs were very significantly cut. In the 2000 budget, most of our programs are held steady state or reduced.

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So from where I sit [inaudible] increase, \$5 million increase is a very big deal. And it really shows the commitment of both ends of the avenue to the support for the CARE Act and the bipartisan support that we have enjoyed up to this point and I believe we will continue to receive from the White House and from the Hill. So, we are happy with that \$95 million increase and we are optimistic about this appropriation cycle.

Now reauthorization is also underway and we've been working from HRSA with the department and with the lawmakers on the Hill to reauthorize it since the day it expired on September 30th. That is in process and I really can't give you a predication of when that will actually come about, but in the meantime, we will continue to operate under the 2000 Act. The President has, on a lot of occasions, talked about his principle for reauthorization including in his State of the Union message. Now I have to tell you then in Washington, getting a mention for a program in the State of Union is a big deal. And people do the wildest, craziest things to get their programs into the State of the Union. What you have to know is that all I have to do is be part of you. Your program speaks for itself. Your program was an automatic in the State of the Union. The President took great pride in including it in the State of the Union and he talked about his principles for reauthorization. They are to serve the neediest first, to focus

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of life-saving and life-extending services, to increase prevention, increase accountability, and increase flexibility. We'll stay tuned to see how that process goes. And as I said I can't give you a timeline, but I think we're on the right direction.

I'm going to end by encouraging all of you to take full advantage of this wonderful week of programs. Steve has already told you those plethoras of opportunities you have for learning and for sharing. The technical assistance is there for you and we hope you will avail yourself of it. The thing about this meeting is that we listen to you. We took your evaluations very seriously. We heard your requests and we structured a program we believe that is responsive and your technical assistance requests have been heeded.

So what we ask of you is to roll up your sleeves and enjoy a wonderful learning experience with us and with each other. I thank you for your service to America. Your good work makes the world a better place. Thank you so very, very much and have a great conference.

[Applause]

MALE SPEAKER: Hello, I'm [Inaudible] I would like to congratulate you on the progress you've made since the passage of the Ryan White CARE Act. By the work that you do for those whose lives have been affected by HIV and AIDS. You honor the

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life and the purpose of Ryan White. I'm honored to have this opportunity to say you helped those afflicted with HIV and AIDS, you helped keep all of us safe in a world that has no borders here. You helped us better understand AIDS. You give us hope. You are making the difference. You are helping to make the world a better place for all of us that know no one knew from the brutal destruction to IV. It's a threat to all of us, to our friends, our families, and our children. In some parts of the world its raw societies or their infrastructure, preachers, doctors, lawyers, workers, sparing no one, the young, the old, the uneducated, the rich and the poor, especially the poor. Millions of innocent children have been orphaned and millions more have afflicted. These are children who never know a loving touch of their parents. Children deprived of basic necessities like food, shelter, and security.

Years ago, people were terrified by HIV and AIDS, recoiling from its victims, banding children from school, and firing workers from their job. It was then that a brave young man Ryan White with a human face to the disease. He was only 13 years old; he helped a nation see that AIDS wasn't just a disease of the poor or the indiscreet. He showed us that AIDS could find us anywhere, all of us where we live. But not at the risk from working side by side with its victims, not at risk in the classroom. The risk was in not opening our eyes, working

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together. And because of Ryan White, Congress acted. It took years but Congress authorized funding for programs to combat HIV and AIDS. This is the 15th anniversary of the Ryan White CARE Act.

Because of the efforts of Ryan and others there was funding for research, treatment, life saving, and life enhancing services for those who needed it the most, the poor and the uninsured. Funds were also made available for antiretroviral treatment, counseling, testing, and social services for people living with and affected with HIV and AIDS. As a result of Ryan's brave efforts and the efforts of others in your community you are sitting here today. You are our first line of defense against AIDS, against fear, against apathy, and against ignorance. Thank you for your help.

