Vertical Challenge

The Elizabeth Glaser Pediatric AIDS Foundation believes ending mother-to-child transmission is closer than ever.

December 29, 2014 By Oriol R. Gutierrez Jr.

Charles “Chip” Lyons is the president and CEO of the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), which marked its 25th anniversary in 2014. Elizabeth Glaser was the wife of actor and director Paul Michael Glaser. She contracted HIV in 1981 from a blood transfusion while giving birth to her daughter, Ariel.

Through breastfeeding, Elizabeth unknowingly passed the virus to Ariel, who died of AIDS-related complications in 1988. Elizabeth also unknowingly passed the virus in utero to her son, Jake, who was born in 1984. Elizabeth was lost to AIDS in 1994. Jake remains actively involved with EGPAF.

EGPAF programs at work. Far left: Pregnant mothers in a maternity ward in Tanzania. Clockwise from top left: Donation of medical supplies and equipment in Swaziland; Ariel Camp for HIV-positive children in Rwanda; prevention of mother-to-child transmission kit in Lesotho; rapid HIV testing in Zimbabwe.

According to EGPAF, it has reached 20 million women with services to prevent transmission of HIV to their babies. The nonprofit supports more than 7,000 health facilities and works in 15 countries. In addition to services, EGPAF also conducts research and advocacy.

Prior to joining EGPAF in 2010, Lyons focused on global poverty in his role as director of special initiatives in the global development program at the Bill and Melinda Gates Foundation. Previously, he spent more than 20 years in related roles with the United Nations Children’s Fund (UNICEF), including president and CEO of the U.S. Fund for UNICEF.

He is a member of the Human Rights Watch Health and Human Rights Advisory Committee and

has chaired the board executive committee of the Global Alliance for Vaccines and Immunization (GAVI) Fund. In 2011, President Barack Obama appointed him as U.S. Alternate Representative to the UNICEF Executive Board.

Lyons shares upcoming EGPAF priorities, as well as his thoughts on expanding pediatric treatment and ending mother-to-child (a.k.a. “vertical”) transmission.

Watch highlights of the interview:

Tell us more about how EGPAF works.
We’re an operating foundation with about 1,000 staff members, 90 percent of whom are in the field. So our Tanzania office, for example, has 170 colleagues, 98 percent of whom are Tanzanians, and that model continues across the countries we’re in.

We work primarily through public systems, so we work closely with ministries of health at the national, provincial, district and site level. We do an enormous amount of training, coaching, advising, program evaluation and data collection.

We pay a lot of attention to testing and counseling, first and foremost, but a great deal of attention as well to getting kids and moms and dads to come back for services, in the case of kids and moms in particular after giving birth.

There’s a real weakness there. We lose track of a lot of kids and other potential patients. We are involved in operational and clinical research to figure out new approaches in which we can reach more people more efficiently.

What are some upcoming priorities?
Our mission is to end AIDS in children. The sustainable accomplishment of that mission is resource-dependent, and is dependent on health systems that deliver in a reliable and qualitative way.

As for policies, there are a number of them. We want to maximize the number of people who are tested and initiated on treatment. However, there’s a dearth of doctors and a shortage of qualified health care workers.

So allowing nurses to initiate treatment is a big deal. Anything and everything we can do to maximize the number of health care workers in general is a big policy area.

Dramatically increasing the number of kids who are tested, counseled and initiated on treatment consistent with World Health Organization (WHO) guidelines also is a big area.

We’ve done a better job over the past years in reaching adults with care and treatment, but we’ve not done nearly as good a job with kids.

Only about 25 percent of kids are identified, tested, counseled and initiated on treatment. For an HIV-positive child, mortality rates are around 50 percent by age 2 and 80 percent by age 5. If those kids aren't on treatment, the consequences are truly grave.

We also need the most effective and sustainable supply of pediatric medicines, which have to be formulated properly for kids.

Is there progress in expanding access to pediatric treatment?
Yes. The 2014 Accelerating Children's HIV/AIDS Treatment (ACT) Initiative seeks to add 300,000 kids onto treatment. There's a dedicated $200 million for that purpose: $150 million from the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) and $50 million from the U.K. Children's Investment Fund Foundation (CIFF).

Hopefully, EGPAF will be one of the implementing partners asked to find more creative approaches to identifying those kids who are exposed or who can be tested. Or who have been tested but aren't on treatment, to get them on treatment and then follow them. It's not a business-as-usual approach.

There are different ways to consider by combining forces and programming. For example, the terrific work being done around child survival. Immunization coverage rates in some countries are north of 80, 85 and even 90 percent.

Nutrition centers are yet another example. Kids who are poorly nourished, undernourished, malnourished are found in a number of countries to also be HIV exposed and HIV positive.

Charles "Chip" Lyons

Are we close to ending vertical transmission of HIV?
The global goal of virtually eliminating pediatric AIDS by the end of 2015 will be achieved in a number of countries. We wouldn't have said that as confidently just a few years ago, when the global plan laying out those goals was launched. However, we're not close in other countries.

Zimbabwe has done a phenomenal job of rolling out prevention of new pediatric HIV cases all across the country. Their vertical transmission rate 12 years ago was in the range of 28 to 30 percent. Six years ago it was 18 percent. In 2013, it was at 8 percent and it's moving dramatically downward.

EGPAF is their lead implementation partner. Our role includes training, strategizing, monitoring and evaluation, supervisory visits and coaching of public health system teams. We're working hand in hand with the health ministry, which has provided outstanding leadership and technical capacity.

In Zimbabwe, there was a strong base established by its government but also from other sources, such as the Global Fund to Fight AIDS, Tuberculosis and Malaria, as well as PEPFAR. Additional investment from CIFF increased the number of districts providing prevention of mother-to-child transmission (PMTCT) services from about 50 percent to 100 percent.

South Africa also has done a phenomenal job. After struggling for years to right that ship, the government has fundamentally changed how it views the epidemic.

It's a cliché, but it is about political will. You provide the resources necessary if the epidemic is approached from a scientific point of view.

What motivates you to do this work?
Being in the field is what motivates me—the people I get to work with, the people I meet, and the families that I meet.

I spent much of my career with kids in the field through UNICEF. You start to see these kids the way you see your own, which is a core emotion that's a driver.

Over time, you see changes that people thought were utterly either unthinkable or naive. We can do these things, and we've seen them get done over the past decades.

What about the HIV/AIDS response has ever been modest? Political will matters and resources are crucial, but the activist community being really loud over more than 30 years, that's what's driven the response.

On the bad days and the bad weeks, and sometimes even the bad months, being able to remember what actually is possible to achieve, that is the driver. There's nothing I'd rather do than what I'm doing.

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