

A Community Advisory
Board (CAB) Newsletter
published by:

**The Pediatric HIV/AIDS
Cohort Study (PHACS) CAB**

INSIDE THIS ISSUE

From Our CAB Chairs	<u>1</u>
What is Migration?	<u>2</u>
My Migration Story	<u>3</u>
Symbolic Animals	<u>5</u>
Advice for Migration And Change	<u>6</u>
But I'm Here	<u>7</u>
PHACS Member Profile	<u>8</u>
Migration is Beautiful	<u>9</u>
HECC Update	<u>10</u>
Resources	<u>11</u>
Upcoming Events	<u>11</u>
CAB Glossary	<u>12</u>
PHACS Teams Quiz	<u>12</u>
CAB Kids	<u>13</u>
PHACS Teams Quiz Answers	<u>15</u>

From Our CAB Chairs

Kimbrae, PHACS CAB Chair

My migration journey started way before I became the PHACS CAB Chair. About 25 years ago, I was so excited because I was becoming a new mother. In the middle of February of 1997, my whole existence shattered. Little did I know, that this was the beginning of me becoming the advocate, mother, and woman I am today.

Through my migration of learning about what it meant to be HIV-positive to now knowing how powerful it is to have a voice, I was propelled into a new life. Basically, I was no longer dreading or not celebrating my HIV birthday. For those who don't know what that means, it means the day you initially receive your diagnosis. It also means the start day of your next migration in life. It can also bring you to a crossroads in life, where you have to decide how you will handle this new journey.

There were many pathways I could have taken to reach this path now. I know I have made mistakes. I wish I would have said a whole lot more to people I have lost to the disease, but I am happy about who Kim is today. I hope that I can be a beacon of light to those who are just starting their migrations. I want to be a beacon of hope for those who are tired and weary on this road.

There is a reason you are part of your migration. I know you have the strength to keep going on until the end, and hopefully that means a cure or a vaccine. I love you all! Spread your wings like eagles and fly!



Exzavia, PHACS CAB Vice Chair



Over the years, PHACS and the Health Education and Community Core (HECC) has always been a place for migration. Migration, by definition, happens when you relocate from one place to another. Most of us deal with migration in our own ways, things that happen in life can sometimes be a reason to migrate. When I think about migration and how it plays a role in our lives, I think about everything that has been accomplished through PHACS and the HECC. For example, the CAB and the PUG have been amazing accomplishing goals for future generations. They have been setting trends for those who will come after.

Whether it is a CAB member, a PUG member, or someone willing to share knowledge and support, we can all learn from each other on how to deal with migration. Another great example of migration is how we all have made changes during the COVID-19 pandemic to remain safe and still engaged in research studies. While there have been so many challenges, I believe that we have all migrated in our own way. My way of coping with life challenges, including migration, is to give myself and others encouragement.

WHAT IS MIGRATION?

CAB Members discussed the many personal meanings of this newsletter's theme of migration. The CAB noted that while some migrations are by choice, some are forced. Although migration is not always a positive experience, CAB members expressed the importance of sharing their experiences. Even with negative experiences, sharing stories may still help others.

Below are several words/phrases associated with migration submitted by CAB members:

**CYCLES
LEAVING
GOING BACK AND FORTH
TO THE SAME PLACE**

**REBIRTH
EXPERIENCE**

**HEALTH
MOVING
DEPARTURE**

EXODUS

MY MIGRATION STORY

**Several CAB members shared stories about their experiences with migrations in life.
Please read their stories below:**

Born and raised in the busiest border of the world, Tijuana-San Diego, my entire life I've experienced, lived and witnessed the process of Migration. One fence that makes the difference of two countries in every aspect of our lives. One fence that separates families and opportunities for a better life, and yet magical for those who can cross the border every day and experience the beauty of both worlds.

First for me, I lived the American dream migrating from Tijuana to San Diego and starting my own family. My first born child had a transfusion of blood with HIV in it in the mid 80's, participating in the first PACTG's and receiving the experimental drugs that gave him the opportunity to live 20 more years. Something that Tijuana/Mexico didn't have for children with HIV. Then my husband was diagnosed with brain cancer two years after the diagnosis of my son.