Because of you and others in the CARE Act community, over 500,000 people have been helped. Now people with inadequate health insurance have access to the drug, Norvir at a price four times lower than that on the open market. Ryan White died in 1990 but his memory and his legacy are right here in this room. You are the heart of our nation. Thank you.

[Applause]

STEVEN YOUNG, MSPH: Thank you again Dr. Duke for your comments and joining us this morning. We are part of a bigger picture here under the Ryan White program. It's always helpful

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to get that context as we strive to serve the underserved through our program. Sort of a, we see the Kid Act as sort of a safety net for the safety net so to speak. And I have to credit Jen Katz from Kaiser Family Foundation who coined that phrase at a recent policy session that we at the Bureau.

I would like to now turn to our next speaker, Dr. Deborah Parham Hopson. Deborah is our associate administrator for the HIV/AIDS Bureau and has been our leader since 2002. She has a long history at HRSA, at Health and Human Services, and the Institute of Medicine. Many people probably don't know this but at one time Deborah was an intern at HRSA a few years back. And in 2003, Deborah was promoted to the rank of assistant Surgeon General. You have come forward Deborah with a rank well deserved.

Now Dr. Parham has been quoted as having said that 20 years ago did not exactly where you wanted to be but you knew you wanted to managed a program for the underserved, a health program for the underserved. Well, for that we are truly fortunate. And I just want to let everybody know that every single day that I come to work, I see the contribution that this "officer and a lady" makes. I don't know how strongly I can say it to you but the Ryan White community is truly blessed to have Dr. Parham administrating this program. For her leadership, toughness, foresight, logic, compassion, and humor

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- we laugh sometimes. Her door remains open to the staff of 150 people at the HIV/AIDS Bureau and I am honored to open that door for you.

Ladies and gentlemen, let me present my boss, my colleague and friend, our leader, Dr. Deborah Parham Hopson.

[Applause]

DEBORAH PARHAM HOPSON, PH.D., R.N.: Good morning everyone. Dr. Duke is right I can barely see you but I know that you're there. I know when I came in last evening, I noticed that there were chairs in the ceiling so I'm really glad that 2400 of you have joined us today for the opening of this meeting. It's great to see all of you. I can see that you are excited. I'm excited. I can feel your energy.

I want to open my remarks today by recognizing and thanking the executive planning committee of this meeting for their outstanding and untiring work. They began this work at the conclusion of our last grantee meeting in 2004. Under the leadership of Ms. Gwen Mister and Mr. Paul Billsby [misspelled?] everyone on the committee and the subcommittee have done an absolutely fabulous job in pulling this meeting together. And I would like to pause now and ask them all to stand and please give a round of applause.

[Applause]

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Thank you. As the week proceeds, I'm sure you will agree that this is the best conference ever. So please put that on your blue evaluation form.

As you can tell I am very glad to be here today and I know that you are as well. Isn't it great to have a chance to get away from the day to day and to focus on the bigger picture. In my phrenetic world of work and family and trying to keep up with a two year old, that doesn't happen very often. And I know I see a few smiles in room, so I guess you can understand what, that you're struggling with some of the similar issues. I know I saw several children in the hotel yesterday. The fact is that most days there just isn't time to stop and to ponder. The short-term problems are there. Those problems are big. They are very real. And so that's what we tend to focus on.

For those of you working on the front lines it can be helping a client who has lost her housing or a young man who is struggling with adherence issues. For me it may be dealing with the latest departmental deadline or answering yet another question on ADAPT or the Title 1 formulas. But then we have those special days. We hear or read something that puts us back in touch with the vision that brought us to this work.

That was the case earlier this year when I picked up an article about the history of AIDS in the United States. It as

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written by Michael Herston [misspelled?] and published by the Massachusetts General Hospital in their periodical called *ProDo* [misspelled?]. Herston began his article like this, "twenty-five years ago, casual sex carried little fatal risks, and homosexuality was seldom discussed in mainstream society. But that all changed in the summer of 1981 when several gay men in New York and California died of rare infections their bodies should have fought with ease." Herston goes on to say, "that the new affliction was soon christened with what became a terrifying acronym, AIDS. It lead to seismic shifts in the sexual attitude and forever changed the relationship between patient and the medical system."

