

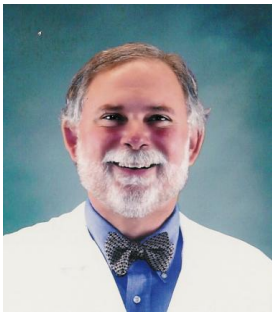
PHACCS

In focus

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PHACS MEMBER PROFILE



Russell Van Dyke, MD is Professor and head of the Section of Pediatric Infectious Diseases at Tulane School of Medicine. Russell currently researches mother-to-child transmission of HIV, medical management of HIV-infected children, and long-term outcomes of HIV-infected and HIV-exposed infants and children. Since 1990, Russell has been the Principal Investigator (PI) for the NIH-funded Tulane/LSU Pediatric AIDS Clinical Trials Unit as part of the PACTG and IMPAACT networks. These

networks conduct worldwide multi-centered clinical trials for HIV treatment interventions in women and children. He is currently Protocol Chair of P1032. This study is conducted in Thailand to identify strategies to prevent the development of resistance among women who receive single-dose nevirapine during labor to prevent HIV transmission to the infant. He is also PI of the PHACS Coordinating Center and Chair of the Scientific Leadership Group and Executive Committee. PHACS is an NIH-funded multi-centered study in the US with two objectives: to determine the safety to the infant of *in utero* exposure to antiretroviral therapy; and to define the long-term outcomes of older children and adolescents with perinatal HIV.

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ONLINE RESOURCES

These sites were shared by the October speaker from Planned Parenthood. We offer these sites as a resource only; the PHACS project is not responsible for the content.

- www.advocatesforyouth.org
- www.siecus.org
- www.teenpregnancy.org
- www.sexetc.org
- www.talkingwithkids.org
- www.plannedparenthood.org
- <http://www.plannedparenthood.org/mid-east-tennessee/index.htm>

UPCOMING EVENTS

- December AIDS Awareness Month
- December 1 World AIDS Day
- December 17 PHACS CAB Call – ATN
- January 28 PHACS CAB Call – IMPAACT
- February 2 National Black HIV/AIDS Awareness Day

FROM THE CAB

MY ADOLESCENT SON

As an HIV Positive woman, I have dedicated the latter part of my life to education, empowerment, and awareness of this epidemic. I have surrounded myself with other knowledgeable individuals who can help me along this journey, in order that I may pass along to others, the hope, that is so necessary. I have traveled

both near and far, internationally and domestically and have found that there is a certain amount of resolve in dealing with this disease by having the benefit of willingness to learn. I have been successful in my attempts to provide other individuals the facts as to the developments on the horizon and have volunteered my

time in an effort to be a voice for my community. To me, I have done the best I can with the resources available to me.

So how did it happen? In addition to all the different “hats” I wear, how did I miss the biggest lesson of all? I am mother to an HIV-positive child, now an adolescent, who has been on this journey with me since he was able to walk. He has been to presentations, other countries, conferences and on my job. He has heard all there is to hear, seen all there is to see and watched the outcomes for others who have made their individual decisions regarding adherence. He has watched his friends in the clinic pass away. He has heard the horror stories of the trips to the hospitals and observed the worst-case scenarios for people living with HIV. He has been dubbed “The youngest advocate in the history of HIV at 3 years old” and followed his mother from place to place, listening to my bouts of emotions regarding taking care of ourselves. How did he miss the message? Did he not hear me telling others that research has proven that if we are in care, adherent to our medication and healthy in our lives, we can live to 70 years old? Was he not really listening?

And so there I was, in the clinic with my son’s doctor. His viral load, which had been undetectable for years, was now on the rise. I was stunned. I had heard that when adolescents get to be adolescents, they make silly decisions. But not my little boy, right? He would never do that, or at least that’s what I thought. However, I could not ignore the proof before me. I turned to his doctor and slowly stammered, “He has not been taking his medication?” Oh, the dismay. All the work I had

been doing in my community was of no use at home. All the attempts to be encouraging and helpful failed for my son. The anger I was feeling wasn’t so much at him, but at me, then him. I was saddened that I had to admit that I had trusted my little boy, that I thought he was okay with his circumstances, and I never sat down and asked him what he thought. I was so caught up that I forgot that of all the people who needed support, it was him.



