

PHACS

In focus

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PHACS MEMBER PROFILE

Dr. Rich is a pediatric immunologist at the University of Illinois at Chicago. He is the SMARTT Protocol Chair and the Co-Principal Investigator for the PHACS Coordinating Center. He is also the Principal Investigator of a SMARTT clinical site. After graduating from college, he spent two years in the Peace Corps in Malawi in East Africa. He then went to medical school at Tulane University in New Orleans. He did Pediatric, then Pediatric Immunology training at UCLA. While there, he provided care for those children born without the ability to fight infection such as the famous "boy in the bubble".



After moving to Chicago, he started to see children who had symptoms similar to children born without a functional immune system, but who did not completely fit the profile. Eventually it became clear these children were infected with HIV. At the time, little information was available about the virus, the definite identification of those infected, and the treatment. He became the Principal Investigator for the Chicago site of the Women and Infants Transmission Study (WITS) in 1998, a landmark study for understanding the transmission of HIV from an infected pregnant mother to her infant. He later became the Principal Investigator of the national WITS study. The study continued to 2006 and was one of the studies that helped provide the scientific and patient basis for PHACS.

Thus, his career spanned the time from before HIV infection was defined in children to the time when transmission of the infection from mother to baby could be prevented in most cases. He continues his contribution through his work in PHACS, where we hope to add to the understanding of prevention of HIV transmission from mother to baby and provide additional information about safety of the many different treatments that are available to prevent transmission.

Camp Hope In The Hill Country Of Texas

Theresa Aldape, Texas Children's Hospital

In July 2009, children and young teens with HIV/AIDS will be attending Camp Hope. Camp Hope is a recreational camp for children with HIV held at Camp For All in Burton, Texas. It began in 1996 as children in Houston were reaching the age of 7 years, and a little girl asked the AIDS Foundation Houston, Inc. (AFH) for a camp for children with HIV/AIDS just like the one in New York City. AFH presented the idea of camp to the Allergy and



Immunology staff at Texas Children's Hospital (TCH). We accepted the opportunity and challenge and began to review children's demographic information and began talking with families to inquire about their interest in camp. Many of the families were enthusiastic and wanted to know more. They expressed a sense of ease when they became aware that the TCH physicians, nurses, social workers and child life therapist as well as the AFH staff and volunteers would attend camp. To our surprise and jubilation, approximately 15 families trusted us to care for their

children for a weekend at Camp John Marc. Since then, the number of children and adolescents who attend Camp Hope for a week each summer has grown to over 100 children from different medical centers across the nation. The campers are 7 – 15 years of age, and they come to Texas from Florida and cities across Texas. This year we anticipate close to 130 children at Camp Hope.

On July 19, the children and teens will travel from Florida, Houston and several surrounding cities in Texas to begin their week-long outdoor recreation camp adventure. During camp, the children are all assigned to a cabin with children their same age and gender. Each cabin has 2-4 counselors to support the campers during their daily activities and also to help the children take their medications. The counselors are all volunteers with AFH, and many of the dedicated and caring volunteers have been coming to Camp Hope for many years. Campers receive medical and psychosocial support from health care professionals that volunteer onsite and collaborate with AFH.



The camp activities include swimming, canoeing, horseback riding, fishing, arts and crafts, cooking, group sports, a high and low ropes challenge course, archery, ice cream socials and of course the end of camp dance for all of the campers, staff, volunteers and Camp For All staff. Needless to say, everyone has a wonderful time at camp. Everyone on campus is extremely supportive of the campers and love seeing the children have a

wonderful time and have the opportunity to meet new friends.

Not all of the children are aware of their HIV diagnosis. However the development of “Teen Talk” provides an opportunity for HIV disclosure and a forum to talk about living with HIV. Health educators introduce topics such as, medication adherence, peer pressure, modes of transmission and risk behaviors affecting teens. Camp Hope provides a safe environment for teens



to talk about HIV. Teens are able to identify with their peers and renew their friendships in this safe recreational environment. At the end of the week-long camp experience, campers return home with a healthier outlook on life and a renewed sense of hope.

It is an awesome experience to see so many children smiling, laughing, caring for their fellow campers, taking charge of their lives and living to the fullest every day. We are preparing for Camp Hope 2009 and look forward to having a wonderful week: July 19–24. To learn more about camp, you can email me at tmaldape@texaschildrenshospital.org or Lenora Noroski, MD at lnoroski@texaschildrenshospital.org or visit the AFH at <http://www.aidshelp.org>.

Life affords no greater responsibility, no greater privilege, than the raising of the next generation.
-C. Everett Koop

CAB GLOSSARY

Audio Computer-Assisted Self-Administered Interview (ACASI) - A survey system designed for laptop administration to reduce discomfort at answering questions of a personal or illegal nature.

Clarification Memo - A formal explanation of a particular protocol section/issue.