Now I want to repeat that last part. It forever changed the relationship between patient and the medical system. The article described how the epidemic changed the lives of four people. Their careers lead them straight into the base of the storm that was building in the early 1980s. Herston recalls the moment when he or she came face to face with the strange new disease.

For Tony Valchee [misspelled?] now the director of the National Institute of Allergy and Infectious Diseases, it was when his mentor asked why are you diverting a great career for disease involving 40 people. For Robert Gallo whose destiny was to co-discover HIV, it came when a speaker asked where are

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the virologists who need to be addressing this disease. Matilda Crim a research scientist who became the founding chairman of the American Foundation For AIDS Research or AMFAR, Matilda who grew up in Europe during Holocaust, knew that AIDS was her fight when she saw the fear and the indifference towards those who were different. Bruce Walker was still an intern. His defining moment came when a patient asked I feel great, am I going to die. Walker now a professor of medicine at Harvard is still haunted and inspired by that question.

There are several things that struck about Herston's article. One, is that you and I stand on the shoulders of people who changed their lives to address AIDS in the early part of the epidemic. I know that it sounds like cliché but the fact is if it were not for them, you and I may not be here today. Second, I believe that there are new Tony Valchees and Matilda Crims right here in this room. We may read about you one day or perhaps your work will only be known by your patient and your colleague, either way you are absolutely incredible. Third, you and I have something that people in the first years of this epidemic did not have. It's really impossible to put a price tag on it. That something is fence of community and common purpose that we share with one another. And it is something that we shouldn't take for granted.

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The article reminded me of the importance of understanding our history. And I want to spend a few moments focusing on our history this morning. In 1905, and I'm really not going to go back that far, the poet George Santanos [misspelled?] said those who can not remember the past are condemned to repeat it. That familiar statement is very important to us. We have been dealing with AIDS for more than 25 years now. We have a proud and rich past. Think about it. When other medical staff would not go into an AIDS positive person's hospital room, we did. When catering staff left meal trays outside patient doors, we picked them up and we walked right in. when families left sons and daughters to suffer in silence and die alone, we provided companionship. We provided compassion. We provided caring.

In other words, we went to the front line even when we couldn't see them clearly. Initially we could see that people were coming into the hospital room, people were admitted to the ICU and most of them very quickly died. So in those early years, we responded by improving hospital based systems of care. People like the nurse Cliff Morrison in San Francisco helped his hospital build the country's AIDS ward. This ward meant that people were less exposed to the discrimination and to the stigma from within the health care system. It meant that people would be cared for by people who wanted to care for

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them. Helen Dermottias [misspelled?] a mother of six who didn't become a nurse until she was 39, helped bring training to hospital staff and clinicians who weren't comfortable with the strange new disease or with those who were living with it.

By the mid-1980s, we were beginning to learn what we were dealing with and none of that was really good. We knew that AIDS destroyed livelihoods and created dependence and early death. We knew the communities were struggling to respond. We knew that we were dealing with an infectious agent. And we knew that it was going to get worse. Suffering was everywhere, in the ICUs in the hospitals, in apartments where people were dying alone, and in a small Indiana town where a boy named Ryan was waging a battle to be just another boy.

Stigma and discrimination were getting in his way. But Ryan fought back with dignity and with grace. He gave us courage and to America not ready to stop the blame game, he gave us a blameless face of AIDS. So, to Jeanne White-Ginder, I say thank you for Ryan.

