

**A Community
Advisory Board
(CAB) Newsletter
published by:**

**The Pediatric HIV/
AIDS Cohort Study**

BUILDING BRIDGES



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FROM OUR CAB CHAIRS

Kimbrae, PHACS CAB Chair

What is a bridge to another human being? Recently I experienced something that when I heard the opinion of one it shook me to the core to the point I was in tears for days. I even started to doubt myself as well as the planks of the bridge that I have placed for the last 13 years while advocating with PHACS. But what I found was I was not the only one placing the planks of wood and I wasn't the only one building a bridge. Us caregivers sometimes need to have care and be shown love and the overwhelming support I saw just reunited the fire of the Phoenix.

I always said that PHACS is a big wheel inside of a wheel. Most important, there is no I in team, but there is one in family. We have to always remember that if we're building a bridge to each other as human beings first, our colleagues, and our families then we first have to realize that just like the letter I in family we will always represent individual. Each individual in PHACS has a purpose, none greater than the other, but they are all special in every way. The next time when you think you are alone, I am living proof that you are not, and I know how special and loved you are in this organization. So continue to build the bridges with your colleagues, your staff, your participants, and most important each other in CAB/PHACS, no matter what your role is. I will leave it with this: if no one has told you today I will tell you you are special and never let anyone clip your butterfly wings. But by chance, if it does happen just remember you are a Phoenix and you will rise again to be a powerful force to be reckoned with.

Exzavia, PHACS CAB Vice Chair

Hello to all of my extended family members (PHACS), both the PUG, CAB and Researchers. Building Bridges is like connections from city to city. The PHACS Network has allowed us to use our voices, share the knowledge and information from every site that participates in research while bettering the lives of the children and families that are infected or affected by HIV. Building bridges has paved the way for many of us and will continue to do so as long as communities and researchers work together. Creating new connections is meaningful because it starts a healing process for so many that may be afraid, embarrassed or just confused on how to live or deal with HIV. No matter the distance, in the PHACS network, friendship is the show of support, encouragement and the welcoming environment that says “you can” and makes you feel safe and welcome to be who you are no matter what we face, by facing it together.

It was a pleasure to get to see everyone in person after all we have been through in the previous years. I’m looking forward to all of the new endeavors that we will partake in moving forward by putting our thoughts and ideas together to continue to help PHACS better the lives of many that will come.

Love You all, Your Vice Chair, Exzavia



BUILDING BRIDGES

Read below for stories about the importance of new connections and friendships!

How has your community helped build you up and ground you in an unpredictable world?

Making new connections and friends as an adult is difficult. Along with everything else going on and our own responsibilities on top of that. I was lucky to have made a friend who invited me to their community. It has made the city life feel more like home, instead of feeling like I want to move again. Suddenly a place that I thought was insufferable has felt like home.

- Anonymous

The world can feel so overwhelming at times, especially when it comes to making new friends as an adult. But sometimes in the most unlikely places you can find your community. It was at one of my most challenging jobs, one in which I sold overpriced shoes to very impatient and cranky customers, that I met some of my best friends.

Sharing baked good, tips on how to do taxes or call a doctor's office, we supported one another when times got tough, both on and off the sales floor. One could say, we built our community among a sea of stinky feet and sweaty socks! Today, we all no longer still work for the company, and some of have moved to different cities and states, but we continue to support one another as we pursue new jobs and stages in life.

- Anonymous

RECIPE: Black Bean Burger

Even as a passionate meat eater, these black bean burgers have quickly become one of my favorite recipes! I was first introduced to the burgers during the first summer of COVID, when restaurants were selling off their canned reserves, and we needed to find a use for 6 pounds of canned black beans! (Don't worry, the recipe does not call for that many beans!)

Tasty and spicy, one of the secrets to the recipe is the pickled red onion topping! (See recipe on [Page 6](#))

INGREDIENTS:

- 3 cups cooked black beans, drained and rinsed
- 1/3 cup grated yellow onion*
- 2 garlic cloves, minced
- 2 chipotle peppers from a can of chipotles in adobo, diced, plus 2 tablespoons adobo sauce
- 1 tablespoon tamari
- 1 tablespoon balsamic vinegar
- 1 teaspoon cumin
- 1/2 teaspoon sea salt
- 1/2 teaspoon black pepper
- 1 egg
- 1 cup panko bread crumbs
- Extra virgin olive oil for brushing
- Cooking spray, if grilling
- Hamburger buns and desired fixings for serving**

