TRANSITIONS

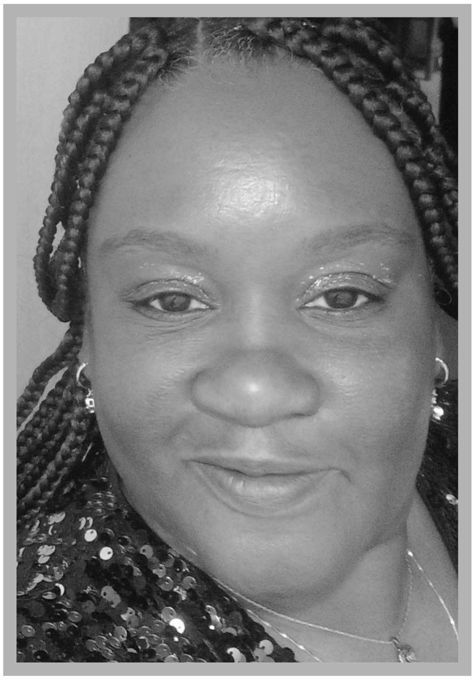
pHACS
Pediatric HIV/AIDS Cohort Study
A Study of the National Institutes of Health

A Community
Advisory Board (CAB)
Newsletter
published by:

The Pediatric HIV/
AIDS Cohort Study

INSIDE THIS ISSUE:

From Our CAB Chairs



Kimbrae, PHACS CAB Chair

Hello my fellow CAB members. I will not use the word goodbye; it will be “I will see you later.”

This newsletter is about transitioning and all the aspects of it. Transitioning can be good, but it also can be scary and painful at the same time.

I have a lot of emotions right now, and I’m sure you do too. One thing you should remember is, “Ain’t no mountain high enough, Ain’t no valley low enough to keep me from you.” I promise I will always be here with you and always be there for you. Know that each and every one of your voices made an impact on this wonderful research study, and I challenge you to take what you learned and go forth, and continue to be an advocate for the fight. Please be the phoenix that I see in each and every one of your hearts, and especially the fire that I see in your eyes.

Just like a phoenix, we will fight and continue to always be heard and make a place at the table. We will always rise from the ashes. Know this: you not only made change, but you are also a part of history. So well done, my faithful CAB members. Well done.

Exzavia, PHACS CAB Vice Chair

Here are some words Exzavia found inspiring and wanted to share!

Transitions of Our Journey

To my CAB family, with love we write,
The final pages, where dreams take flight.
A journey of hope, where hearts unite,
In this tapestry woven, we shine so bright.

Women with HIV, with courage so rare,
Pregnant with hope, with stories to share.
Parents and caregivers, with strength untold,
In the warmth of research, their truths unfold.

PHACS, our beacon, leading the way,
In knowledge and love, we find light each day.
Together we stand, a community strong,
Where every voice echoes a powerful song.

Community members, in unity we stand,
Professionals, advocates, with hearts in hand.
Social workers and specialists, hearts so pure,
Together we strive, together we endure.

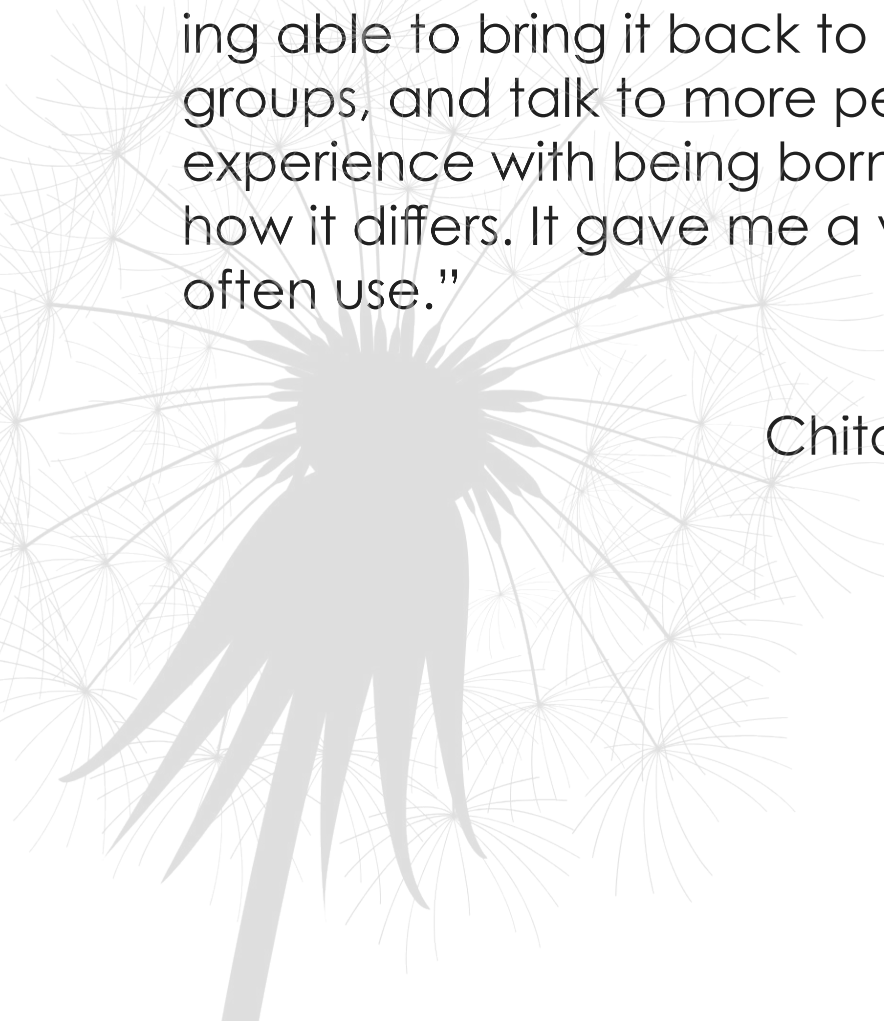
From PUG's peers, united in grace,
To YACAB's youth, each finding their place.
Health education, a radiant glow,
Guiding us forward through all we know.

The PHACS Film Series, like stars in the night,
Telling our stories, burning bright.
"Just the PHACS Digest," a treasured embrace,
Every word, a reminder of our shared grace.
As we transition, our journey's complete,
The bond we've nurtured, forever sweet.
A community that rises, hand in hand,
In love, in unity, we will forever stand.

TRANSITIONS

Transitions can be both exciting opportunities for growth and new experiences, while also challenging and bittersweet for losses that can be inevitable with change. How do we honor the multifaceted nature of transition?

“As a person with HIV, [the CAB is] a place where I belong, because my demographic of being born with it had been overshadowed. I have a story and it can be told, and I have people who can understand exactly what I’ve been going through. And that was amazing, and having that community was just so impactful and being able to bring it back to my own small groups, and talk to more people about my experience with being born with HIV and how it differs. It gave me a voice that I didn’t often use.”



Chitara

Hola! Heey Tu Si Tu!! Si eres VIH positivo resientemente oh ya tienes tiempo , no te desanimes ni tengas miedo Gracias A Dios Y A La Virgen Santisima! Que Ya Hay tanta tecnologia en la ciencia medica que avanzado mucho con nuevos tratamientos y nuevos medicamentos que puedes vivir una larga vida no pierdas La Fe no te desanimes Lucha Por tus seres amados por los que te quieren oh por los que no te quieren tambien talves necesitan un abrazo tuyo y no te as dado cuenta lucha.
Porti mismo que Vales Oro si estas aqui es por un proposito de Dios si te sientes triste decaida y sin esperanza llora grita patalea sonrie, pero levantate no te dejes caer que no estas sola hay tantas personas como tu y oh peores y tienen Fe Y Esperanza! Heey! Gracias A Dios Y A La Virgen Santisima Tengo 35 Años con VIH no ha sido facil pero Gracias A Dios Y A La Virgen Santísima por todos los avances en la ciencia medica que hay! Aqui estoy mi nombre no te lo doy porque no me conoces pero desde el Fondo de mi corazon te mando un fuerte abrazo!! Sonrie no desaproveches esa linda sonrisa tan bonita que tienes recuerda que es gratis. Sigue Adelante no te rindas jamas! Que Dios Y La Virgen Santisima Te Bendigan Protejan Y Acompañen Siempre En Compañia De Tu Bendecida Y Bonita Familia.

