Working Group Updates

PHACS Fall 2014 CAB Retreat

Adolescent Behaviors WG

Co-Chairs:
Claude Mellins, PhD
Barbara Moscicki, MD
Katherine Tassiopoulos, DSc

Purpose

To ask questions about the different behaviors of adolescents and young adults in PHACS. We are interested in the ways these behaviors affect their physical and mental health outcomes. Finally, we are also interested in their readiness to be young adults.

Areas of Focus

Behaviors

- Starting sexual activity
- Disclosure
- Use of alcohol, cigarettes, marijuana and other substances
- Adherence to HIV medicines
- Transition to adult HIV care
- Transition to adult life

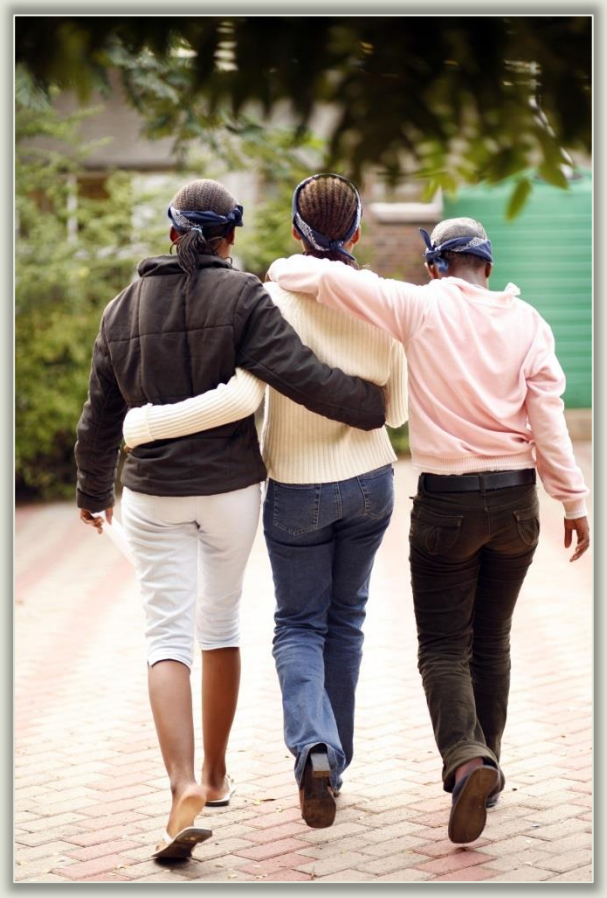
Health Outcomes

- Sexually transmitted infections
- Pregnancy
- Psychiatric outcomes

Accomplishments

Significant accomplishments over the past two years:

- Medication Adherence and Viral Load in Youth with HIV;
- Youth with HIV and Risk of Substance Abuse;
- Youth with HIV and Sexual Risk Behavior; and
- AMP Up.



Significance for the Community

Findings from the Adolescent WG may influence the work of HIV providers:

- Development of services that reduce risk;
  - Risk of health complications due to poor adherence may be reduced;
  - Transmission to partners or babies may be reduced;
- Development of services that promote healthy behaviors;
  - Health intervention; and
  - Services and screenings that may help youth grow up to be healthy functioning adults.

Why the Adolescent WG?

There are many reasons why researchers joined the Adolescent WG:

- To help youth transition into adulthood;
- To help youth understand the importance of medication adherence and management;
- To continue to study the physical and mental health of youth born to mothers with HIV; and
- To overcome barriers associated with transitioning to adulthood.

Works in Progress

- Medication adherence over time;
- AMP Up protocol development;
- HPV vaccine, lasting effects;
- Problems associated with substance use;
- Development of the Amp This Up website;
- Technology use in study retention; and
- Factors that lead to STIs.