***Grate the onion on the large holes of a box grater. As you grate it, the onion will release a lot of liquid.**

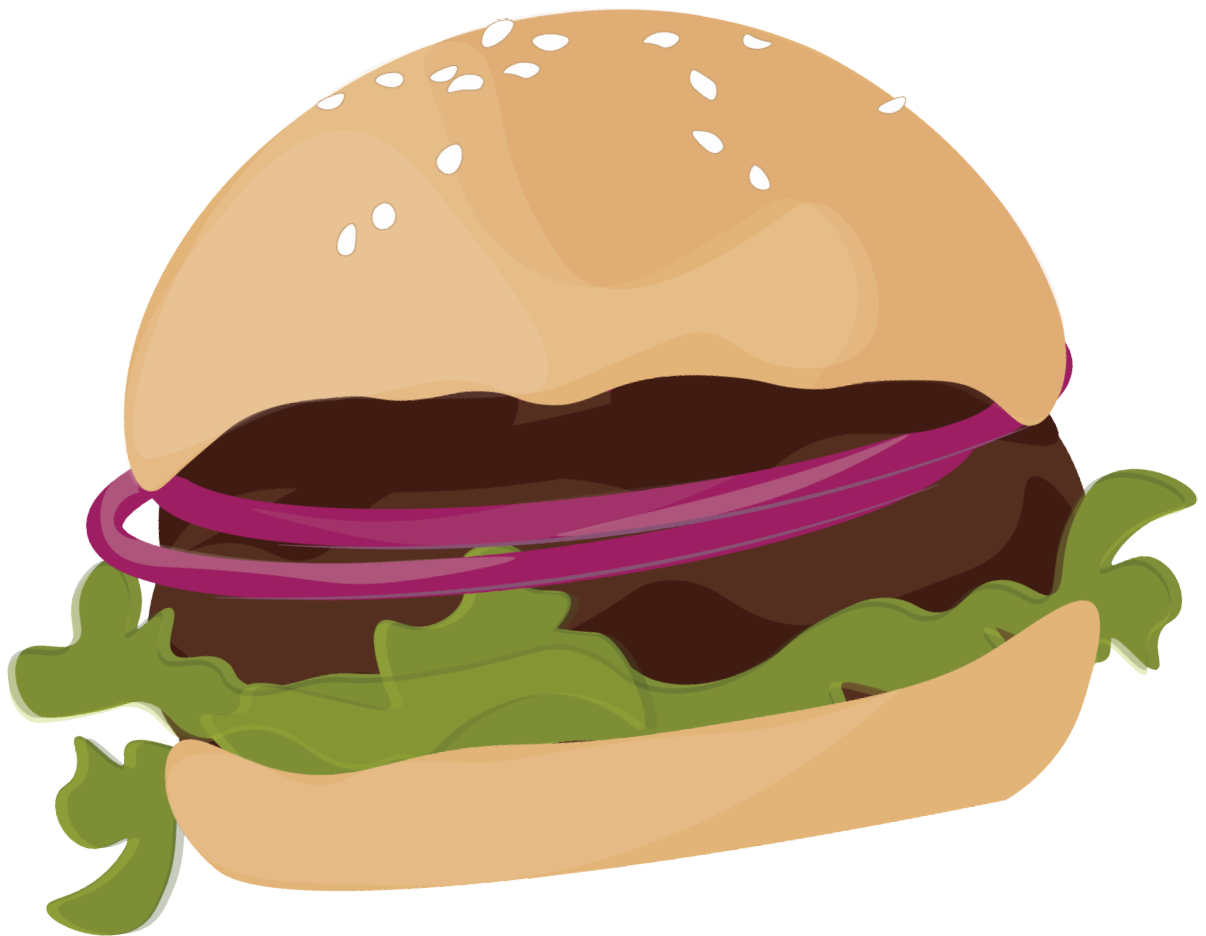
That's normal!

**** Avocado and/or grilled mushrooms are great fixing options for the burgers!**



DIRECTIONS:

1. In a large bowl, combine the beans, onion, garlic, chipotles, adobo sauce, tamari, balsamic, cumin, salt, and pepper. Use a potato masher to mash until the mixture holds together but still has some visible chunks of black beans. Add the egg and use a spatula to fold until combined. Then, fold in the panko.
2. Use your hands to form the mixture into 6 patties. The mixture should be cohesive and a little wet. If it's too wet to handle, chill in the fridge for 20 minutes to firm up or mash your beans a little bit more.
3. Heat a cast-iron skillet over medium heat. Brush with a little oil and cook the burgers for about 5 minutes per side, until charred on both sides, turning the heat down as necessary. The exact timing will depend on the heat of your stove and cookware.
4. Alternatively, preheat an outdoor grill to 400°F. Lightly brush the patties with olive oil, spray the grill grates, and grill for 8 minutes on the first side and 4 minutes on the second side.
5. Serve with hamburger buns and desired fixings.



Recipe Source: loveandlemons.com

RECIPE: Pickled Red Onions

INGREDIENTS:

- 2 small red onions
- 2 cups white vinegar
- 2 cups water
- 1/3 cup cane sugar
- 2 tablespoons sea salt

OPTIONAL:

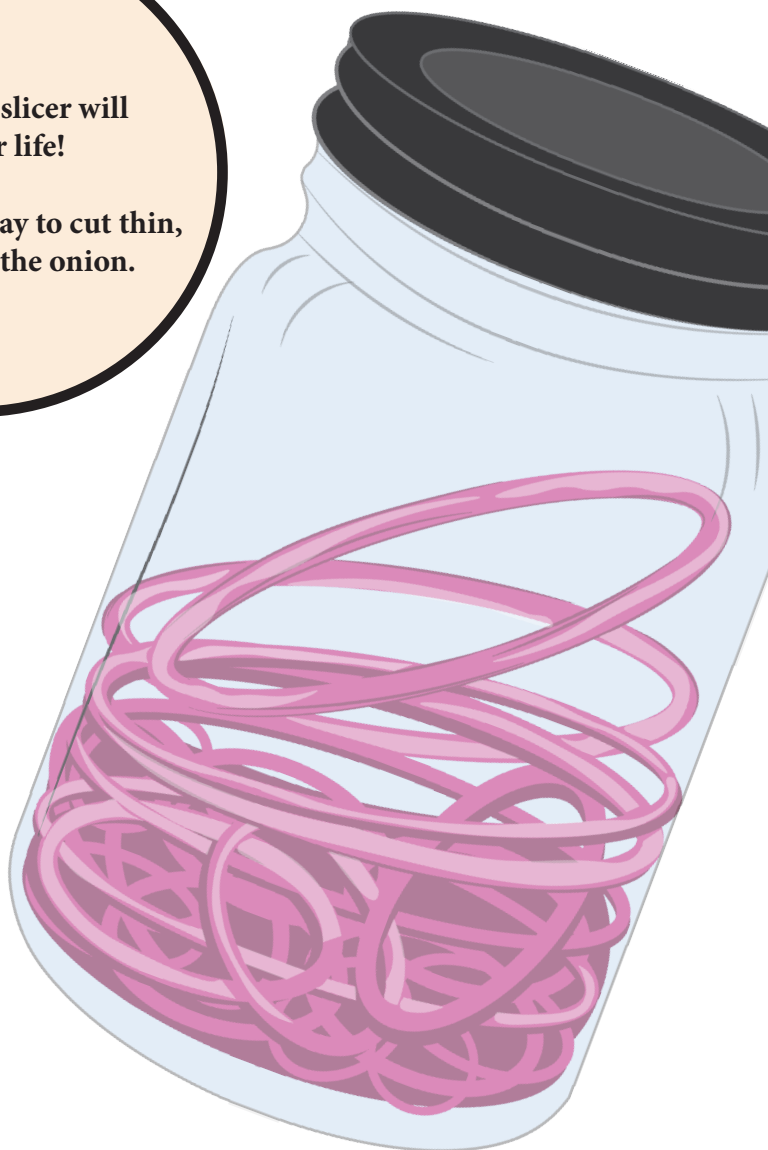
- 2 garlic cloves
- 1 teaspoon mixed peppercorns

**A mandoline slicer will
save your life!**

**Quick and easy way to cut thin,
even, slices of the onion.**

**You will need at least two 16oz
or three 10oz mason jars to pickle
and store.**

**I love to use old
pasta sauce jars!**



DIRECTIONS:

1. Thinly slice the onions (it's helpful to use a mandoline), and divide the onions between 2 (16-ounce) jars or 3 (10-ounce) jars. Place the garlic and peppercorns in each jar, if using.
2. Heat the vinegar, water, sugar, and salt in a medium saucepan over medium heat. Stir until the sugar and salt dissolve, about 1 minute. Let cool and pour over the onions. Set aside to cool to room temperature, then store the onions in the fridge.
3. Your pickled onions will be ready to eat once they're bright pink and tender - about 1 hour for very thinly sliced onions, or overnight for thicker sliced onions. They will keep in the fridge for up to 2 weeks.

Recipe Source: loveandlemons.com

PHACS MEMBER PROFILES

SAM LYND (HE/HIM/HIS)

PHACS CREATIVE PROJECT ASSISTANT

My name is Sam Lynd, I'm from Rochester, New York and I am joining the PHACS team as a Creative Project Assistant! I am working on projects like the Coco coloring pages! I graduated from the Cleveland Institute of Art in 2022 with a degree in Biomedical Illustration. I specialize in scientific drawings, animations, and 3D models for educational purposes.

My personal interest is specifically patient education that focuses on breaking down complex topics for a lay audience. I also focus on making my work accessible through picking dyslexic-friendly fonts, and including subtitles with all of my content that includes sound.

I found PHACS through an online job posting and thought that my interests in education and accessibility aligned with the core values at PHACS and I've thoroughly enjoyed my first few months! I have primarily been working on the Coco coloring pages from conception through design and I can't wait to see colored versions once they're released!

When I'm not working, I enjoy nature walks, reading, listening to podcasts, playing Dungeons and Dragons, and I'm currently working towards my black belt in Issyn-Ryu karate. I have a cat named Parker, after Peter Parker, who loves cuddles and interrupting Zoom (usually he interrupts the calls to ask for cuddles haha).