Hello! Hey you - yeah, you! If you were recently diagnosed with HIV or living with it for a long time, don't get discouraged or afraid. Thank God and the Blessed Virgin that there is so much technology in medical science that has advanced a lot of new treatments and medications that you can live a long life. Don't lose faith and don't get discouraged. Fight for your loved ones, for those that love you. Or for those that don't love you but possibly need a hug. We don't know. For yourself or for another a larger purpose, God willing, if you feel sad, down, or without hope; cry, scream, fight, or smile, but get up and don't give up. You are not alone, as there are many people like you or in worse situations. Have faith and hope. Hey! Thank God and the Blessed Virgin that I'm 35 years old with HIV. It hasn't been easy, but I'm grateful for the medical science that's available. Here I am. You don't know me but from the bottom of my heart, I send you a big hug. Smile and appreciate your beautiful smile; it's free! Keep moving forward and never give up. May God and the Blessed Virgin protect and accompany you and your beautiful family.

- Anonymous

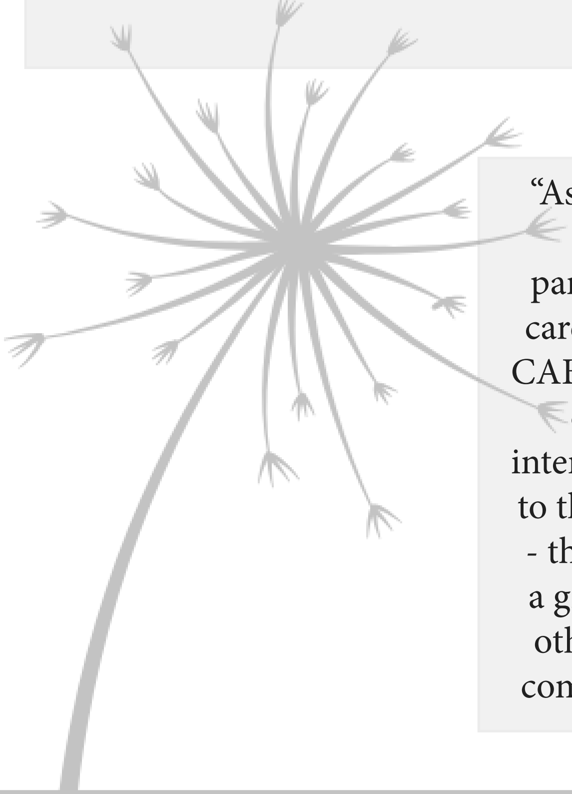
Your IMPACT

If you're **wondering about how much of an impact you've had by being part of the PHACS and HOPE community groups, here are some quotes from researchers and fellow community members** to illustrate just how much you have helped push positive change forward in a way that will carry on even after the studies end.

From our Researchers:

"The level of community engagement that took place during these PHACS years and as part of the PHACS project is incomparable. I can't imagine any other study doing what this study group has done. Often when we think about community engagement, we think about people living with HIV coming and giving a testimonial, but the level of integration of the community in every step of the research that we've done is truly phenomenal. It's the most incredible model I've seen, with our members shaping and guiding research in the right direction to ensure it meets the needs of the community. It's truly incredible and it makes me so sad that we're at the tail end of this. But I think they'll talk about this for years to come."

- Mariam



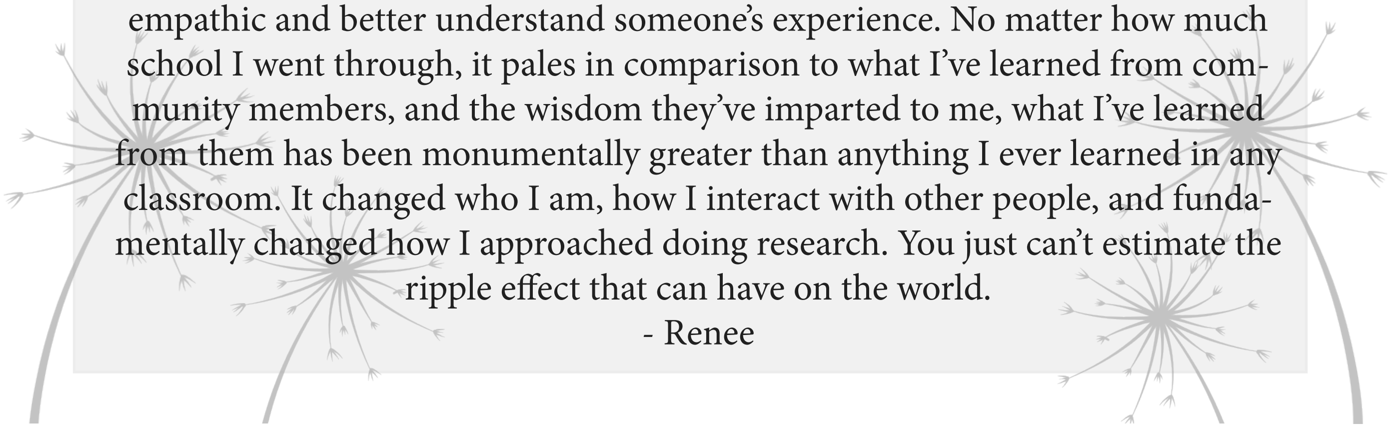
"As researchers, we know that participation in studies is also a selection process, meaning the people who participate are more likely to also be engaged in clinical care. The beauty of the HECC is that we also heard from CAB members who could talk to us about the experiences of people who were not in our studies, and how to interpret results for those folks, too. Beyond contributions to the science, I'm proud of how we created a community - the creation of the community not just in being part of a group, but where the group members are helping each other and supporting each other. Creating a supportive community is really amazing and so important." - Kunjal

"While working with the CAB and Task Force members over the last five years, I feel like I was able to become a better researcher by learning from their experiences and the wisdom they imparted…[in particular], the "Experiences of Discrimination" scales we explored to use in our surveys and how the follow-up question asked what the participant thought the reason was for that discrimination, with an option being "my race". One member pointed out that it's not their race that was the cause, but the perpetrator's racism. That seems so obvious, but it's something that I had overlooked and not even crossed my mind before then - how questions can be more appropriately and accurately phrased to not put the blame on the victim…Being part of this community really had an enormous impact on my personal and professional growth, and I'm sure these interactions will shape how I approach my work moving forward."

– Jessica

I've been working in pediatric HIV since shortly after the start of the epidemic, so I've seen the evolution of including community in research. The difference I felt is that while the research was always really interesting, when we began listening to community, it became interesting AND much more impactful. Our questions got better, because we were listening to what was a priority for the community. The way we asked our questions got better. How we interpreted findings got better, because we incorporated community input, so it went from learning a lot to also coming up with research that had a much more important impact on individual lives. And to be able to watch that evolution is the greatest gift of my professional career. And those lessons sink in - it doesn't just affect you professionally, it affects you personally. When you can listen to someone and their journey and they let you walk beside them and hear their stories, it's the biggest gift you can ask for because you're able to become much more empathic and better understand someone's experience. No matter how much school I went through, it pales in comparison to what I've learned from community members, and the wisdom they've imparted to me, what I've learned from them has been monumentally greater than anything I ever learned in any classroom. It changed who I am, how I interact with other people, and fundamentally changed how I approached doing research. You just can't estimate the ripple effect that can have on the world.