I went home eager to find out what he was thinking. Of course, this was not the time to be gentle. This was serious, and I had to be stern. When I confronted him, it was like a relief that he admitted that he made this decision because no one was paying him any attention. He mentioned that he was trying to get away with this action, and he expressed that he also knew he was wrong. We both sat quietly, and then I asked him to write an essay on this matter. In the end, he understands that taking his medication is the most important thing, next to doing his homework. We agreed that we would “partner” together and be available when it is “medication time.” We shook hands on the idea that if he ever felt this way again, we would talk. Now each night, he reminds us that it is time to watch him take his medication. I do not think it is about us watching that he enjoys, it is the time with his family that matters, and we are an important part of his life.

Samantha, PHACS CAB Chair

HIV QUIZ

1. The American Disability Act protects people living with HIV/AIDS. True or False?
2. “High-risk situations” that raise the risk of HIV transmission among adolescents include all of the following except:
 - a. Sharing “works” (syringes, spoons, cottons, water) with another person while shooting drugs.
 - b. Having sex with someone who might not know they have an infection (herpes, gonorrhea or syphilis).
 - c. If you are going to have sex, properly use a condom during sex every time with every person...no exceptions.
 - d. Not understanding how HIV is passed from person-to-person.
 - e. Having sex with an HIV-positive person without condoms, especially if the person doesn’t take their medicine.
3. Women make up 25% of the almost 40 million people living with HIV/AIDS. True or False?
4. Does the presence of other sexually transmitted diseases (STDs) facilitate HIV transmission? Yes or No?

DOC UPDATES

SMARTT CONTROLS PHACS has been awarded funds to enroll a SMARTT Reference Cohort. The funds come from the Eunice Kennedy Shriver National Institute of Child Health and Human Development.

In SMARTT, we are studying children who have been exposed to HIV drugs and are watching for any problems as they grow or develop. To do this, we enroll children born to mothers with HIV. A reference cohort is

a group of people not affected by the thing being studied. Therefore, the reference cohort for SMARTT will have children born to mothers not infected with HIV.

There is an important reason why we are enrolling these children. In order to understand what happens in children born to mothers with HIV, we need to know what happens in children who are born to mothers without HIV. We will ask both groups of children and their caregivers some of the same questions and do some of the same tests. Then we will compare the answers and test results to see if there are differences between the groups.

There will be 200 children in the reference cohort. Their caregivers will also be enrolled. These children and

caregivers will have their study visits at the same hospitals and centers that all other SMARTT children and caregivers have their visits.

The members of the PHACS network are very excited about having a SMARTT reference cohort. It allows PHACS researchers to draw better conclusions about the information they collect in SMARTT. The reference cohort is in the planning stage. PHACS plans to start enrollment in early 2010. Please feel free to contact the PHACS DOC Project Director, Julie Alperen, if you have questions. She can be reached at 617-432-6762 or jalperen@sdac.harvard.edu.

CAB GLOSSARY

Clinical Trial / Clinical Research – A study designed to determine the potential beneficial effects and/or determine safety and efficacy of a drug, biologic or device in human subjects.

National Institute of Allergy and Infectious Diseases (NIAID) – Strives to understand, treat, and ultimately prevent the myriad infectious, immunologic, and allergic diseases that threaten millions of human lives.

Network – a group of clinical sites brought together to conduct a single or multiple studies.

Office of AIDS Research (OAR) – Located within the Office of the Director of NIH, the OAR is responsible for the scientific, budgetary, legislative, and policy elements of the NIH AIDS research program.

Subject – A person who participates in an investigation, who may be a healthy human or a patient with a disease.



QUIZ KEY

1. **True.** An individual has a "disability" if he or she has a physical or mental impairment that substantially limits one or more major life activities, has a record of such impairment, or is regarded as having an impairment. Persons with HIV disease, both symptomatic and asymptomatic, have physical impairments that substantially limit one or more major life activities and are, therefore, protected by the law.
2. **Answer C.** Consistent condom use during sex does not raise the level of risk of HIV.
3. **False.** Women make up half (50%) of the almost 40 million people living with HIV/AIDS.
4. **Yes.** STDs increase the risk of acquiring HIV infection as well as the chances of transmitting it to others. For example, the risk of infection increases by as much as 50 to 300 times per each sexual contact with a person who has a genital ulcer.

Source: New York Department of Health

Please send all questions, comments, and suggestions for the CAB newsletter to RosiaWarner@westat.com