CAB Contribution

"In the medical research community, we see things from a medical research point of view with everything. Our educational blinders sometimes prevent us from understanding the whole picture. That's where you come in, the CAB. The CAB helps us to see the whole picture. "

Future Goals/Plans

- To study adolescent behaviors and how they affect their health;
- To study risk behaviors;
- To examine healthy behaviors; and
- To study and support youth transitioning into adulthood.

Cardiopulmonary WG

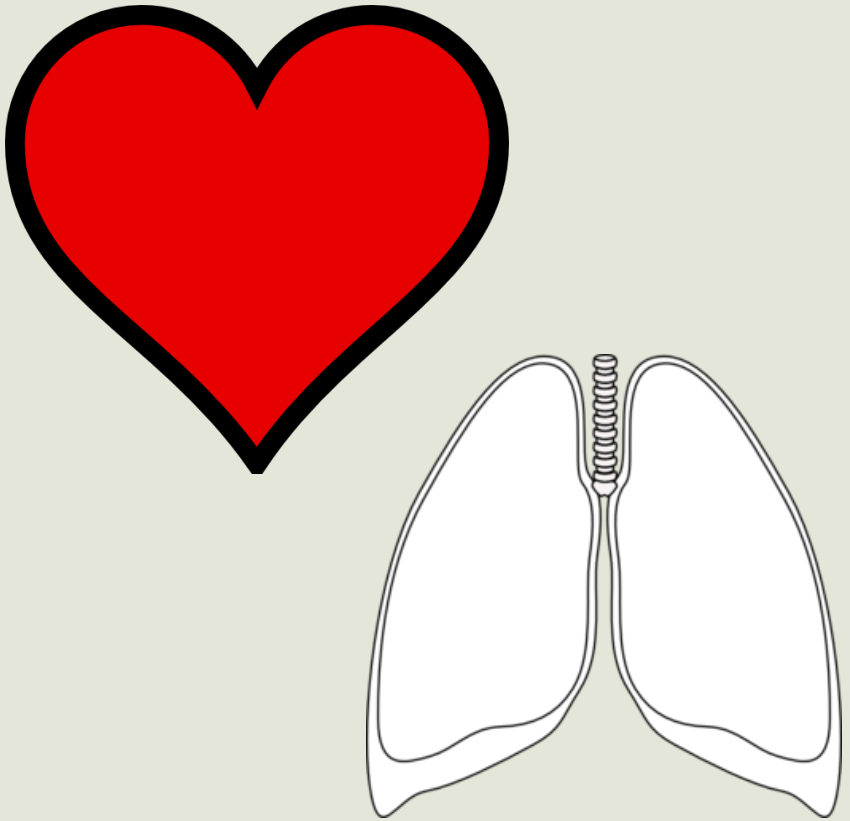
Co-Chairs:
William Shearer, MD, PhD
Paige Williams, PhD

Purpose

The purpose of the Cardiopulmonary Working Group (CPWG) is to give scientific direction and support to studies of the heart and lung within PHACS. The CPWG has 10-20 experts in heart and lung medicine. Many experts also study the immune system. Some are also experts in pediatrics, biostatistics, and epidemiology.

Areas of Focus

- To evaluate the safety of antiretroviral (ARV) treatment given to pregnant mothers with HIV on the heart and lung health of their children; and
- To evaluate the effects of HIV and ARV treatment on heart and lung function in children born to mothers with HIV.



Accomplishments

Significant accomplishments over the past two years:

- Evaluation of chemicals in the blood of children born to mothers with HIV to find out if there were signs that HIV and ARVs had affected the hearts of children born to mothers with HIV;
- Using an echocardiogram (ultrasound) test to check the heart health of youth born to mothers with HIV who took HAART and youth with HIV from the P2C2 study (most of whom did not take HAART); and
- Performing lung function tests on youth born to mothers with HIV.

Significance for the Community

- In the early days of the HIV epidemic, youth born with HIV had problems with their hearts.
- The CPWG continues to study the hearts and lungs of youth born to mothers with HIV to determine if there are any long-term effects.
- PHACS community members may be concerned about the high rates of asthma in their children.
- The CPWG continues to study risk factors associated with asthma and other lung problems to help the community to change factors to lower their risks.