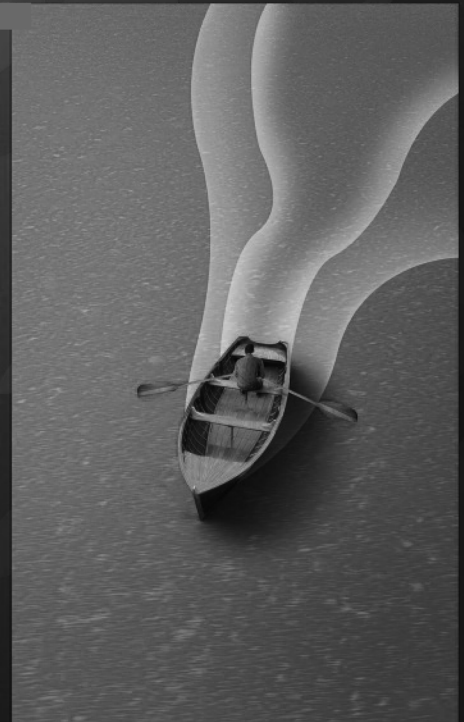
After my husband's loss, my career changed from administrative business into healthcare being the first Family Advocate for children and their families at the UCSD Mother, Child and Adolescent HIV Program. The first to start a Family Advisory Board for our program and to dedicate my life to making the difference for any child living with HIV/AIDS at the border of Tijuana San Diego, starting my own non-profit organization in my son's memory after he passed in 2009.

Growing up in an unhealthy environment, then watching movies that have both positive and negative outcomes and the outcome the individual wants to end in. In my life's migrations, I've found that it is the choice of reality one self wants to live.



MY MIGRATION STORY

Moving to Boston was nerve wracking and exciting all at the same time. I had been unexpectedly laid off my previous job and was living in Western Massachusetts. The choices were: Move back home with mom or move to a new location. The year was 2019 and I was already at an age where moving back with my mom, albeit economically helpful, would put my mental health at risk. The choice to move to Boston came from my close friends already living there. Their optimism for my success was very contagious and I made a leap of faith. Packed a uhaul while my best friend drove my car with my pets. The whole day of moving felt like an out-of-body experience Trying to lean into the excitement for change felt so far of a reach. I kept focusing on how I was spontaneously laid off, and hoping to somehow make ends meet. Months flew by with no job opportunity coming up. When one finally did, it was one I was overqualified for. But ends needed to meet and bills had to be paid. Years later, I wish I can go back in time to to let myself know that it will all work out. Just had to hold on to hope with whatever energy I had left.



Truly it is my season to be going through migration or change in my life and for me it is to remain healthy and provide myself some "me" time.

Symbolic Animals

CAB members discussed migration imagery. Below are several animals that CAB members identified as being personal symbols of migration:



Advice for Migration and Change

We asked CAB members to share their advice for how to cope with migrations and changes in life based on their experiences. The following pieces of advice were submitted by CAB members:

Be strong, be smart, be kind, be patient for the opportunities a change can bring to you. Changes are good if you take it in the best way possible. If you are optimistic good things will happen. Educate yourself and learn about the culture you are about to join.

The advice I would like to share is to stay focused and committed to any change that you may have.

Everything happens for a reason. You'll never have a challenge come up that you can't overcome.

Life is unexpected. There are twist, turns, unexpected circumstances that will happen. It is inevitable. However, keep looking into that long-term goal. The eye of the storm will come but it will also pass. Stay Positive.



BUT I'M HERE



You told me we must go
But I went the other way

You told me now's the time
But I wanted to stay

I didn't ask for help
You didn't want to hear

I thought it wasn't time to leave

But I'm here

It might have been your time
It didn't feel like mine
Not sure I had a choice
But I'm here
And I think I'm fine

I didn't want to go
You didn't want to stay
But I'm here now

Submitted by: A

PHACS MEMBER PROFILE

Karim Bermudez

Hi PHACS!

I am a research assistant at Westat. I joined the PHACS network in March 2021. During this time, I have had the opportunity to work with amazing people and learned a lot about the work that has been done on PHACS. As a research assistant, my role is to support the coordination of several committee meetings, the Community Advisory Board and HECC. In addition, I help with the updates to the PHACS website and support the development of the new and updated policies and procedures.

Before working at Westat, my professional career started in Puerto Rico. When I was in graduate school, I started working for the Department of Health as an evaluation consultant. During that time, I had the opportunity to work on different tasks such as developing reports of public health issues, participating in the Healthy People 2020 initiative to develop a strategic plan for Puerto Rico, and administering surveys on patient satisfaction with services in primary healthcare facilities. After working in the Department of Health, I started working in a health insurance company as a statistical analyst. During that time, my tasks were focused on developing reports about health care utilization. In addition, I had the opportunity to support the clinical areas of the company by providing metrics to assess their operational processes and created interactive dashboards for easy data visualization.

In 2019, my husband and I decided to move from Puerto Rico to Maryland with our 4-year-old son. This was not an easy decision, thinking about the language and being away from our family.

I was fortunate that shortly after arriving to Maryland, I started working at Westat (November 2019). The first project I worked on was a clinical trial to determine the safety and efficacy of a study drug for patients with parainfluenza infection. The project was conducted at 90 sites across 12 countries. At that project, I was responsible for assessing the quality of documents and uploading them into the electronic Trial Master File. In addition, I provided support with data entry and coordinated translation requests (given that the study was conducted in several countries).

