

A Community
Advisory Board
(CAB) Newsletter
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The Pediatric HIV/
AIDS Cohort Study

TRADITIONS

MARKING AND CELEBRATING GROWTH



FROM OUR CAB CHAIRS

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Kimbrae, PHACS CAB Chair

Hello, my fellow CAB members – this is your chair! I wanted to say Happy New Year to each and every one of you. I wanted to relay the message that I am so proud of each and every one of you and the growth that you have made. Each and every one of us has accomplished some milestones through blood, sweat, tears. I want you to take your flowers and if no one ever told you I am proud of you and happy to be called your friend. We know that we grow, and if we are not growing then we are not progressing. The fact that you are working hard to be advocates and voices for so many others takes a special kind of person. Each and every one of us gained this heart and the fight because of different situations, but we've grown to know that if we take our past fights and make them our present strength, that we can grow and accomplish anything and everything we want to do. So I applaud your growth and can't wait to see what is in your future accomplishments.



Exzavia, PHACS CAB Vice Chair

Happy New Year to all of my fellow CAB members. Farewell 2022, although I experience changes and challenges throughout the year, I am grateful for all of it, the good, the bad, and the ugly. New Years traditions have always been a big part of change in my life because it's when family and friends get together, whether it is bringing the new year in, in church or counting down with family and friends while cooking, playing cards, listening to music and enjoying one another. This year has changed the way any tradition ritual goes for me. Therefore, moving forward in 2023, the changes and growth I will partake in is to continue to further my education by earning a Bachelor's degree and Master's in social work. Be the best mother and grandmother, while living my life to the fullest and loving on me. Happy New Years everyone and a great big thank you to PHACS for always supporting our decision and concerns when it comes to helping others affected by HIV/AIDs by ensuring that our opinions and thoughts can be voiced and heard.