If you'd like to see more of my work, I have an online portfolio available at samlynd.com



AUGUST

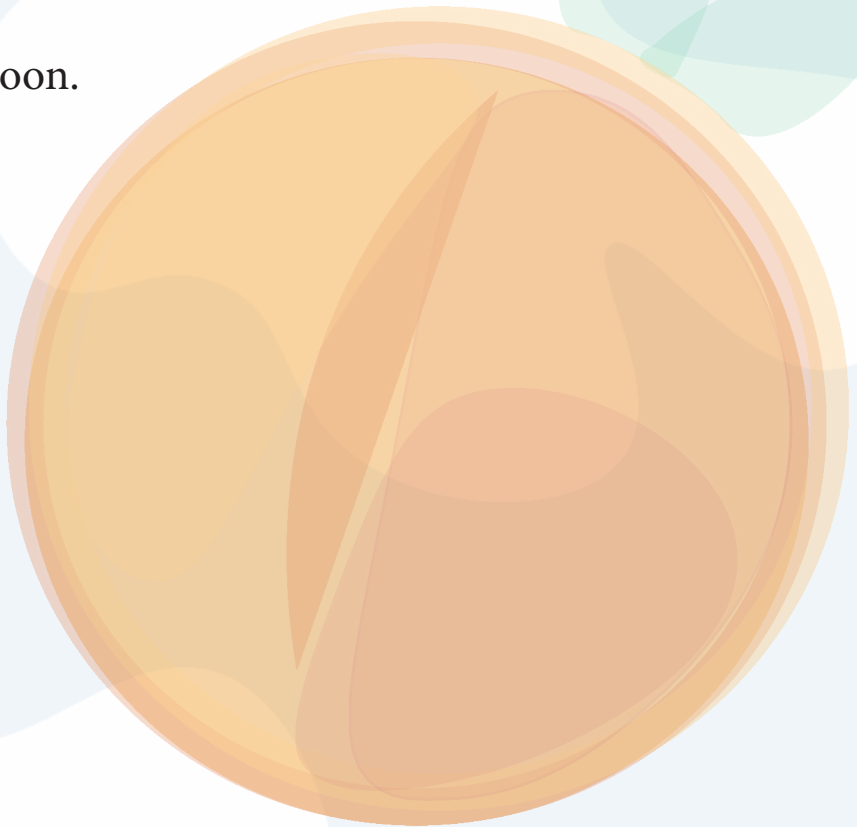
By Federico García Lorca

August.

Facing the sunset
peaches and sugar,
and the sun inside the evening
like the stone in a fruit.

The ear of the corn holds intact
its hard yellow laughter.

August.
Children eat
dark bread and tasty moon.



SPOTLIGHT


Launching the National Spanish-Speaking CAB

As a nationwide network with ever-growing community engagement within our studies, it is essential to create spaces that are accessible to all our members. After speaking to community members and study coordinators from our clinical sites across the country, it became clear that with a robust and growing Spanish-speaking population in PHACS, more safe spaces for Spanish speakers to converse openly and freely were a priority to the network. Thus, the Spanish-Speaking CAB, or CAB en Español, was born!

The CAB en Español will operate nationally and is open to participants in SMARTT or AMP Up throughout the US and Puerto Rico. Whereas the current national CAB is held entirely in English, all meetings and activities for the CAB en Español will be held entirely in Spanish. This space will be a welcoming space for both monolingual Spanish-speaking PHACS participants as well as other participants who feel most comfortable conversing in Spanish. The CAB en Español will operate adjacent to the current CAB in English, working on similar community advocacy and engagement projects while addressing needs unique to Spanish speakers, such as navigating healthcare systems in different languages. The group will meet virtually once a month.

While the group is still in development, we are excited that Eduardo Vergara (Harvard T.H Chan School of Public Health) and





Karim Bermudez (Westat) are slated to operate as liaisons and co-facilitators for the group. Eduardo has been with PHACS for over two years, including collaborating with the HECC's Spanish-speaking Task Force members. He has shown an immense passion for community building; "I am excited to continue my community involvement with PHACS through this project. There are so many opportunities that we can provide our participants through active engagement and bridging the accessibility gaps of language barriers."

Karim has been working at Westat since 2019 and works closely with the HECC and Spanish-speaking Task Force members, translating PHACS materials into Spanish and soliciting feedback; "I am very happy to have the opportunity to work on this project. It is important to understand the unique needs and experiences of Spanish-speaking participants in PHACS."

Enrollment for the group is anticipated to begin this September. We are so excited by our growing engagement opportunities at PHACS, made possible by dedicated community members and staff.

SPRING ACTIVITIES: USC CAB

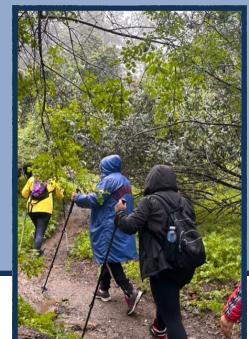
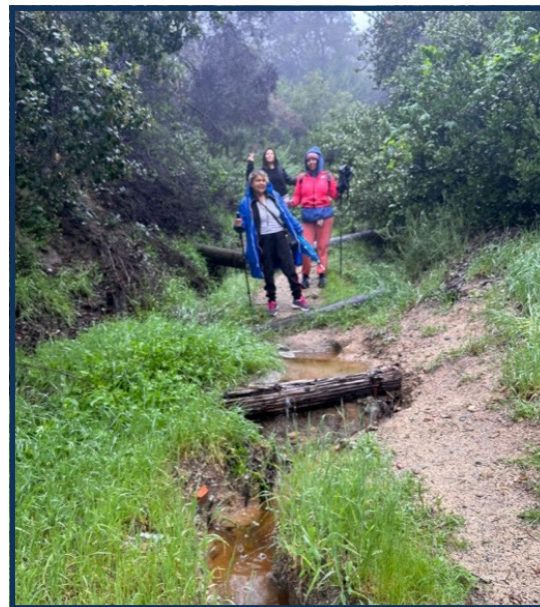
MCA* Spanish-Speaking CAB at University of Southern California

*Maternal Child and Adolescent/Adult Center for Infectious Diseases and Virology

The community involvement in the area of HIV/AIDS is important because the engagement in the community helps the group to develop and implement interventions and resources that community will be receptive to. One strategy that our local Spanish-Speaking CAB (SCAB) at USC has used to promote this engagement is working as liaisons between the community and the institutions. One of the outcomes due to this liaison work has been some community events.