After living in Maryland for one year, we had to move again because the weather in Maryland was not good for our son's health. We moved to Florida in the summer of 2020. In Florida, we love that the weather is similar to Puerto Rico, allowing us to spend time outside all year long.

In my free time, I love spending it with my husband and son. We love going to the beach, pool, going to the movies, building Legos (my son is a Lego fan) and riding roller coasters. In addition, I love seeing movies and series on Netflix.

My personal and professional journey has been defined by "migration." I had several jobs that allowed me to do different tasks and work with different people. Not only has it allowed me to learn different skills over the years, but it has also given me the opportunity to meet people with different cultures and points of view.



In addition, moving from Puerto Rico to Maryland was the most exciting, scary and challenging situation that I have experienced. Since our main language is not English, there is always the fear of not being able to communicate correctly. It was scary, as a parent, to know that our son was starting his school years in a place where most people speak English, even though he did not know the language at that time. Three years after our move, it is great to see how much I have learned from the experiences in this journey. I look forward to continuing to support the amazing work that is done at PHACS and keep learning from all of you!

Migration is Beautiful



Submitted by: Liz

RESOURCES

Black Emotional and Mental Health Collective:
<https://beam.community/>

HIV and COVID-19 Basics:
<https://www.cdc.gov/hiv/basics/covid-19.html>

Black Women's Health Imperative: Blogs:
<https://bwhi.org/blogs/>

10 Steps for Coping with a Chronic Condition:
<https://www.health.harvard.edu/staying-healthy/10-steps-for-coping-with-a-chronic-condition>

Self-Care Resource Center:
<https://www.apa.org/topics/working-psychologist/self-care>

10 Ways to Cope with Big Changes:
<https://www.psychologytoday.com/us/blog/here-there-and-everywhere/201701/10-ways-cope-big-changes>

UPCOMING EVENTS



August 29: National Faith HIV/AIDS Awareness Day

September 18: National HIV/AIDS and Aging Awareness Day

September 27: National Gay Men's HIV/AIDS Awareness Day

October 15: National Latinx AIDS Awareness Day

November 1-3: PHACS Leadership Working Retreat (Virtual)

December 1: World AIDS Day

CAB Glossary



Clinical Trials Network: A group of hospitals and clinics in different locations that cooperate to develop and conduct clinical trials. These trials may be related to preventing or treating a specific health problem. Participants from many different locations may enter the same clinical trial.

Financial Disclosure Form: A form that discloses any financial arrangement between the sponsor and the researcher. This is meant to document whether these financial arrangements could influence the outcome of the study, or vice versa.

Institutional Review Board (IRB): A group of professionals who must review and approve research plans. They review the research protocol, informed consent forms, study advertisements, and patient brochures to make sure the study is safe for humans to take part in.

Protocol Team: A team that develops the protocol and is responsible for oversight of its conduct.

Scientific Consultant: A scientist who provides expertise in a certain area. They may be asked to join a protocol team and/or to provide advice on a particular subject.

Source Document: The document where a participant's information is first recorded. This is the written proof that the participant exists and is eligible to enroll in the study. Examples of source data could be a patient's medical file or a hospital record.