Data and Operations Center (DOC) - The institution within PHACS primarily responsible for management of the network. Among other duties, this includes selecting, funding, and overseeing the clinical sites; monitoring site performance; organizing semi-annual network meetings; and data analysis. The DOC for PHACS is the Harvard School of Public Health.

Domain - An area of scientific interest to the study, typically used when a study will explore multiple areas of interest. For example, the SMARTT domains are metabolic and growth, cardiac function, neurologic / neurodevelopmental, behavior, language, and hearing domains, while the AMP domains are growth and sexual maturation; metabolic risk factors for



cardiovascular disease; cardiac function; bone health; neurologic, neurodevelopment, language, hearing, and behavioral function; and adolescent gynecology and HPV infection.

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) - Guides research on fertility, pregnancy, growth, development, and medical rehabilitation and strives to ensure that every child is born healthy and wanted and grows up free from disease and disability. NICHD is the lead NIH institute providing funding for PHACS.

Letter of Amendment - A written description of a formal protocol change.

Source Data - All information in original records and certified copies of original records of clinical findings, observations, or other activities in a clinical trial necessary for the reconstruction and evaluation of the trial. Source data are contained in source documents (original records or certified copies).

Sponsor - The entity that initiates a clinical investigation, but does not actually conduct the investigation. The sponsor may be an individual or pharmaceutical company, governmental agency, academic institution, private organization, or other organization.

Trigger - A clinical or laboratory result, which falls outside a predetermined acceptable limit. This result is said to “trigger” additional testing.

Working Group (WG) - Within PHACS, a group of individuals who review the data, monitor triggers, and develop conference and publication materials related to a particular domain.

HIV QUIZ



1. When considering whether to disclose their child's HIV status with people directly involved in the child's life (for example, babysitters, friends, relatives), parents and guardians should consider:
 - a. how disclosure would be helpful to the child
 - b. how disclosure would be helpful to the parents or guardians
 - c. whether the person can be trusted with confidential information
 - d. all of the above
2. Good things for an HIV-positive person to do to protect their health include all of the following **except**:
 - a. Getting enough sleep.
 - b. Eating foods that are good for you instead of only “junk food” or “fast food”.
 - c. Deciding **on your own** to skip your medicine for a while.
 - d. Getting a good doctor that you can trust, who knows that you have HIV infection.
 - e. Taking care of your whole self – body, mind and spirit.
3. The schedule of routine care is **the same** for children who are infected and living with HIV:
 - a. True
 - b. False
4. According to CDC estimates, at least 1/2 of all new HIV infections each year occur in people under the age of 25:
 - a. True
 - b. False

Source: New York Department of Health
See quiz key on page 4.

Questions, comments, or suggestions for the CAB newsletter?
Send them to christinagarber@westat.com.



UNDERSTANDING PHACS

This is a basic introduction to the Pediatric HIV/AIDS Cohort Study, better known as PHACS. PHACS is a network operated by two primary organizations: The Harvard School of Public Health and Tulane University. Harvard serves as the Data and Operations Center (DOC), while Tulane University serves as the Coordinating Center (CC). Together, they run SMARTT and AMP, the main studies in PHACS.

The Surveillance Monitoring for ART Toxicities Study in HIV-uninfected Children Born to HIV-infected Women (SMARTT) follows two cohorts of HIV- and ART-exposed but uninfected children to estimate the incidence of conditions and diagnoses potentially related to *in utero* exposure to antiretroviral therapy and/or exposure in the first two months of life among children born to HIV-infected mothers.



The Adolescent Master Protocol (AMP) is designed to define the impact of HIV infection and antiretroviral therapy on pre-adolescents and adolescents with perinatally acquired HIV infection. This study will enroll both HIV-infected and -uninfected children ages 7 – 16 years old, who were born to HIV-infected mothers.



For a more detailed overview of PHACS, go to <https://phacs.nichdclinicalstudies.org/overview.asp>.

ONLINE RESOURCES

These sites offer additional information on HIV/AIDS. We offer these sites as a resource only; the PHACS project is not responsible for the content of these sites.

<http://www.womenchildrenhiv.org/> hosts resources on preventing mother-to-child transmission and treatment of pediatric HIV.

<http://hivyouthproject.org/> is the website of the United AIDS Project, a youth-led initiative.

<http://www.thebody.com/> is the “Complete HIV/AIDS Resource” on 550+ topics.

<http://www.adolescentaids.org/> is the website of the Adolescent AIDS Program. Based in NYC, the AAP serves as a local and national resource.

<http://www.youthaidscoalition.org/> The Global Youth Coalition on HIV/AIDS is a youth-led initiative involving 150 countries across the globe.

UPCOMING EVENTS

- July 21 National Clinicians HIV/AIDS Testing and Awareness Day
- Aug 1 PHACS turns four
- Sept 18 National HIV/AIDS and Aging Awareness Day

Quiz Key:
1. D 2. C 3. False 4. True