The SCAB Spring events focused on education and wellness. The SCAB organized the National Women & Girls HIV/AIDS Day celebration in two days: one day focused on wellness (Hiking Day) and the second centered on education (Dinner Day). Although, during the Hiking Day it was raining, the participants were not afraid of the rain and had so much fun together playing and hiking under the rain. During the Dinner Day, the participants received current information about Women & HIV while they were eating dinner.

Continued on page 12.



Additionally, the SCAB works together with other institutions in organizing events to support the well-being of women with HIV/AIDS well-being. The SCAB assisted the Los Angeles Women's HIV/AIDS Task Force on the events they organized. The SCAB invited and participated in the Mother's Day Brunch which was only for mothers and daughters and the Women's Wellness Summit that was an event only dedicated to prioritizing work-life balance. It was a day where participants really unplug from their daily activities and relax.



SPOTLIGHT

HOPE CAB

The first meeting of the new HOPE CAB was held on Thursday, July 20th! The call was attended by five participants from four different HOPE sites, and co-facilitated by Kimbrae Sanders, Renee Smith, and Claire Berman. It was a wonderful first meeting, held virtually via Zoom. One person even joined us right as she was leaving her very first HOPE visit! We heard a story from Kimbrae about her own journey to advocacy, got to know each other a little bit, and discussed some feedback about the HOPE study visits - including the positive experiences that several folks had had at their study visit and some questions about some elements of the study visit and what researchers hoped to learn from that data.

Our second call was held on Thursday, August 17th, and 5 people from 4 sites attended. We had a very lively discussion providing feedback on HOPE's first capsule on using wearable devices to track sleep and physical activity in HOPE participants. Both calls have been so rich with insights from everyone. Oh, and we may have had a few belly laughs along the way from our silly icebreakers! The group offered some wonderful feedback about the first two meetings as well, with several people sharing that it "already feels like a family." The space truly felt affirming and uplifting, and we're so excited to continue!

We're extremely thankful to our study coordinators, site staff, and PHACS CAB members who have helped us find HOPE participants who may want to be part of the CAB. We couldn't do this without you. If you or someone you know is interested in learning more about the HOPE CAB, please contact Renee, Claire, and Kim! The HOPE CAB meets on the third Thursday of each month at 12 pm EST.

Contact the HOPE CAB:

Renee Smith: resmith@uic.edu

Claire Berman: cberman@hsph.harvard.edu

Kimbrae Sanders: kimbraels@gmail.com

SPOTLIGHT

GO WITH COCO: SERIES

Our newest member of the PHACS family is Coco the Tortoise! After receiving requests for new materials from our SMARTT participants, the HECC, in collaboration with our CAB, PUG, and Task Force, began developing a coloring and activity book this spring. Considering the sites' specific needs, including resources and the age of participants, the HECC created an interactive activity book jam-packed with coloring pages, a word search, and a find-and-seek. The book is adapted for participants attending their 5-, 7-, and 9-year study visits, will be available in Spanish, and can be taken home or to school with no study or protocol specifics attached to the pages.

The first installment of *Go with Coco* follows our tortoise at a doctor's visit and is designed to depict experiences participants might have at either a doctor's appointment or a SMARTT study visit, such as getting their blood pressure measured. The book is meant to entertain and comfort participants while they navigate new experiences during study visits. We hope to continue Coco's adventures with books tailored to other protocol procedures, such as an MRI scan for a TERBO study visit, a visit to the tooth fairy for tooth collection in SMARTT, or to explore other means of health education, such as a visit to a grocery store.

The first pages have been piloted with several children in our lives, as well as with our PUG and CAB at the Spring 2023 meeting. The finalized activity book is slated to be available to sites at the end of summer, with a website link to download and print. So, go ahead and introduce yourself to Coco in this newsletter edition's CAB KIDS pages!