Why the Cardiopulmonary WG?

Co-Chair: Paige Williams, PhD

- Passion for heart and lung research; and
- Research that comes out of the CPWG helps to make the community aware of risk factors that may contribute to heart and lung problems.

Works in Progress

- Heart structure and function using results from echocardiograms (ultrasounds);
- Heart functioning;
  - In association with vitamin D;
  - Chemical markers in the blood of AMP participants who were born to mothers with HIV;
- Standardizing echocardiogram (ultrasound) parameters; and
- Pulmonary substudy.

CAB Contribution

"Several of the new proposed studies will require extra tests to be done in AMP or SMARTT. The CAB can make very helpful contributions to the design of these studies. CAB members can give input on how their children will handle the procedure and how likely they would be to participate in certain studies."

Future Goals/Plans

- To study heart biomarkers and vitamin D;
- To study the genetic makeup of youth born to mothers with HIV in the PHACS AMP studies; and
- To study Natural Killer (NK) cells and asthma.

Complications WG

Co-Chairs:

Kunjal Patel, DSc

Russ Van Dyke, MD

Purpose

The primary aim of the Complications Working Group (WG) is to identify complications of HIV disease and evaluate their associations with antiretroviral (ARV) therapy. This WG focuses mainly on the AMP participants in PHACS. They study youth born with HIV and uninfected youth born to mothers with HIV.

Areas of Focus

- To look at trends in HIV medication use;
- To study CD4 counts, viral loads, and clinical events;
- To compare the effectiveness of vaccines;
- To look at the relationship between Tenofovir use and kidney disease;
- To estimate the commonness of liver disease;
- To look at oral health;
- To measure the proviral load of youth who start ARV treatment early in life;
- To make a DNA repository for studies that use DNA; and
- To collaborate with international pediatric studies.

Accomplishments

Significant accomplishments over the past two years:

- Immunity to Measles, Mumps, and Rubella in Youth with HIV;
- Number of HIV-Infected Cells in the Blood after Controlling HIV at a Young Age and for a Long time; and
- Factors Associated with Retention of Subjects in the Pediatric HIV.

Significance for the Community

- CAB members and youth can be leaders in encouraging people to get immunizations according to the most recent recommendations.
- Taking HIV medications on schedule is very important. The CAB can help the Complications WG find ways in which to help with adherence to medications in youth with HIV.
- The Complications WG needs continued input and support for the CAB in helping to find ways to come up with strategies that would support continued participation in PHACS.

Why the Complications WG?

- *"I joined the Complications group because we can learn so much, and can share with our youth, about how HIV really can become a chronic infection that when suppressed can result in healthy lives without side effects."*
- *"I joined the Complications group because I wanted to be part of the research group that not only identifies complications of HIV infection and its treatments, but is active in pursing approaches that are designed to minimize/prevent potential complications, and increases the potential for long term health of those affected."*
- *"I joined the working group to participate in studies of HIV and chronic kidney disease."*

Works in Progress

- Genetic markers of ancestral origins (AIMS);
- Youth with virologic suppression who continue to have low CD4 counts;
- A genetic marker of chronic kidney disease;
- Oral health of participants;
- Frequency of viral resistance;
- ARV strategies after HAART failure;
- Immunity to varicella after immunization; and
- Markers of inflammation and immune activation and pulse wave velocity.

CAB Contribution

- Active participation on conference calls;
- Asking questions about specific areas of research;
- Sharing personal experiences that may contribute to future research;
- Bringing information from this group back to the CAB; and
- Inviting Complications Group leaders to participate in CAB Conference Calls when there are issues/questions that need clarification.

How do you think the CAB may contribute to the Complications WG?