- Renee



From our Community Members:

"Being a part of the PHACS community has impacted my life in a good way. I am more thoughtful about my health. I am able to work with world-class professionals, and most importantly, I….contribute to medical research that will have impact on lives and generations to come."

"I really enjoy having a voice in subjects that affect those that are like myself or within the community of HIV. I enjoy being able to give a different perspective other than just a clinical perspective. I also cherished having the community feel."

"Being a part of PHACS has definitely helped me shed some of the stigma on myself that I didn't know I was holding. I was able to be open with my partner about issues in the HIV community and have been able to connect on a deeper level."

"It has allowed me to understand studies that I participate in better. They make sense and I don't see a bunch of scientists judging my lifestyle choices, but looking for ways to understand me."

"Before joining the Community Task Force, I used to be bashful about HIV and not be open to talking about it. Now I share all of my knowledge with my partner and mom and am open about sharing my opinions."

"What I love about the Task Force is the sense of knowing I am heard. It's like-minded people exchanging thoughts on matters that they are affected by."

"One of the most important things that l love about being apart of the Community Task Force is that I know that not only my voice is being heard, but my local CAB members' [voices] are as well."

A Final Letter to our Community

Dear CAB, PUG, Spanish CAB, HOPE CAB, and Community Task Force Members,

I am so grateful for every single one of you. I've known some of you for almost thirteen years—my entire time with PHACS—and some of you for a lot less time. But regardless of how long we've known each other, I have a deep and abiding love for each and every one of you.

Just by participating in research, you were already making a huge contribution towards improving the care for families affected by HIV across the world. But all of you have also stepped even further into the research world by being part of our community groups. You've dedicated countless hours to discussing the research protocols, online survey questions, and study procedures. You've helped identify the resources that other families at your site would want to have, and then you have worked to create them with us. That's how we created the Project Positive website, the HIV Disclosure Comics, the microbiome handout, the whiteboard videos, and our film series. You've presented on panels at PHACS and HOPE Network Meetings and at conferences to help researchers better understand the topics they're studying, like stigma, disclosure, transition to adulthood, and women's health. You've consulted with researchers when problems come up with data collection. Some of you helped lead a qualitative study on stress during pregnancy and motherhood. You've attended Working Group meetings and reviewed research proposals. You've done SO much, and it shows—our model of community engagement has been recognized as outstanding among research networks, and that's because of **you**. We quite literally could not have done it without all of you. And I know that you've done all of this with the hope of making the next person's experience a little better, of improving things for other families affected by HIV, and of helping researchers "keep the human in the data," as Kimbrae has said.

Most importantly, you shared of yourselves—your stories, your experiences, and your immense wisdom and insight. You have been incredible advocates, setting a beautiful example of how to lead with love, empathy, and genuine care for community. I know that if someone shares a difficult experience on a CAB call, it's only a matter of minutes before that person will get several texts and calls from other CAB members checking up on them and wanting to help somehow. Knowing all of you has changed me for the better in immeasurable ways. I truly don't know who I'd be right now without having had all of you in my life for these last 13 years, and I cannot thank you enough for allowing me to walk this path with you.

I know we are all disappointed about the way things are ending. It's not the way we wanted things to go. But as we mourn the pieces of our work that are being lost, I hope we can also have a Celebration of Life for the incredible times we've had together, and for the pieces that I'm sure will endure within each of us: our sense of community and love, of advocacy, and of constantly pushing for better things to come.
As Kimbrae often says, our group is like the mafia—once you're in, you're in for life. I really mean that. Please, please don't ever let yourself be strangers.

With deep gratitude, admiration, and love for you all,

Claire

Two poems by Nayyirah Waheed's book, *salt*:

Where you are
Is not who you are
-circumstances

There are feelings you haven't felt yet
Give them time.
They are almost here.

-fresh

RECIPE: NO-CHURN CHOCOLATE ICE CREAM

INGREDIENTS

- 1/2 cup dutch processed cocoa powder
- 1 can condensed milk
- 2 cups heavy whipping cream or heavy cream cold from the fridge
- ¼ tsp fine sea salt (just a pinch if you're using table salt)
- 2 teaspoons pure vanilla extract

Make delicious ice cream without a fancy machine!

INSTRUCTIONS:

In a small pot, add the milk and sift the cocoa over it. Add the sweetened condensed milk and salt then cook on low, whisking until smooth.

When it starts to steam, remove it from the heat, pour it into a bowl through a fine mesh sieve and set in the fridge for 2 hours to chill.

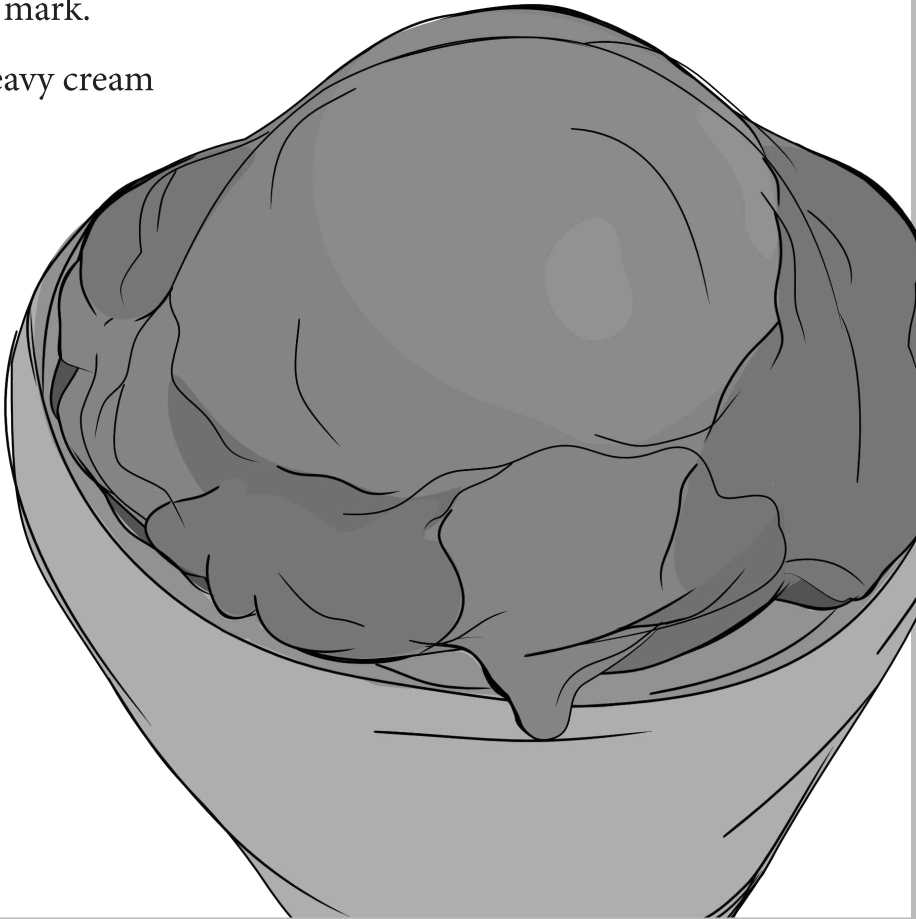
You can speed this up by placing it in the freezer for about 20 minutes, but don't let it freeze and stir it at the 10 minute mark.

Once it's cool, pour in the cold heavy cream and vanilla.

Use a hand mixer or a stand mixer fitted with the whisk attachment to whip the mixture to medium peaks. The mix will be thickened and airy.

Pour into an airtight container or into an open container and seal it with plastic wrap.