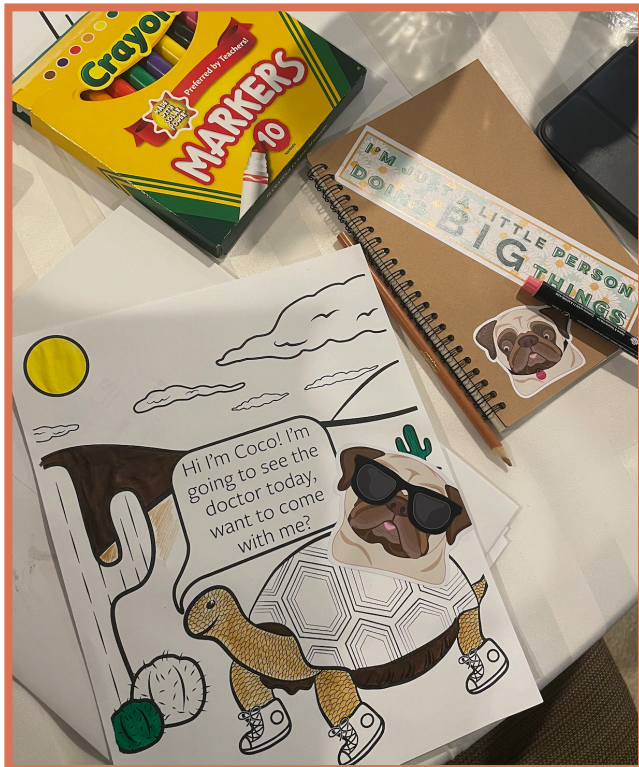


HECC UPDATES

It's been a very busy year for the HECC! This February, members of the HECC hosted researchers Tanvi Rai and Bakita Kasadha of Nourish-UK at the Harvard T.H. Chan School of Public Health. The Nourish-UK project studied infant-feeding decisions of recent parents living with HIV, conducting qualitative interviews about individuals' choices to breastfeed or formula feed. After the interviews were completed, transcripts were created, and actors read these experiences aloud. Researchers uploaded the videos to Healthtalk.org, a free online platform that provides resources on navigating the healthcare system using firsthand experiences. Both teams met for two days in Boston, sharing resources in qualitative research, discussing equity in science, and strengthening partnerships across the pond. Bakita and Tanvi ended their time in Boston by meeting some PHACS community members over Zoom! In this free-form meeting, PHACS members were given the opportunity to speak directly with the researchers, asking questions and sharing their own insights.

In April, the HECC welcomed the team's newest member, Sam Lynd. As our new creative project assistant, Sam has been vital in developing some of our most exciting new projects, such as the *Go with Coco* coloring pages





and an upcoming animation explaining what geocoding is to participants. You can read more about Sam in this month's PHACS Member Profile.

This May, PHACS held its network meeting in person for the first time in almost 4 years. Researchers, clinicians, and community members from across the country reunited in Bethesda, Maryland, to share research and insights about the network. This year's focus was "Whole Person Health," or the multiple social, economic, and political factors that might contribute to an individual's health outcomes. The meeting was kicked off by a keynote presentation by Dr. Helene Langevin, who spoke about stress management in the context of HIV health. The HECC also hosted an interactive panel on self-trust. Self-trust is the concept that individuals know themselves best (their body, their needs, etc.) and thus are the best advocate for their health. Inviting researchers and community members to explore the concept, the panel discussed ways to incorporate the concept of self-trust into PHACS.

PUG, CAB, and Community Task Force members also attended the conference, holding retreats in the days prior! Both retreats centered around the concept of self-trust. PUG members discussed goal setting, leadership, and developing ways to share their stories through audio and visual mediums. The CAB explored concepts of mindfulness and advocacy. The PHACS PIs stopped by both retreats to discuss study developments in PHACS and hear thoughts, concerns, and ideas directly from PUG and CAB members.

At the end of the day, both retreats came together for an interactive mosaic activity, inviting several PHACS researchers to partake in the project.

And, of course, a special shout-out to Kimbrae Sanders, our PHACS CAB Chair, on receiving a 2023 Lagniappe Award! The award is given yearly to exceptional members of the PHACS community who go above and beyond. Kim is an essential part of our network and always doing something “a little extra,” and we’re thrilled for her to have received this award!

In addition to all the impressive events, the HECC has continued to create new health education resources and materials, including:

- A new edition of “Just the PHACS,” our email digest on PHACS publications and news;
- Spanish subtitles for our YouTube videos;
- CAB, PUG, and HECC stickers (working on avenues to make these available at sites);
- The Go with Coco coloring book series (available soon);
- A new website for participants called “Project Positive” (available later in 2023);
- New materials explaining various study procedures to participants, including self-swabs, geocoding, and tooth collection;
- An infographic for SMARTT participants commemorating enrolling 5,000 children (available soon);
- And more new projects coming soon!



As always, a special thank you to our participants and community members who make our work possible!

CAB GLOSSARY

Deviation: A departure from the protocol as written.	Food and Drug Administration (FDA): The agency responsible for ensuring the safety and effectiveness of medicines, vaccines, and medical devices licensed in the US.
Toxicity: Ability to harm the body.	
Prevalence: Refers to the proportion of the population affected by a disease at a particular point in time (like a camera snapshot). For example, in 2003, 25% of the adults in country Y were living with HIV.	Baseline Data: Information gathered about the participant before study treatment begins. To study the effect of a treatment, baseline information is compared with information gathered later in the trial.