For people like Ryan and his mom, Helen and Cliff, and Tony and Matilda played their roles; thousands of others played theirs, case managers, physicians, nurses, social workers, and advocates. Dr. Donna Sweet is one example. Now I believe she is here in the room with us today. Born in rural Kansas, Dr. Sweet never lived in a house with indoor plumbing until she was

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awarded a scholarship and went to college. Over the past 25 years, she has taken HIV/AIDS care virtually to every corner of her state, the state of Kansas. While Dr. Sweet was starting a clinic in Wichita, Dr. Ellen Moore was seeing some of the first children living with HIV/AIDS in Detroit. She has played a pivotal role in adopting treatment guidelines for children, adapting treatment guidelines for children. Today 85-percent of Dr. Moore's patients have undetectable viral loads.

Despite the work of so many, the epidemic not only continued, it grew. The need for care and support outstripped community resources. Hospital, families, and social service agencies were overwhelmed. Help was needed. It was the politically potent gay and lesbian rights movement that first brought the message to Washington. Their early efforts offer a real lesson about what can be achieved when we make democracy work. It was in no small due to their efforts that by 1987 we saw the first federally purported AIDS care projects. But they did not stop and they were joined by those thousands of providers, of consumers, and their families. Allies within government were at work too. Congressional staffers like Tim Westmoreland and Michael Itswitiks [misspelled?] ensured that legislation moved forward. These combined efforts embodied community action as was seldom seen before. The result was the

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passage of the Ryan White CARE Act on August 18th, 1990, almost exactly 16 years ago.

Ryan White had died four months earlier. The death toll as you can see here in the United States numbered over 100,000. Not even military personnel working in times of war are prepared to see so many young people die.

Passage of the CARE Act opened a new chapter in HIV/AIDS services in the United States. Successes of the program began almost immediately. We provided services that reflected our understanding about the role of compassion. From the very beginning, we realized that money does not equal care. We knew instead that compassion plus know how equals care. Money merely fueled the distribution mechanism.

We also use our capacity to develop comprehensive care and then to deliver that care to our clients. We owe consumers a great debt for this capacity because it is they more than anyone else who taught us that if care was going to mean anything, it had to reflect the need of the individual.

Take the case we call Amy. Part of her story is printed in the 2006 Progress Report that you all have in your bag. Amy is a 18 year old young woman living in Detroit. Amy was born HIV positive. She lost both of her parents to AIDS. Her mother's family disowned because of her disease status and Amy moved from foster home to foster home. Her HIV status was

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disclosed at school and the taunting became so bad that Amy dropped out. Through it all, Amy has been supported by her social worker, Janet Nunn and the entire care team at her clinic in Detroit. It is Janet's job to ensure that Amy gets the medical care and the support services that she needs. The relationship between Amy and Janet illustrates beautifully that care goes beyond medicine. Amy found a confidante, a friend, and a supporter in Janet, something she had rarely known. Janet helped Amy overcome incredible odds. Amy earned a GED. Today Amy is in college and a vision of health, of happiness, and of hope.

I believe that our vision of compassion plus know how and our commitment to comprehensive services are the foundation upon which most of our successes have been built. Without them, could we have virtually eliminated perinatal transmission in CARE Act funded grantee. Could we have provided primary care to historically underserved population? Would we have been able to successfully support adherence? Would we have been able to reach people that no one had reached before? I don't think so.

In a few moments this plenary will end and we will go about the work of this conference. As we do so, let's not forget that our successes did not just happen. Let's not forget what HIV/AIDS care was like before we started training clinicians. Let's not forget what services were like before we

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started listening to consumers. Let's not forget what care was like before compassion was added to the care and treatment equation. And let's not forget that the value of care cannot always be measured in T-cells and viral loads. Just as sure as we faced the AIDS emergency in 1990, we face one today. That is why we have come to Washington this week. It is not the same emergency that we faced in the beginning but it is an emergency just the same and it affects us all. More than 1.1 million people are living with HIV and AIDS in the United States. And many of them are counting on you and on me. More than 41,000 people become infected each year. Hundreds of thousands of HIV positive people are not in care. They are counting on you and on me.