Freeze for about six hours. If the ice cream is too difficult to scoop, let it warm up for about 5 minutes on the counter.



2024 in Review: PHACS Spring Network Meeting

By Mandy Flores

The HECC kicked off a fantastic summer with the PHACS Network meeting on June 4th and 5th. Held in Rockville, Maryland, clinicians, staff, and community members across the network attended two days of lectures, presentations, and small group collaborations to celebrate the network's collective efforts over the past year and strategize initiatives for another successful year.


Dr. Ezer Kang (right) presenting at the 2024 PHACS Network meeting. Dr. Ellen Chadwick (left) listens in.

On the first day of the meeting, Dr. Ezer Kang presented a keynote talk, "Living into Adulthood with Perinatal HIV: Mental Well-being of Adults with PHIV" – speaking about the challenges for youth living with HIV in transitioning to adulthood, including navigating changing healthcare settings and social stigmas that can come with being an adult living with HIV. A panel accompanied the lecture, with members of the PHACS network, including our community groups, providing clinical and lived expertise on how to combat the challenges Dr. Kang spoke about and improve the care at sites. On the second day, Dr. Whitney Rice gave an interactive lecture on her mixed methods approach in research, speaking of the collective in utilizing both qualitative and quantitative to develop a more holistic picture within research.


Creative Project Assistant Sam Lynd in front of the HECC resource booth. Individuals could view the latest in HECC resources, including an animated lay summary!

The national CAB met for a day-long retreat on Monday, June 3rd. The theme of the retreat was "Where Next? Honoring Our Past, Current, and Future Selves" and focused on each individual's journey in health, advocacy, and beyond. The day was filled with wellness activities, including a meditation exercise led by Liz Salomon, lively discussions on improving the quality of care and CAB retention, and art activities and writing exercises. The retreat concluded with a visit from Drs. Deb Kacanek and Kate Powis of the HOPE study to discuss recent findings and provide input for areas of research interest.

The PUG also met for a retreat on June 3rd, centering around the theme "Project Positive: Enduring and Connecting." The day was filled with activities run by many of the members themselves, including a session on leadership qualities and skills, an HIV trivia game, and an art session focused on resilience utilizing Kintsugi, a practice of repairing broken pottery with golden glue. The PUG also concluded their afternoon with a scientific session with mPIs Ellen Chadwick and Paige Williams, and Drs. Deborah Persaud, Sean Brummel, Kunjal Patel, and Murli Purswani to discuss a range of topics from the state of HIV cure research to kidney function and ARVs.

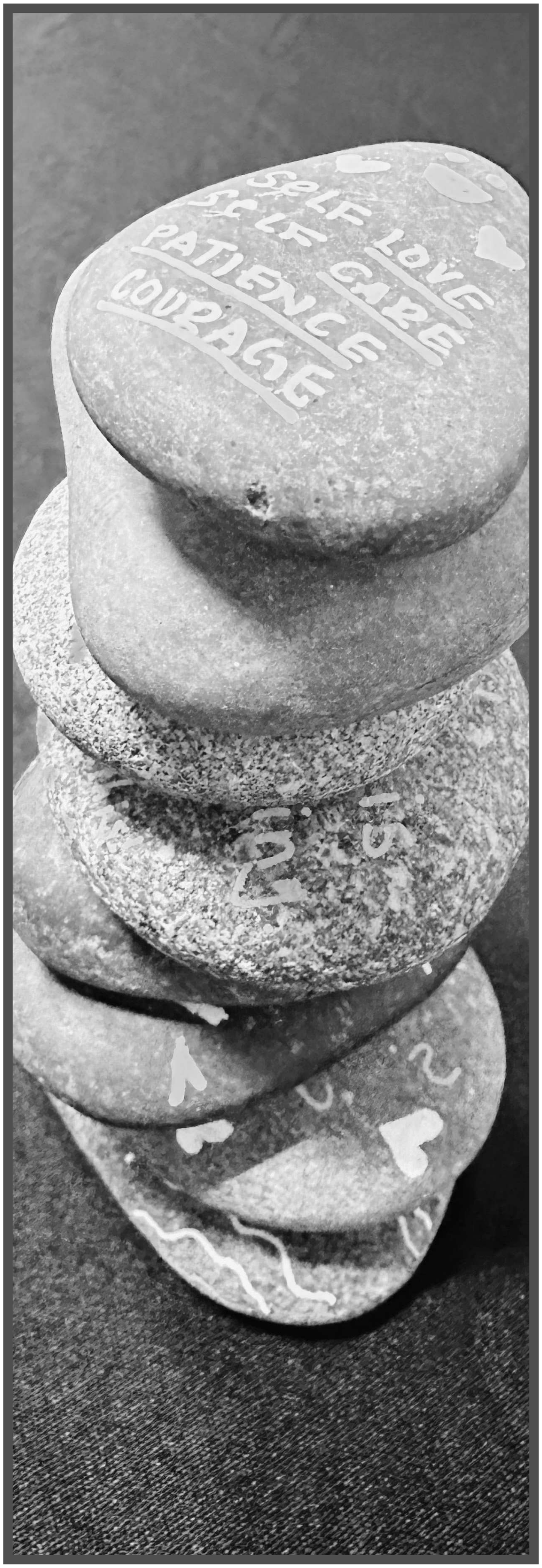
A particular highlight at the meeting was the soft launch of the HECC's newest resource, Project Positive, an interactive website melding the resources and research of PHACS within the greater context of HIV/AIDS research in the United States over the last 40+ years. Attendees were invited to explore the website and even compete for prizes in a Bingo game, finding facts embedded within the website.

FROM PHACS

The mission of the Pediatric HIV/AIDS Cohort Study (PHACS) is to

VISIT

ourprojectpositive.com



2024 in Review: HOPE CAB - A Retreat to Remember

By Renee Smith

The HOPE retreat in June hosted the first ever in-person meeting for the HOPE CAB, which started meeting in July of 2023. The HOPE CAB retreat was attended by 5 HOPE CAB members and its 3 CAB facilitators. HOPE CAB members joined the full HOPE team retreat and participated in the Language Matters panel presentation, the discussion on prioritizing emerging concepts in HOPE, and Kim led a panel with four CAB members to share personal stories behind the CAB's identified research priorities. The panel was moving, insightful, and earned a standing ovation from the room.

Other sessions attended by just HOPE CAB members included: "From Capsule to Manuscript: The Metamorphosis of Research," and two sessions where we created journals and HOPE bracelets as we discussed the topics of parenting neurodivergent kids, stigma, and self-care. There was also a time for CAB members to meet, get to know, and exchange questions and feedback with the HOPE leadership team. Overall, it was a wonderful opportunity for the entire HOPE team and HOPE CAB members to meet each other, learn together, and connect.

2024 in Review: The HECC Goes Abroad

By Claire Berman

I had the amazing opportunity last July to attend the 2024 International AIDS Conference in Munich, Germany and to present a poster on behalf of the HECC, PHACS, and HOPE. The theme of the AIDS conference this year was “Putting People First,” and that theme felt apparent throughout the sessions that I attended. The refrain throughout the entire conference was: trust communities to know the right solutions for them, and to implement those solutions.

Claire Berman in Munich, Germany, presenting the PHACS HECC poster at the 2024 International AIDS Conference

One highlight was of course the poster I presented on behalf of the HECC and all of the co-authors. Quite a few people stopped by to talk to me about it, including people from Argentina, Zambia, South Africa, Zimbabwe, and the US. An infectious disease doctor from Argentina actually hugged our poster because the HECC’s model is exactly what she’s hoping to implement at her own hospital!

There were so many sessions that it was impossible to take in even a fraction of them, but I spent very full days attending as many as I could.