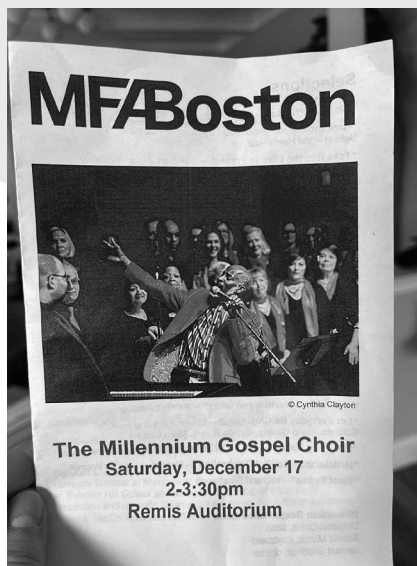
Growth

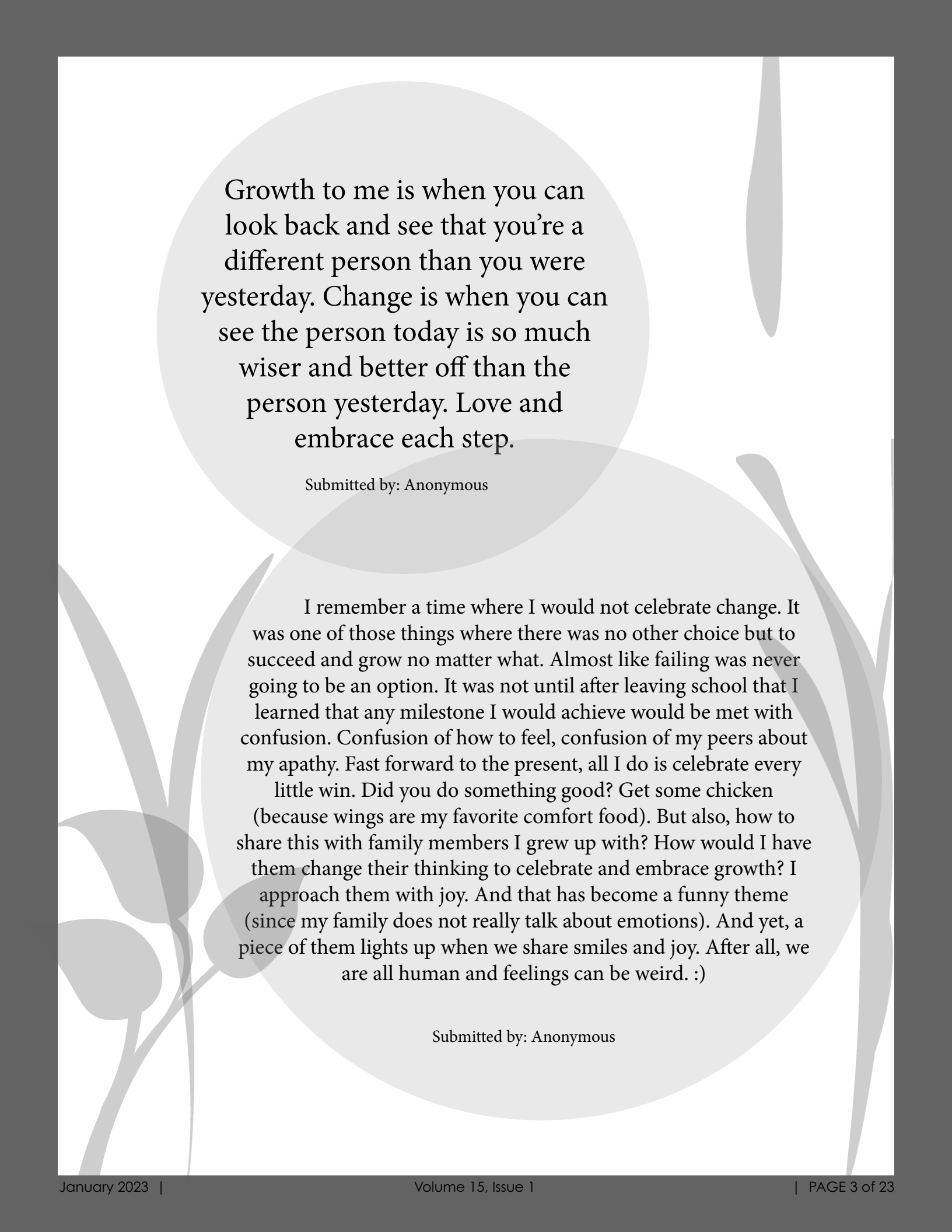
We asked community members to reflect on traditions, growth, and change.

Here are their words.

I've been part of a small spirituality group for the last ten years. Though we are non-denominational, we have a ritual of going to see the Millennium Gospel Choir perform at the Museum of Fine Arts in Boston every December. This choir is special in that it's made up of representatives from many Boston neighborhood choirs who come together only once a year to sing a beautiful lineup of songs. This year was their first performance since before the pandemic, and as I watched and listened, I felt like I'd gotten a shot of joy right in the arm. It is always the best reminder of community and light just as we approach the darkest day of the year.

Submitted by: Claire Berman





Growth to me is when you can look back and see that you're a different person than you were yesterday. Change is when you can see the person today is so much wiser and better off than the person yesterday. Love and embrace each step.

Submitted by: Anonymous

I remember a time where I would not celebrate change. It was one of those things where there was no other choice but to succeed and grow no matter what. Almost like failing was never going to be an option. It was not until after leaving school that I learned that any milestone I would achieve would be met with confusion. Confusion of how to feel, confusion of my peers about my apathy. Fast forward to the present, all I do is celebrate every little win. Did you do something good? Get some chicken (because wings are my favorite comfort food). But also, how to share this with family members I grew up with? How would I have them change their thinking to celebrate and embrace growth? I approach them with joy. And that has become a funny theme (since my family does not really talk about emotions). And yet, a piece of them lights up when we share smiles and joy. After all, we are all human and feelings can be weird. :)