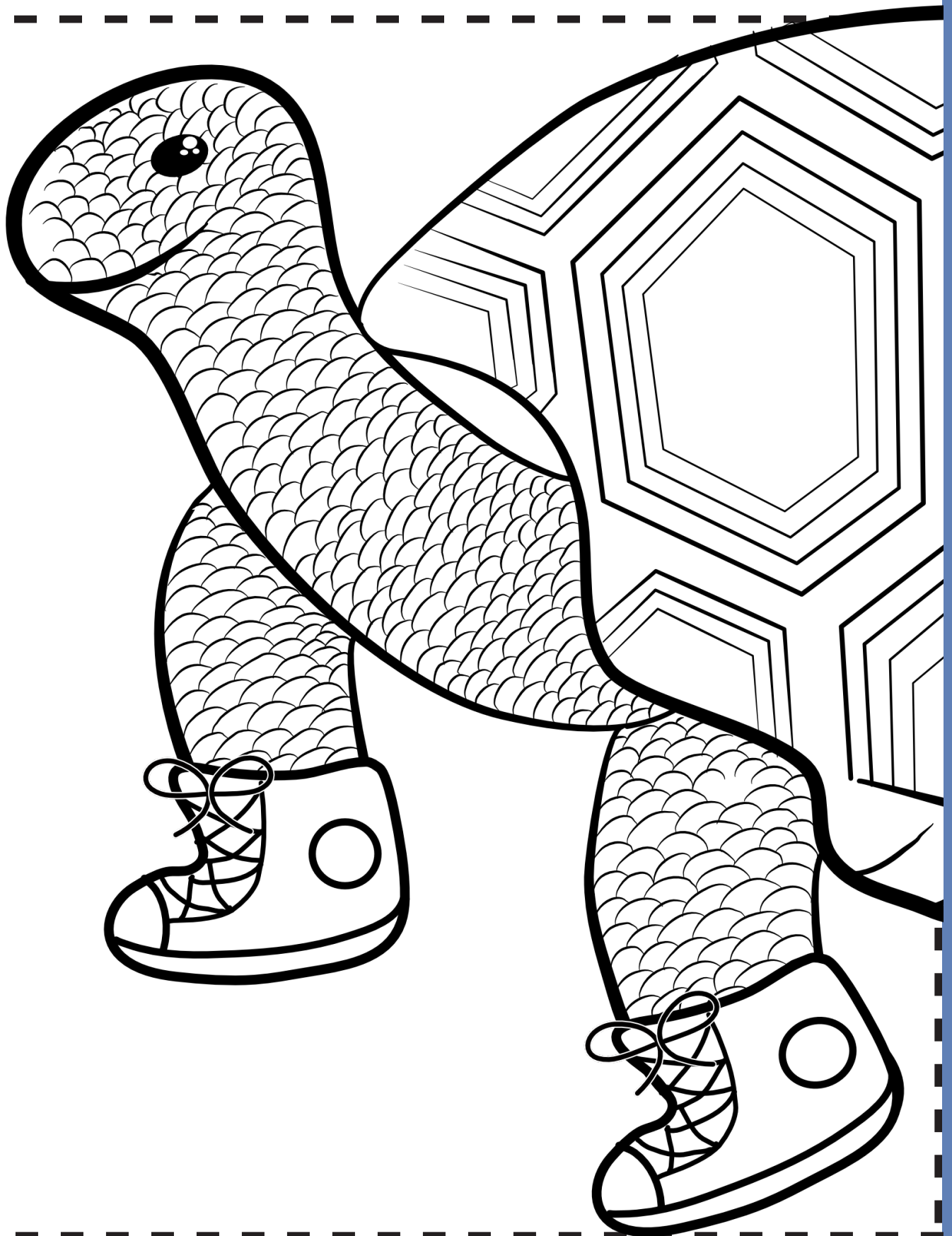
CAB WORD SEARCH

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

BASELINE COMPLICATION DATA DEVIATION EFFECT	FDA MEDICINE PARTICIPANT PREVALENCE PROTOCOL	TOXICITY TREATMENT VACCINE	ANSWERS ON PAGE 21
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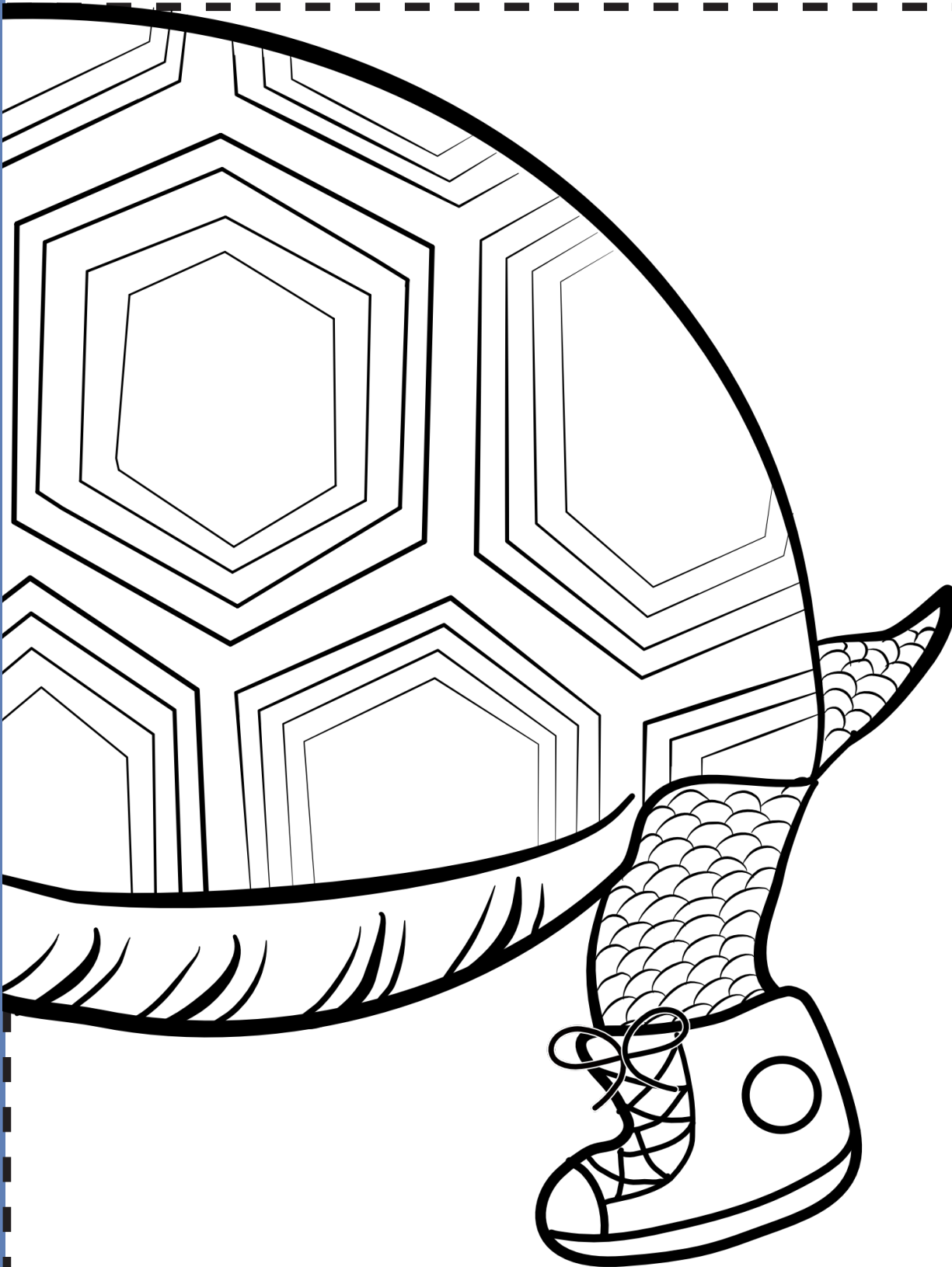
CAB KIDS

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.



WORD SEARCH ANSWERS



Please send all questions, comments, and suggestions for the CAB Newsletter to

Mandy Flores (aflores@hsph.harvard.edu)

DATES TO KNOW



Southern HIV/AIDS
Awareness Day
August 20th



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



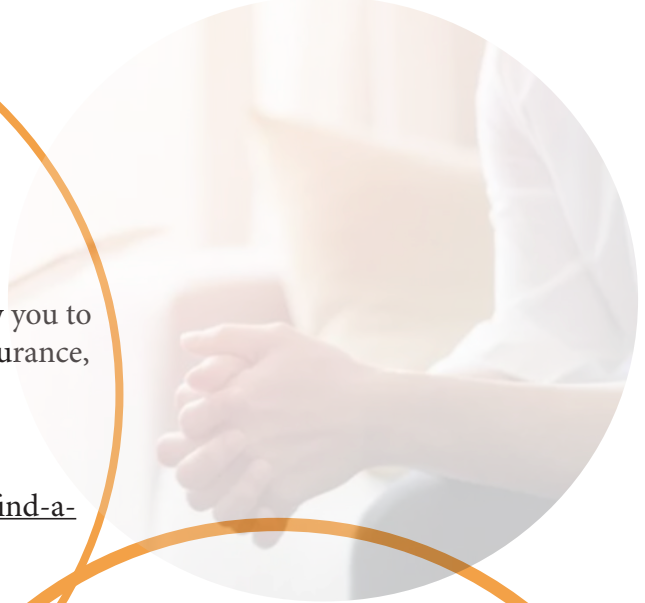
World AIDS Day
December 1st

RESOURCES

THE BOSTON GLOBE: HOW TO FIND A THERAPIST WHEN YOU NEED ONE

The article has great links to search engines that allow you to look for providers in your area based on location, insurance, and speciality.

<https://www.bu.edu/ssw/the-boston-globe-how-to-find-a-therapist-when-you-need-one/>



YOGA WITH ADRIENE

Looking to work on strength and flexibility, or just to relax and get your body moving?

This channel has hours of tutorials for both beginners and advanced practitioners, and allows you to work on specific goals (strength, pain relief, stress relief, etc).

<https://www.youtube.com/user/yogawithadriene>

THE BODY

The website is dedicated to reporting on HIV/AIDS news, as well as providing resources and information on a variety of relevant topics for those living with HIV.

Option to sign up for email updates!

<https://www.thebody.com/>