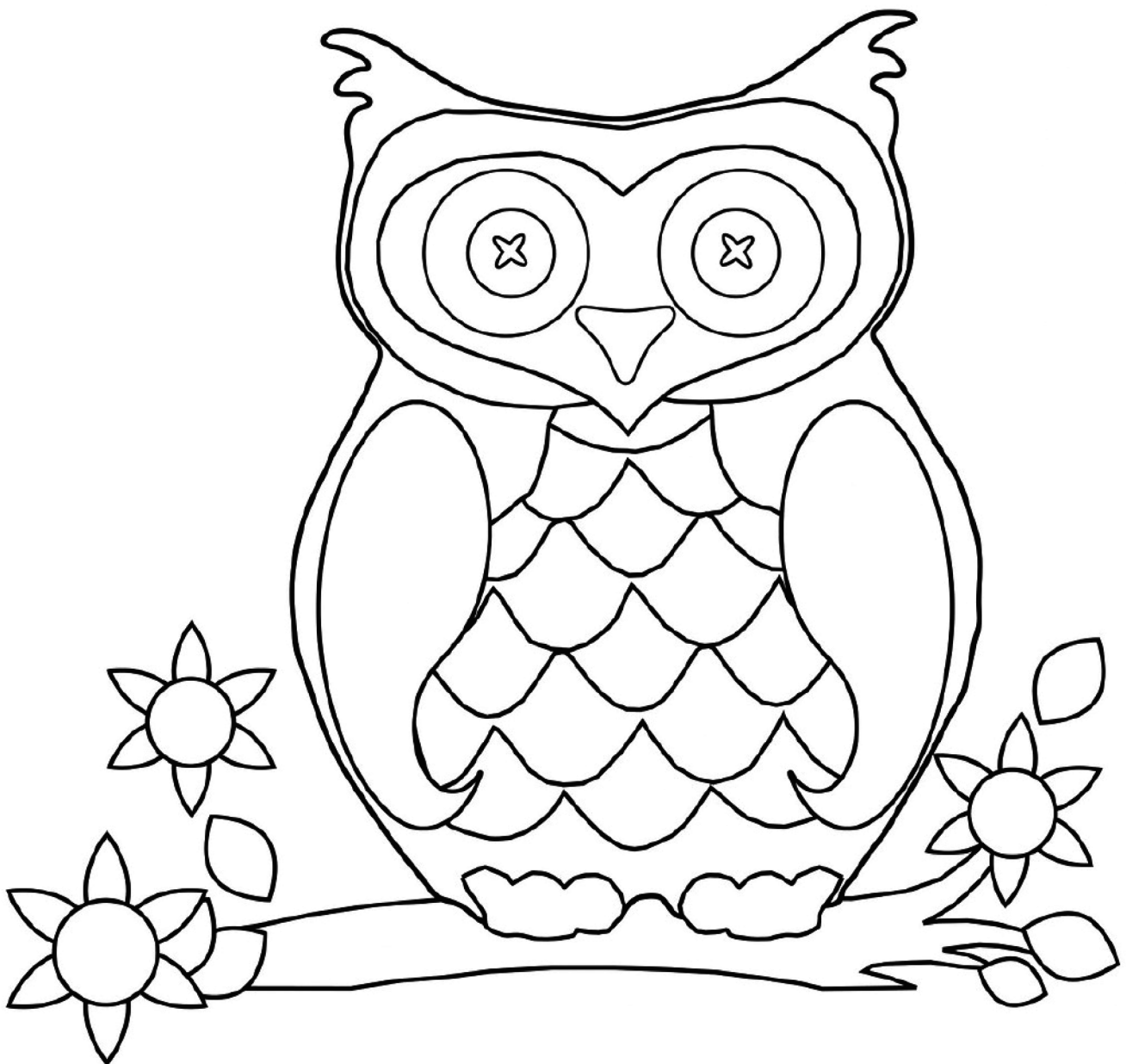
PHACS Teams Quiz

PHACS includes many Committees, Cores, and Groups. Test your knowledge about some of the different PHACS teams by answering the quiz questions below ([Answers on page 15](#)).

1. This Committee is responsible for monitoring the scientific integrity of the PHACS protocols, close examination of the data generated by those studies, and reviewing and evaluating focused substudies proposed for implementation within the PHACS network.
 - A. Site Evaluation Subcommittee
 - B. Scientific Leadership Committee
 - C. Operations Committee
 - D. SMARTT Committee
2. This Core provides oversight, support, and guidance to the Scientific Leadership Committee (SLC), which includes experts in various scientific disciplines.
 - A. Data Resources Core
 - B. Epidemiological and Statistical Methods Core
 - C. Health Education and Community Core
 - D. Scientific Administrative Core
3. This Core supports rigorous, specialized, and appropriate epidemiological and statistical methods in our research.
 - A. Data Resources Core
 - B. Epidemiological and Statistical Methods Core
 - C. Health Education and Community Core
 - D. Scientific Administrative Core
4. This Core provides operations, design, methodologic, and analytic expertise and supports the development of the PHACS research protocols.
 - A. Data Resources Core
 - B. Epidemiological and Statistical Methods Core
 - C. Health Education and Community Core
 - D. Scientific Administrative Core
5. This is a Core that supports the engagement of PHACS participants in all stages of the research process and health communication work.
 - A. Data Resources Core
 - B. Epidemiological and Statistical Methods Core
 - C. Health Education and Community Core
 - D. Scientific Administrative Core
6. This group is the governing body of PHACS, with overall responsibility for the scientific, fiscal, and administrative aspects of the project.
 - A. Leadership Group
 - B. Governing Group
 - C. Oversight Lead Committee
 - D. Head Unity Group

CAB KIDS

Instructions: Cut along the dotted line to remove the CAB Kids coloring pages.



CAB KIDS

Instructions: Cut along the dotted line to remove the CAB Kids coloring pages.



PHACS Teams Quiz

ANSWERS

1. B: Scientific Leadership Committee
2. D: Scientific Administrative Core
3. B: Epidemiological and Statistical Methods Core
4. A: Data Resources Core
5. C: Health Education and Community Core
6. A: Leadership Group

Please send all questions, comments, and suggestions for the
CAB Newsletter to HECC Leadership
(**phacs.hecc.leadership@fstrf.org**).