Future Goals/Plans

- To study how HIV and the immune system change in youth with HIV over time;
- To study what happens to the abnormalities as youth age; and
- To study whether any new problems develop such as:
  - Immune problems;
  - Heart problems;
  - Liver disease; and/or
  - Kidney disease.

Hearing/Language WG

Co-Chairs:
Mabel Rice, PhD
Peter Torre, PhD
Tzy-Jyun Yao, PhD

Purpose

To provide scientific leadership to the PHACS project for studies of hearing, speech impairments and language impairments in PHACS.

Areas of Focus

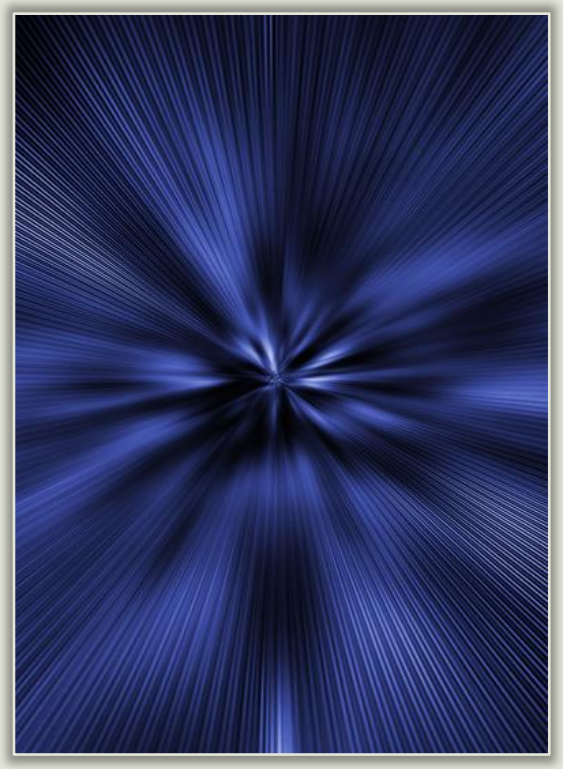
Communication disorders:

- To look at possible increased risk for hearing loss, speech or language impairments, and related impairments in PHACS participants;
- To study the safety of treatment methods; and
- To look for predictors of risk.

Accomplishments

Significant accomplishments over the past two years:

- Hearing Loss in Youth with HIV and HIV Exposure;
- Language Delays in Youth with HIV and HIV Exposure;
- Evaluation of Risk for Late Language Emergence in Youth with HIV Exposure; and
- Submission of a grant proposal, Hearing Sensitivity Characteristics in AMP Up Young Adults.



Significance for the Community

- The outcomes of research led by the Hearing/Language WG will help the PHACS community to understand the effects of HIV and HIV treatment on youth' s hearing, speech, and language development;
- The Hearing/Language WG studies help the PHACS community understand possible risks for impairments and directions for treatments and prevention;
- The Hearing/Language WG is working to find information about the ways in which hearing, speech, and language contribute to youth's cognitive and social outcomes; and
- The Hearing/Language WG is working to help youth transition to adulthood.

Why the Hearing/Language WG?

"The topic area is interesting and is relevant to all youth. Hearing, speech and language abilities closely line up with youth's social development, cognitive abilities, and ability to function well in the world. The research also lines up with their interactions with families, other youth and at school. What we talk about on our monthly calls is informative about challenges in coming up with and carrying out studies relevant to our WG. All comments and input are welcome!"

Works in Progress

- Risk for speech and language impairments in youth with HIV and ARV exposure at 3 and 5 years old;
- Persistence of language impairments in youth with HIV and HIV exposure;
- Otoacoustic emission in youth with HIV and HIV exposure; and
- Newborn hearing screenings in babies with HIV exposure.

CAB Contribution

- Provide feedback to the Hearing/Language WG about experiences with hearing, speech, and language impairments; and
- Suggest ways to better share Hearing/Language research findings with the PHACS community.