Here are some of the highlights of my time there:

- The conference opened with a call that is music to the ears of anyone involved in PHACS: “Don’t forget about the kids!” This was reassuring to hear that they want everyone to remember pediatric HIV and the impact of HIV on children and families.

- Part of why the conference was held in Germany this year was because it is close to Eastern Europe, which is now the region with the fastest-growing rate of HIV in the world. There were many presentations focusing on Eastern Europe, including a spotlight on the war in Ukraine.

View the poster HERE or SCAN the QR code above.

- It was amazing to hear the results of the PURPOSE 1 study, which was conducted with young, sexually active women 18-25 years old in South Africa and Uganda. The study looked at the effectiveness of three different kinds of PrEP (HIV medicines taken to prevent HIV). They compared two different types of oral PrEP (in pill form) and a long-acting injection of the ARV lenocaprovir given once every six months. The exciting result was that the lenocaprovir injection every six months was shown to be 100% effective at preventing HIV in those women. That is: zero of the women who got the injection acquired HIV during that time! There are other PURPOSE trials taking place in other countries and with different populations, and we'll see what their results show in the coming months and years.

- Long-acting injectables for HIV treatment were a big topic as well. These have now been tested and shown to be effective in different populations, including pregnant people and people who are not virally suppressed. However, long-acting injectables were also the subject of many protests at the conference. While long-acting injectables can be life-changing for many, most of the world (especially poor and middle-income countries) cannot access them at all yet, even though they would benefit from having them. In many parts of the world, they are too expensive, and pharmaceutical companies holding the patent won't yet allow generics to be made. Fittingly, the slogan of these protests towards Gilead and other pharmaceutical companies was "Lives over Profit."

- At a pre-conference focused on kids with HEU (HIV exposure in the womb but uninfected), it was fascinating to hear a talk about the state of research on breastfeeding and how HIV is stored in breast milk, and how providers can counsel new moms living with HIV about decisions around breastfeeding their infants. One doctor from South Africa also shared the program her clinic has developed for a breastfeeding support group for new moms.

- I went to several sessions about HIV reservoirs in the body. HIV reservoirs are pockets of the body or internal organs where HIV can "hide out," even if a person's viral load in their blood is undetectable. One session I went to focused on how HIV can hide in the large and small intestines and lymph nodes.

- Many of us know the stories about the small number of people who have been "cured" of HIV; I had the incredible opportunity to hear one of them speak about his experience! Known previously as "The Düsseldorf Patient," Mark Franke is a German man whose HIV was put into remission when he got a stem cell transplant for his acute myeloid leukemia. This method of "cure" is not attainable for most people because it requires the incredibly invasive and dangerous procedure of getting a stem cell transplant; but, on the other hand, learning about which kinds of genetic makeup to look for in potential stem cell donors could give us clues about potentially developing a cure.

• I went to several sessions on HIV and communication. One was a panel of international journalists who report on HIV in their countries, and the way they carefully navigate being scientifically accurate with having strong human interest. There was also talk about navigating social media and HIV.

• There was an interesting session about Intergenerational Advocacy where advocates talked about how different generations can work together and learn from the wisdom that each group brings: the new, fresh solutions that youth bring with their perspectives, and the wisdom of the older generations from lessons learned along the way.

• There was a lot of talk about Artificial Intelligence (AI) and the HIV response, which feels like a brave and slightly scary new world! AI is opening up a lot of new directions in the HIV response, including in disseminating information about HIV.

• The Global Village represents so many facets of the community, with organizations from all over the world and representing so many different communities in one physical space.

• In conjunction with the conference, there was an exhibit at the Brandhorst Museum in Munich focusing on the works of Andy Warhol and Keith Haring, who was an American artist whose works centered around birth, death, love, sex, and war. After his own AIDS diagnosis in 1988, his works centered around AIDS awareness. The exhibit featured many of his works including the poster below, made in conjunction with ACT UP to call for greater public dialogue and action around AIDS.

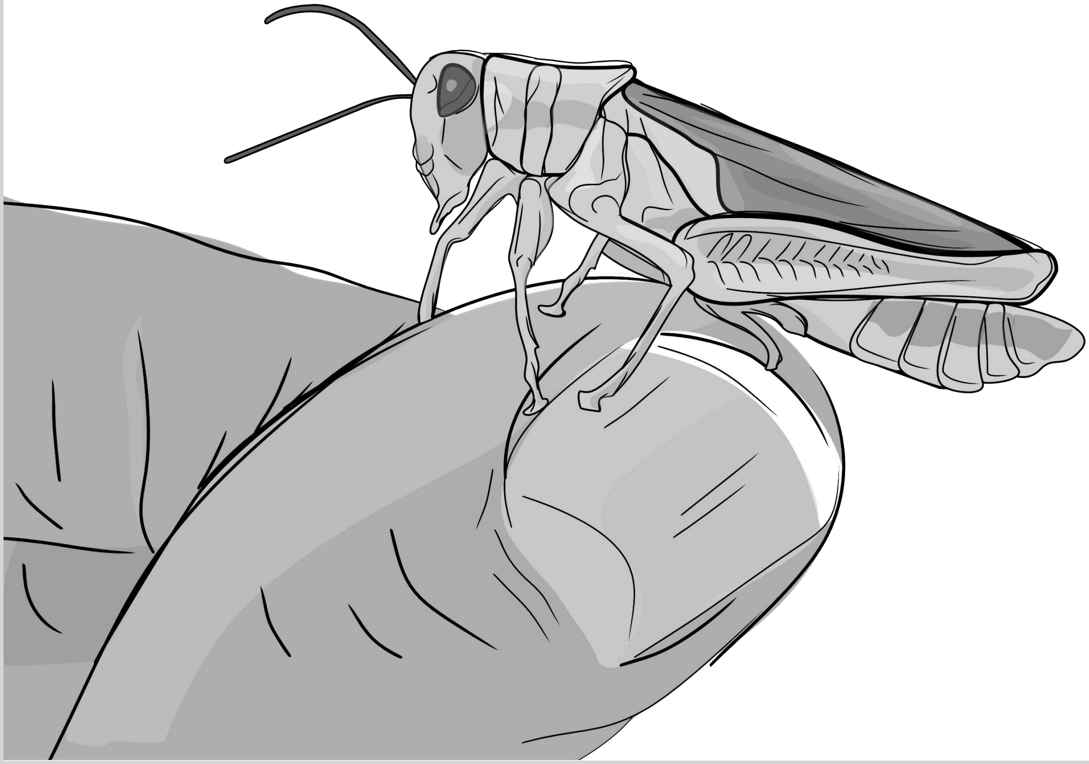
• Finally, the conference was full of protests and advocacy throughout the conference – there were protests about making long-acting injectables available to the whole world, not just the richest countries (“Lives over Profit”), protests advocating for trans rights, for the rights of sex workers (“Sex work is work!”), and reminders that “Communities are Experts.”

It was a truly enriching experience to be at the conference! I learned so much about the state of HIV research and the broader global community that continues to work so hard on the HIV response – and most importantly, about ways to follow the lead of community. Thanks to all of our community groups for bringing so much of yourselves to this work and our research.

The Summer Day

By Mary Oliver

Who made the world?
Who made the swan, and the black bear?
Who made the grasshopper?
This grasshopper, I mean—
the one who has flung herself out of the grass,
the one who is eating sugar out of my hand,
who is moving her jaws back and forth instead of up and
down—
who is gazing around with her enormous and complicated eyes.
Now she lifts her pale forearms and thoroughly washes her face.
Now she snaps her wings open, and floats away.
I don't know exactly what a prayer is.
I do know how to pay attention, how to fall down
into the grass, how to kneel down in the grass,
how to be idle and blessed, how to stroll through the fields,
which is what I have been doing all day.
Tell me, what else should I have done?
Doesn't everything die at last, and too soon?
Tell me, what is it you plan to do
with your one wild and precious life?

