

**CAB Conference Call
May 25, 2017
12:00 EST
Meeting Minutes**

Participants:

Alexandria	FSTRF
Brandon	University of Florida, Jacksonville
Claire	Harvard University
Delia	University of Miami
Exzavia	Children's Diagnostic and Treatment Center
Jennifer	San Juan Hospital
Joel	University of Puerto Rico
Juanita	Tulane University
Julie	University of Alabama, Birmingham
Julie	Westat
Kimbrae	Texas Children's Hospital
Kylie	Texas Children's Hospital
Latrina	University of Alabama, Birmingham
Lesley	Texas Children's Hospital
Lourdes	San Juan Hospital
Marilyn	Bronx-Lebanon Hospital Center
Megan	Westat
Rosetta	Bronx-Lebanon Hospital Center
Russ	Tulane University
Stephanie	University of California, San Diego
Stephanie	University of Miami
Theresa	Texas Children's Hospital
Veronica	University of California, San Diego

• **SPRING 2017 LEADERSHIP RETREAT REVIEW – GENOMICS RESEARCH PRIORITIES AND AMP UP LITE**

Dr. Russ Van Dyke talked about the Spring 2017 Leadership Retreat. He said that during the Spring 2016 Leadership Retreat, PHACS Leadership voted on research priorities for PHACS. Three priorities were picked for AMP and AMP Up. The first priority was to study the relationship of DNA (genomics) with the outcomes of HIV and HIV treatment. The second was screening for heart disease with a cardiac Magnetic Resonance Imaging (MRI) exam. This priority would also involve looking at the lungs with computerized tomography (CT) scans. This priority is starting up as a small study in Boston, Massachusetts. The third priority was to explore young adults transitioning into adulthood.

The first priority about genomics was discussed at the Spring 2017 Leadership Retreat. Genomics is the study of looking at a person's genes and seeing how they relate to different conditions. Conditions could include illnesses. Researchers are also interested in looking at seeing how genes relate to a person's health. Some changes in genes can make a person more likely to have an illness. Other gene changes can protect a person from getting an illness.

There is a lot of research on genomics and other diseases. Sickle cell disease has been studied by researchers for a long time. Sickle cell disease is a mutation in the gene that makes hemoglobin. Hemoglobin is the protein in blood that helps carry oxygen. Researchers discovered that people who have the sickle cell mutation develop anemia and other complications. There is an upside to having the sickle cell mutation. Some people who have the sickle cell mutation appear to be resistant to getting malaria. They may also be less likely to develop severe malaria.

There is also a mutation in a protein CCR5. HIV can use this protein to infect a cell or infect another person. The mutation is known as CCR5-delta32. This mutation can prevent people from getting infected. People who have this mutation are less likely to get infected with HIV when exposed. People who have two of these mutations are the most unlikely to get infected. The "Berlin patient" was a person who had HIV and leukemia. Part of the treatment for leukemia included a bone marrow transplant. During the transplant, the Berlin patient received bone marrow from another person with the CCR5-delta32 mutation. When the bone marrow established inside the Berlin patient's body, the patient now had the mutation. This made him resistant to HIV and the virus went away.

There is also a mutation called APOL1. People with this mutation have an increased risk of kidney disease. People living with HIV who have this mutation are 3-4 times more likely to get kidney disease.

Antiretrovirals (ARVs) are metabolized by the body. Mutations in genes that are involved with metabolism can affect how well the drug works in a person's body or produces side effects. Some people have a mutation in the genes involved in metabolizing Efavirenz. People who have this mutation metabolize Efavirenz more slowly. Therefore, the drug levels are higher than expected. This can cause them to develop side effects.

Gene mutations can affect health. Gene mutation can affect treatment for conditions like HIV. Genomics help researchers to understand how drugs work, how HIV progresses, and side effects. Many participants in AMP and AMP Up have given DNA samples. Researchers want to look at the DNA to break it down to look at all the genes within the DNA. They want to figure out which genes are which and compare them to other databases. These databases show the ranges of genes that people have. This includes changes that people normally have and changes that are associated with different diseases. The databases are like a gene dictionary. This study is being done at the Human Longevity Institute in San Diego, California. For example, researchers are interested in looking at Autism. There are genes that are associated with autism. This research will allow researchers to look at whether children in PHACS have any mutations associated with autism. This will help researchers gain a better understanding of gene mutations in PHACS participants.

Kim talked about confidentiality. **Kim** wondered whether participants will consent to having their DNA samples used in future studies. **Russ** explained that the AMP and AMP Up consents include a part to consent for samples to be used for future studies.

Theresa asked about the Human Longevity Institute databases. **Russ** explained that the databases include data from over 10,000 people. This includes samples from people all over the world.

Russ talked about AMP Up Lite. AMP Up Lite is a simplified version of AMP Up. AMP Up was developed in order to follow young adults as they age into adulthood. The researchers want to continue to keep in touch with participants who were born with HIV. This is important in order to monitor what health conditions these young adults experience in adulthood. In AMP Up Lite, participants will go into the clinic for the first visit. After the first visit, all visits will be done over the phone or computer.

• **APPROVAL OF MINUTES**

The minutes from the April 27, 2017 call were approved with no changes.

• **PHACS CAB EVALUATION SURVEY RESULTS**

Megan talked about the survey. There were 8 responses. Topics suggested through the survey included:

- Progress reports;
- Explanation of laboratory tests; and
- Review of the results of the Client Diagnostic Questionnaire (CDQ).

- **2017 CAB CHAIR AND VICE CHAIR ELECTIONS**

Megan talked about the CAB Chair and Vice Chair elections. **Megan** thanked all nominees for running for the positions.

Stephanie from San Diego, California was elected as CAB Chair. **Brandon** from Jacksonville, Florida was elected as CAB Vice Chair.

- **PHACS CAB NEWSLETTER, JULY 2017 EDITION**

Megan talked about the PHACS CAB Newsletter, July 2017 edition. Suggestions for the newsletter theme suggested through the survey included:

- Tools for success;
- Endurance, strength, and survival;
- Coping with HIV; and
- Transitioning to adult care.

Lesley suggested that the CAB vote for the theme through the survey. **Megan** encouraged the CAB to vote for a theme within the next week. **Megan** will announce the theme by email next week.

- **HEALTH EDUCATION AND COMMUNICATION COMMITTEE**

Claire talked about the Health Education and Communication Committee (HECC). The HECC has completed the PHACS film series with **Staffan**. Three films were created using the footage from the PHACS Fall 2016 Network Meeting. **Claire** and **Megan** created several short video clips from the interviews. Many of these clips may be featured on the PHACS website. **Claire** will contact each interviewee for approval to use their clip on the website.

Claire talked about an upcoming workshop. **Claire** was invited to speak on a panel about HIV health literacy in communities of color. **Claire** invited the CAB to assist in planning for the workshop. CAB members may volunteer through the survey.

NOTE: The next CAB call will be on Thursday, June 22, 2017 at 12:00 pm EST.