Future Goals/Plans

- To study growth of children with hearing, speech and language impairments; and
- To look at how HIV treatment or exposure can affect risks for impairments, also how it can affect social outcomes or school achievement.

Nutrition, Growth, and Metabolism (NGM) WG

Co-Chairs:
Denise Jacobson, PhD
Tracie Miller, MD

Purpose

To try to understand how youth with HIV, or who were exposed to HIV, grow, and what factors might cause these youth to have problems with under or over nutrition. This WG is also interested in understanding why youth with HIV or who were exposed to HIV sometimes have problems with high lipid levels, have diabetes or show signs that they will develop diabetes. They are looking at why these youth might have risk factors for heart attacks or strokes at an earlier age than expected. In addition, they are evaluating how strong the bones are in these youth and if they have greater number of fractures than the average youth and if so, why that would be.

Areas of Focus

- Growth;
- Nutrition (diet); physical activity;
- Lipid levels;
- Cardiovascular disease risk;
- Diabetes;
- Bone health; and
- Maternal nutrition health.

Accomplishments

Significant accomplishments over the past two years:

- Youth with HIV and Overall Risk for Heart Disease;
- Age at Start of Puberty in Children Born with HIV;
- How HIV Affects Bone Health; and
- How Youth with HIV Make Energy.

Significance for the Community

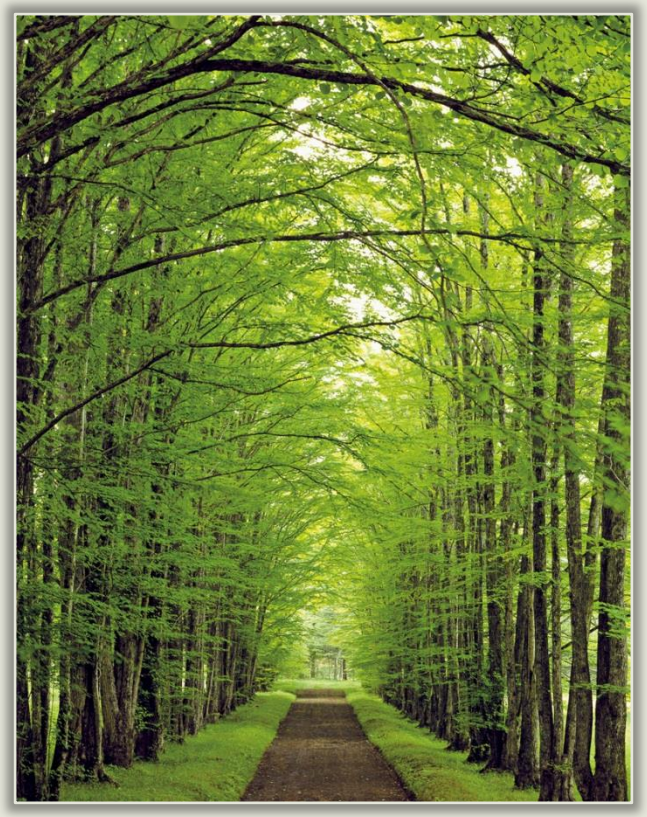
- Youth born with HIV and/or uninfected youth born to mothers with HIV may have some problems in their growth;
  - Youth with HIV were shorter and lighter (in weight) than national norms; and
  - Uninfected youth born to mothers with HIV have higher than expected rates of obesity;
- Youth born with HIV have higher rates of bone breaks earlier in life compared to uninfected youth;
- Youth born with HIV have higher heart attack and stroke risk compared to uninfected youth; and
- Youth born to mothers with HIV should be followed carefully for growth and nutritional problems.

Why the NGM WG?

"We have had many years interest in nutrition and growth of youth with chronic illness and how nutrition affects the child's health (in both good and bad ways). Studying HIV and nutrition in youth has shown us that if we can optimize nutrition, along with good medical care in youth born to mothers with HIV, we can help keep them healthy."