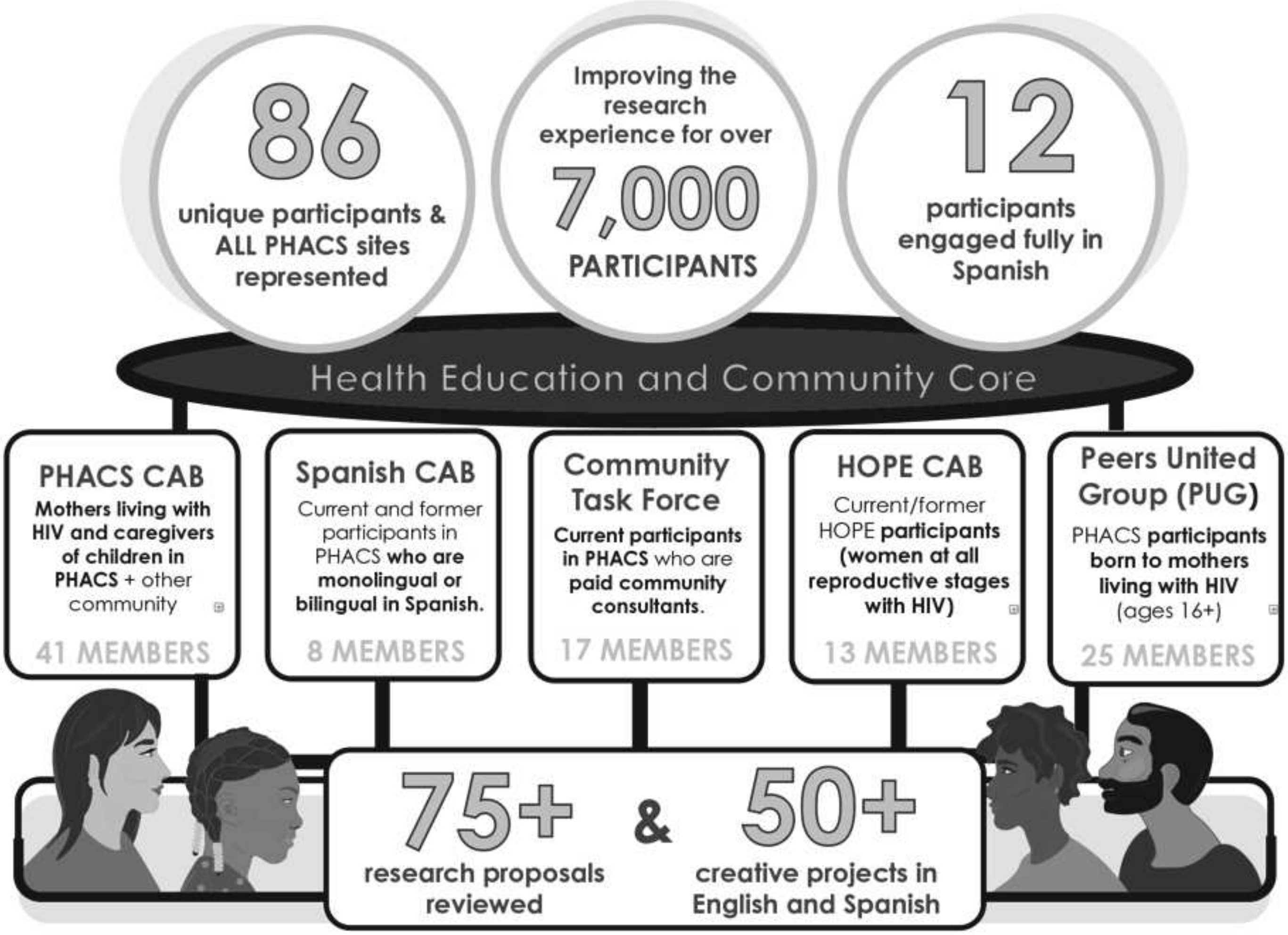


By the Numbers: Looking Back at Our Work Together

By Claire Berman

Over the last 13 years, we've had very impressive participation across our groups! We have had over 100 members across our groups, and 86 unique individuals have participated. All 86 of you have, in turn, been bridges between us and so many others at your local sites.

Many of you have shared with us what you hear from your local participants, and then you share with them what you learn from PHACS. Together, we have reviewed over 75 research proposals, providing critical input on a range of health topics and making sure that researchers are understanding how our participants actually experience these health issues, and what affects them. We have also created over 50 creative resources in both English and Spanish, guided by what you tell us our study participants need.



86
unique participants & ALL PHACS sites represented

Improving the research experience for over
7,000
PARTICIPANTS

12
participants engaged fully in Spanish

Health Education and Community Core

PHACS CAB
Mothers living with HIV and caregivers of children in PHACS + other community
41 MEMBERS

Spanish CAB
Current and former participants in PHACS who are monolingual or bilingual in Spanish.
8 MEMBERS

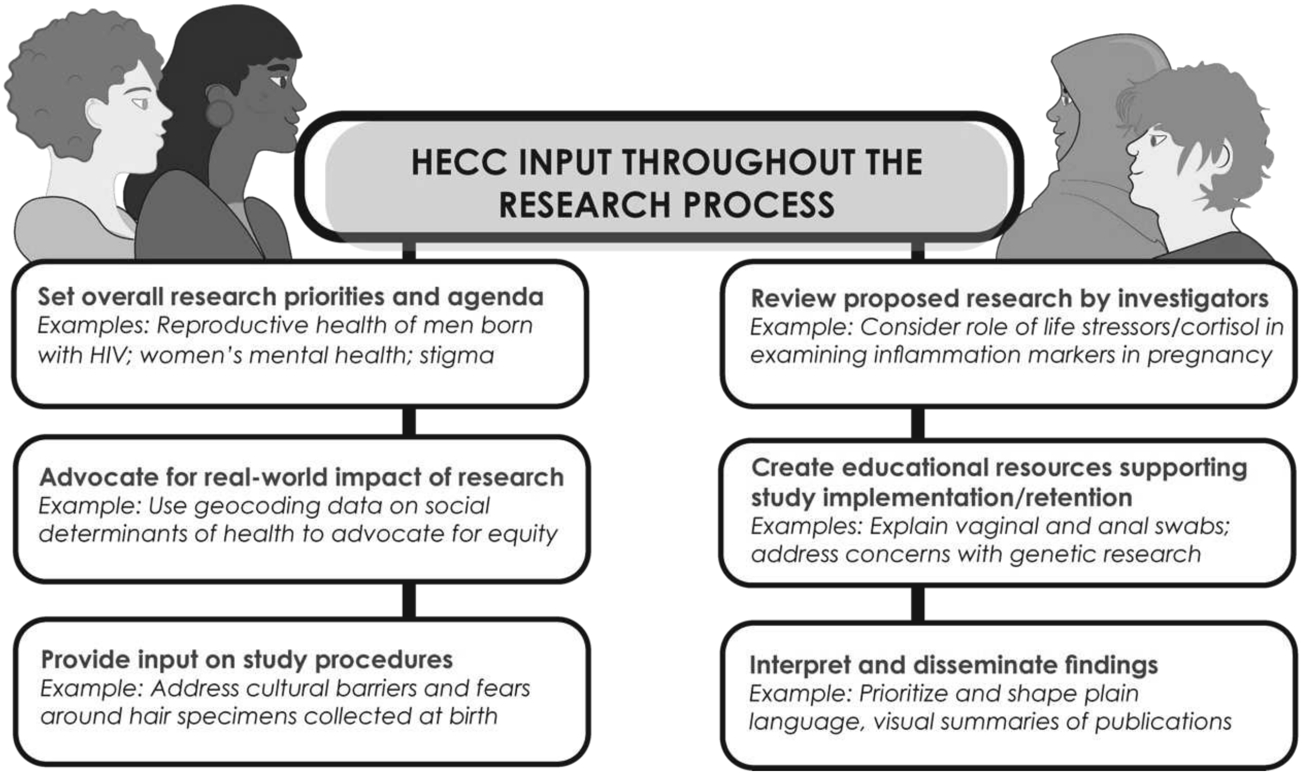
Community Task Force
Current participants in PHACS who are paid community consultants.
17 MEMBERS