The bottom line is this. Unless we stay in the fight, unless we bring our compassion to the battle, unless we offer comprehensive services on the front line, people will suffer more than they have to. And they will die a lot sooner than they need to. I believe that you and I stand on a line of demarcation. On one side lies hope, on the other side lies hopelessness. On the hope side, people live with access to care and the possibility of improved health and quality of life. But on the hopeless side of the line, there is very little access to care for the uninsured and the underserved.

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Our job is to bring people over to the hope side of the line. Together we can do that. Together we are doing that. We are reaching populations that haven't often been reached before. We are going into communities where many won't go. We are combining know how with compassion. And the results are that we are reaching historically underserved people. Did you know that 59-percent of CARE act clients are racial minority and an additional 24-percent are ethnic minority. Did you know that one in three is female? That only 11-percent have any private health insurance and 50-percent live below the poverty line. They are all counting on us.

We are here this week to learn how we can build on these results in the face of some pretty difficult circumstances. These challenges include things like the rising HIV prevalence among the poor, limited resources, rising healthcare costs. They include things like HIV, Hepatitis B co-infection. The burden of HIV/AIDS among people of color, especially the high incidences among young men of color.

These problems appear in your clinics and in your community-based organizations. You see the uncertainty in the eyes of your clients. These daily challenges can be overwhelming and leave no time for the big picture. The big picture about where we are going and what we are trying to achieve. We continue to do what we do because we share a

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vision. The kind of vision that causes people to hang with it when the going gets tough. The kind of vision that sends people like Denise Wetherspoon [misspelled?] who works at the Brooklyn Hospitals PATH Center out into the community to find people that no one has ever tried to find before. The kind of vision that motivated people in Hattiesburg, Mississippi to build a community based system of care that responds to people that no one has ever responded to be before. The kind of vision that caused a small group of nuns in Youngstown, Ohio to pause one Christmas Eve and ask what should we be doing about HIV/AIDS.

I believe that we share a vision of a world without HIV/AIDS for our sons and daughters and loved ones, of a world without stigma, of a world where people don't face violence, eviction, and discrimination because of HIV infection. We share a vision of a world where people have access to care and to treatment, of a world where people are treated with dignity and with respect, a vision that Ryan White and so many others died trying to create. A vision that is worthy of our lives. Look at what we bring to the pursuit of such a vision. We have compassion and know how. We have commitment to comprehensive care. We have continuity with one another that people who began their work 25 years could have never imagined and above all, we have that single most important component of success. What is

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that component? It's people called to do this work. The consumers like Amy who have the courage to tell us what they need and the providers like Janet and Donna and so many others, all of you, who have the courage to provide it.

The most critical component of our success is the people in the audience today. The most critical component is you. Thank you so much, for who you are and for what you do. Thank you.

[Applause]

STEVEN YOUNG, MSPH: Thank you, Deborah, for refocusing us and sharing your thoughts on the vision with us.

A couple of housekeeping items for the meeting. The one thing I wanted to do is acknowledge the various division director meetings. If you look at your agenda based on the type of funding that you receive from us, you will see that there are a variety of title program meetings both Monday night and Wednesday night with the division directors and the staff. Also there are some times set up on the other evenings for project officer and grantee meetings so please refer to the agenda so you know where you need to be.

Also would like to announce a room change on one important session that did not make it into your program before it was printed and that Session 576 entitled Determining and Moving HIV Data to the Formula, Tuesday morning from 8 to 9:30.

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We understand that there may be a fair amount of interest in this session, so we moved to a bigger room from Maryland C to Exhibit Hall B-North-6. That's Exhibit Hall B-North-6 for Determining and Moving HIV Data to the Formula.

I think that's it in terms of notes and that's it for our opening plenary. We will send you on our way. We have lots of time for some networking before the first round of workshops. We'll see you together again right here for our clinical update lead by Dr. Laura Cheever at 2:30, so have a good morning.

[Applause]

[END RECORDING]