Works in Progress

- How and why youth develop diabetes or sugar intolerance over time;
- Evaluating if low vitamin D level contributes to low bone density in youth with HIV;
- Bone breaks in youth born to mothers with HIV;
- Cholesterol and lipid levels in youth with HIV over time;
- Diet during pregnancy and its affect on baby growth and development; and
- Problems with mitochondria.



CAB Contribution

- Help contribute to recruitment and retention of young adults in PHACS; and
- Help contribute general feedback regarding study direction in terms of nutrition, growth, and metabolism.

Future Goals/Plans

- To track young adults as they age into adulthood;
- To look at what might be causing youth to lose or gain weight;
- To look at what might be causing youth to have high lipid levels;
- To find out why youth with HIV may be more prone to bone breaks; and
- To find out about risks for developing diabetes.

Brain Development and Mental Health WG

(*Neurodevelopmental and Neurology*)

Co-Chairs:
Rohan Hazra, MD
Kay Malee, PhD
Renee Smith, PhD
Katherine Tassiopoulos, DSc

Purpose

To study how HIV and HIV medications affect brain development, learning, and the emotional-well-being of youth and young adults. This WG is looking to try to figure out how health and development change if HIV disease becomes more severe over time.

Areas of Focus

- To examine the mental health and brain development effects of HIV and/or ARVs on youth who were born to mothers with HIV;
- To study potential short- and long-term consequences of exposure to or infection with HIV and its treatment on cognition, academic achievement, and on the neurological, emotional, and behavioral development of youth over time; and
- To look at how environment and other possible factors contribute to all of these developmental outcomes.

Accomplishments

Significant accomplishments over the past two years:

- How Blood Flow Affects Brain Function in Youth with HIV;
- How HIV Affects Long-Term Mental Function in Youth;
- Impact of HIV Severity on Cognitive and Adaptive Functioning During Childhood;
- Safety of Baby Exposure to HIV Medicines and Outcomes;
- Biomarkers and Brain Development in Youth to Mothers with HIV;
- Mental Health and Substance Use in Mothers Living with HIV; and
- Cognitive and Academic Achievement Outcomes in Youth with HIV Exposure.

Significance for the Community

- These studies can help PHACS learn about children's health and development during different stages of life; and
- This research can help figure out how to best support youth and young adults so they can look forward to a healthy and happy future and avoid risky behaviors that may place their well-being in jeopardy.

Why the Brain Development and Mental Health WG?

"The Neurodevelopmental and Neurology Working Group is a team of people who are interested in the health and development of children, teenagers and young adults affected by HIV. This includes youth who were born with HIV or who are uninfected but born to mothers with HIV."

Works in Progress

- Memory substudy;
- Neuroimaging study;
- Executive function and adherence;
- Viral suppression and impact on neurocognitive function during childhood;
- Executive function in children born with HIV;
- Mental Health diagnoses in SMARTT;
- Lead exposure and mental health outcomes;
- Relationships among HIV disease severity, caregiver and home environment, psychosocial factors and cognition upon mental health functioning of youth born to mothers with HIV; and
- Prevalence of mental health diagnoses and treatment services in SMARTT and AMP.

CAB Contribution

- Participate in meetings/ discussions of proposed projects. Offer advice and feedback;
- Suggest research questions of interest to CAB, family members and PHACS participants;
- Attend working group meetings at PHACS meetings;
- Communicate with leadership and members of the WG who will share your input with the entire WG; and
- Share what we all learn together with the members of your local CAB.

Future Goals/Plans

- To continue to study the results of past and ongoing evaluations of youth in PHACS;
- To try to understand the strengths of youth and families affected by HIV;
- To understand aspects of development that might be affected by HIV and HIV treatment;
- To come up with possible interventions and therapies that could support youth and their families when problems exist;
- To learn how to prevent difficulties; and
- To give youth better opportunities for good health and a productive adult life.

Maternal Exposures WG

Co-Chairs:
Deborah Kacaneck, ScD
Kenneth Rich, MD