HOPE CAB
Current/former HOPE participants (women at all reproductive stages with HIV)
13 MEMBERS

Peers United Group (PUG)
PHACS participants born to mothers living with HIV (ages 16+)
25 MEMBERS

75+ research proposals reviewed & **50+** creative projects in English and Spanish

Here is a graphic showing how you all have helped shape the research from start to finish in PHACS and HOPE:



HECC INPUT THROUGHOUT THE RESEARCH PROCESS

Set overall research priorities and agenda
Examples: Reproductive health of men born with HIV; women's mental health; stigma

Advocate for real-world impact of research
Example: Use geocoding data on social determinants of health to advocate for equity

Provide input on study procedures
Example: Address cultural barriers and fears around hair specimens collected at birth

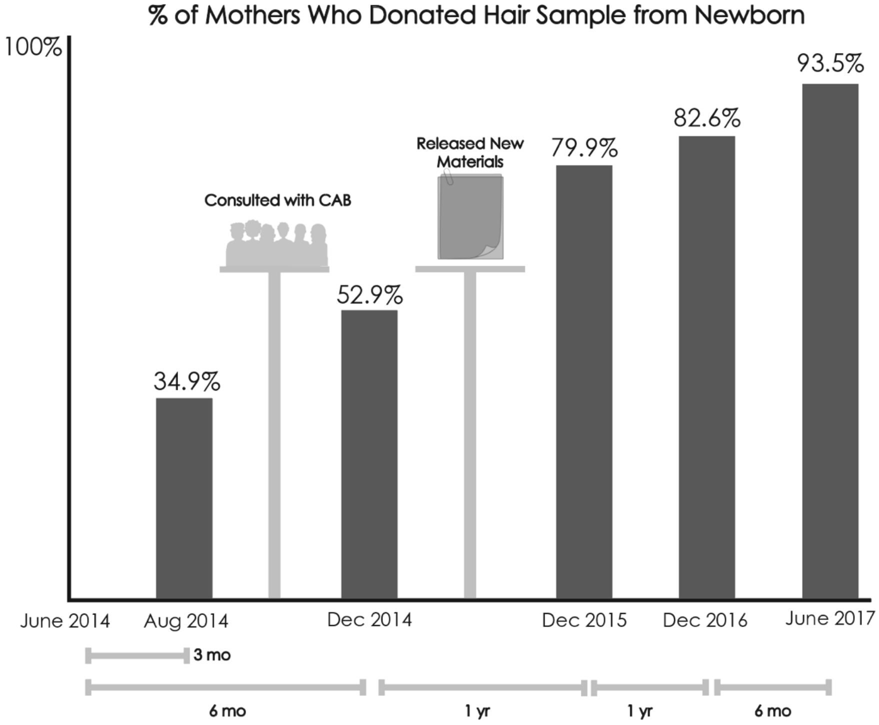
Review proposed research by investigators
Example: Consider role of life stressors/cortisol in examining inflammation markers in pregnancy

Create educational resources supporting study implementation/retention
Examples: Explain vaginal and anal swabs; address concerns with genetic research

Interpret and disseminate findings
Example: Prioritize and shape plain language, visual summaries of publications

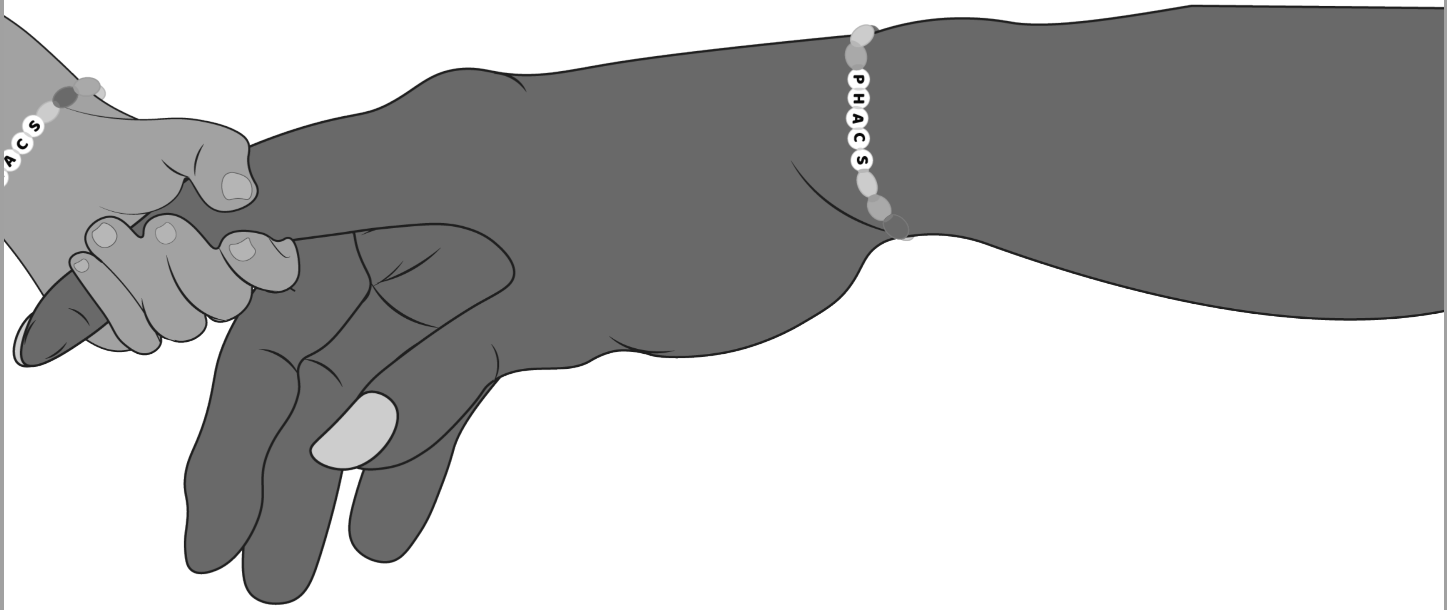
We don't often have data to demonstrate the CAB's impact with numbers, but many of you probably remember the hair collection study that began all the way back in 2014. Newly delivered moms were asked to donate 100 hairs from both themselves and their newborn so researchers could analyze them and understand how much medication babies were exposed to over the course of the pregnancy.

As you can see in this graph, in the first three months of data collection, only about 35% of moms were saying yes to this, and only about 53% in the first six months.


% of Mothers Who Donated Hair Sample from Newborn

Then, the researchers came and consulted the CAB. Why were so many moms saying no to this request for hair? You all had so many insights to share: Wouldn't moms feel like 100 hairs is a lot, and worry that people would notice their baby's hair missing? What would that look like for different types of hair? What about cultures where baby's first haircut is a big deal and doesn't happen until at least one year of age?

Using your insights, PHACS created new resources for introducing the topic and addressing these questions. And guess what happened? The number of samples donated shot up to 80%, 83%, and then 94%! This allowed researchers to get enough samples from moms and their newborns to publish findings around these research questions.



CAB GLOSSARY

Confounding Factor: Any characteristic other than the treatment that might affect the results of a clinical trial.

Department of Health and Human Services (DHHS): A cabinet department of the United States government, which oversees several key government organizations including the National Institutes of Health and the Food and Drug Administration.

Morbidity: Illness

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, neurological, neurodevelopmental, behavior, language, and hearing domains.

Good Clinical Practice (GCP): A standard for the design, conduct, performance, monitoring, auditing, recording, analysis, and reporting of clinical trials.

CAB WORD SEARCH

H	S	P	X	C	Y	R	I	L	L	N	E	S	S	H	C	X	H	R	U	M	W	L
B	E	H	A	V	I	O	R	Z	B	Q	C	T	C	A	A	R	D	Q	A	H	F	B
K	V	X	O	E	R	N	B	B	T	X	A	J	O	L	Q	C	Z	O	C	O	J	I
Y	C	X	Z	V	W	G	D	L	D	O	R	O	N	A	Z	B	I	Z	M	S	J	W
D	M	O	R	B	I	D	I	T	Y	L	D	W	F	C	M	O	O	G	Z	A	D	U
K	L	A	N	G	U	A	G	E	Q	Q	I	Y	O	I	Z	Y	R	Z	M	C	I	R
A	Y	H	T	W	O	R	G	I	P	R	A	S	U	N	P	Z	J	E	O	U	R	N
J	S	I	S	Y	L	A	N	A	D	O	C	T	N	I	P	R	A	H	N	H	P	T
A	G	B	K	M	B	U	S	S	D	C	J	Y	D	L	F	J	G	E	I	C	S	C
N	N	E	U	R	O	L	O	G	I	C	A	L	I	C	U	P	R	A	T	P	B	O
G	A	X	J	M	T	T	J	R	U	M	R	K	N	X	B	P	J	R	O	Z	D	W
J	F	P	I	O	S	U	O	U	M	U	Q	C	G	R	T	O	A	I	R	A	H	F
U	P	F	I	N	K	M	H	T	B	K	H	D	J	S	Q	B	G	N	I	V	O	D
G	K	M	U	I	J	U	T	M	E	T	A	B	O	L	I	C	I	G	N	J	U	V
K	F	H	B	L	D	R	G	L	K	P	H	Q	I	A	X	O	Z	R	G	N	H	V
S	U	P	N	E	U	R	O	D	E	V	E	L	O	P	M	E	N	T	A	L	W	O

ANALYSIS
BEHAVIOR
CARDIAC
CLINICAL
CONFOUNDING
DOMAIN
GROWTH
HEARING
ILLNESS
LANGUAGE
METABOLIC
MONITORING
MORBIDITY
NEURODEVELOPMENTAL
NEUROLOGICAL

CAB KIDS

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

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

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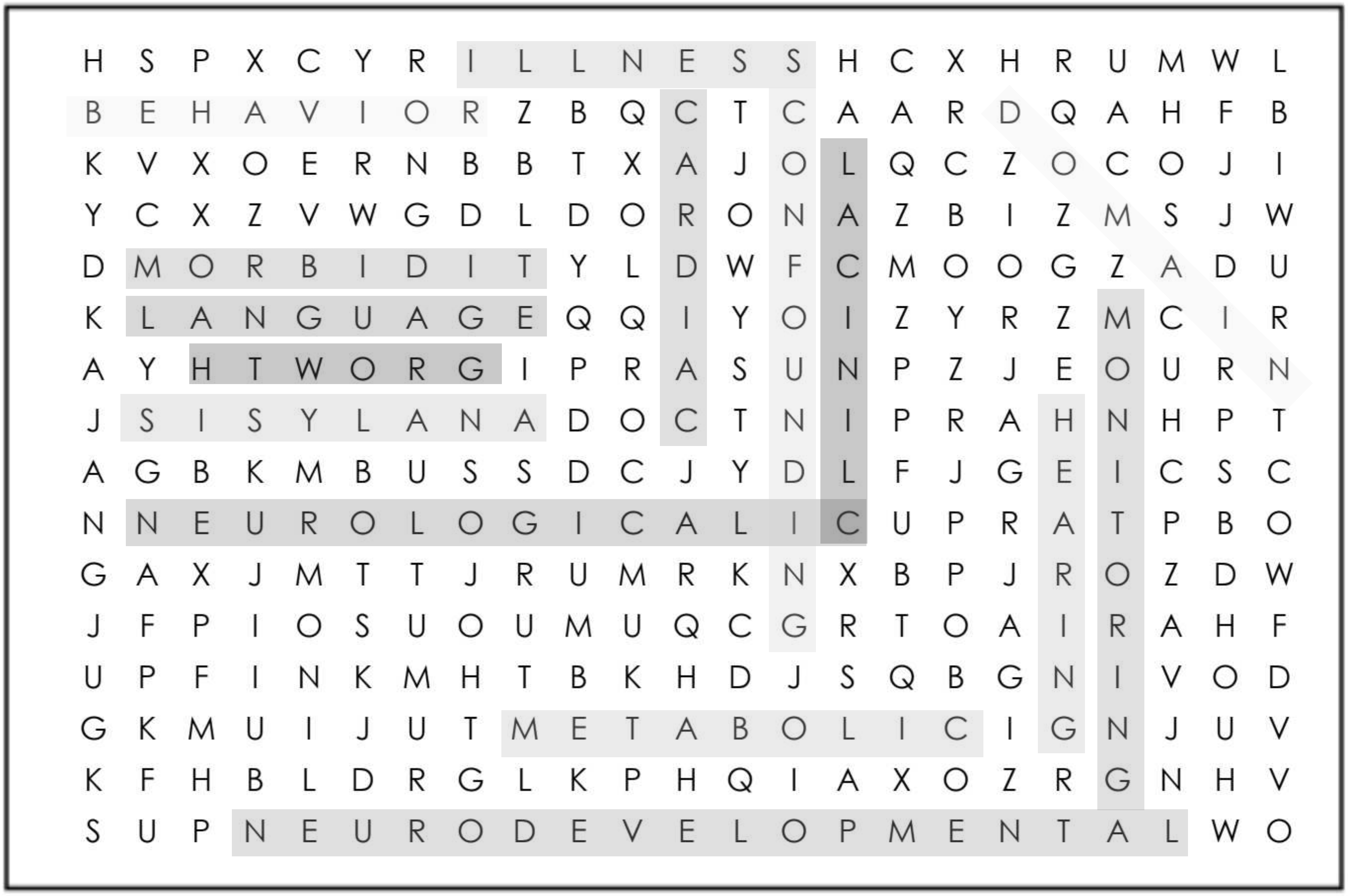
CAB WORD SEARCH ANSWERS



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K V X O E R N B B T X A J O L Q C Z O C O J I
Y C X Z V W G D L D O R O N A Z B I Z M S J W
D M O R B I D I T Y L D W F C M O O G Z A D U
K L A N G U A G E Q Q I Y O I Z Y R Z M C I R
A Y H T W O R G I P R A S U N P Z J E O U R N
J S I S Y L A N A D O C T N I P R A H N H P T
A G B K M B U S S D C J Y D L F J G E I C S C
N N E U R O L O G I C A L I C U P R A T P B O
G A X J M T T J R U M R K N X B P J R O Z D W
J F P I O S U O U M U Q C G R T O A I R A H F
U P F I N K M H T B K H D J S Q B G N I V O D
G K M U I J U T M E T A B O L I C I G N J U V
K F H B L D R G L K P H Q I A X O Z R G N H V
S U P N E U R O D E V E L O P M E N T A L W O
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DATES TO KNOW

National HIV/AIDS and Aging Awareness Day

September 18th

National Gay Men's HIV/AIDS Awareness Day

September 27th

National Latinx Aids Awareness Day

October 15th

World AIDS Day

December 1st

RESOURCES

Unlock free resources with your library card

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https://www.overdrive.com/apps/sora/