Submitted by: Anonymous

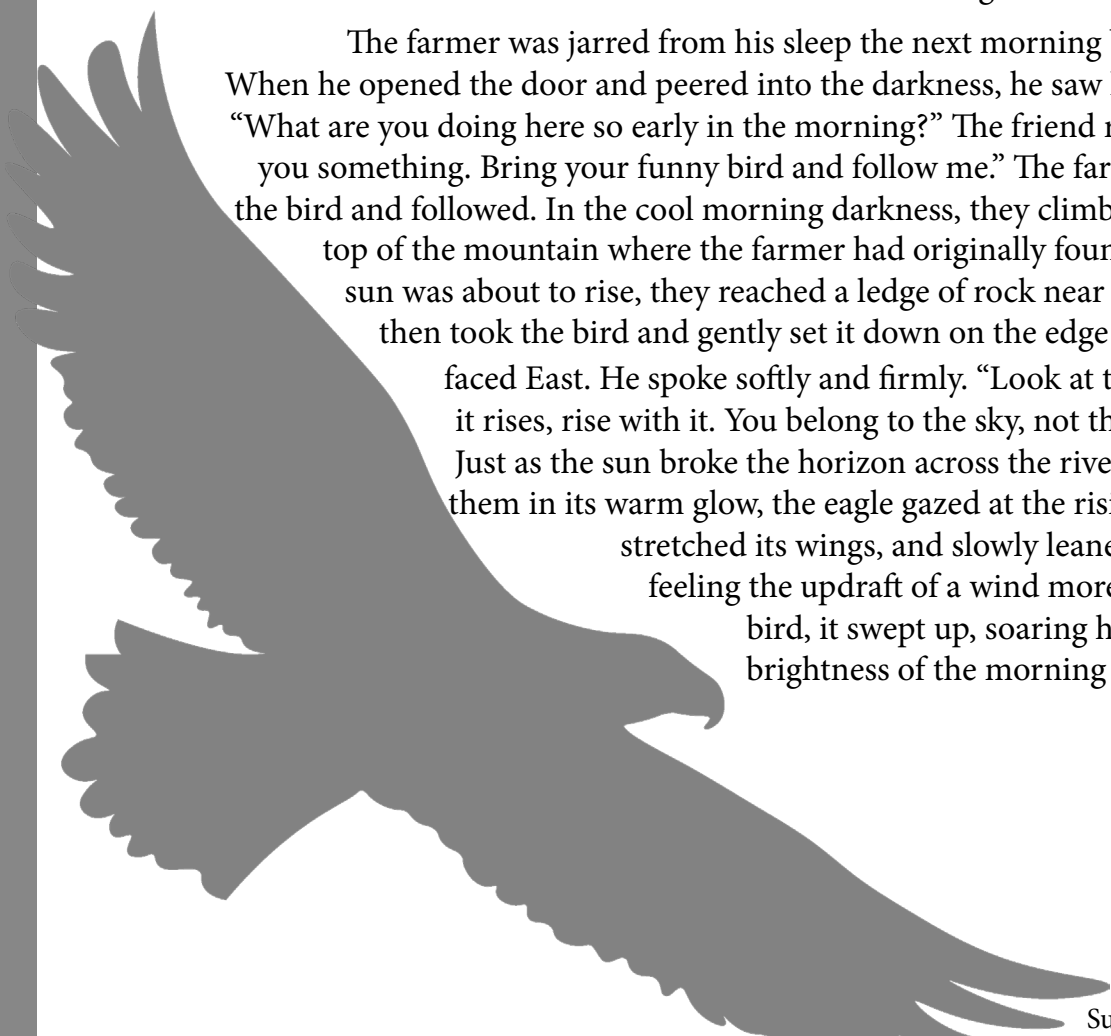
A Fable: The Eagle

According to an African story, an eagle chick fell from its mountain nest during a night storm when it was only a few days old. A farmer discovered the young bird and took it home. When he had nursed it to health, he placed it among his chickens. Though made to soar in the sky, this gorgeous bird grew up thinking it was a chicken.

One day, a friend saw the now full-grown bird among the chickens. He told the farmer, "That large bird among your chickens is an eagle!" But the man only laughed. He said, "No. It looks like an eagle but watch it closely. It walks like a chicken, scratches like a chicken and it eats like a chicken. It is a chicken!" The friend said, "Let me prove that it is an eagle." And he took the large bird and tossed it in the air, but the bird only meekly flapped its large wings then landed among the chickens and proceeded to scratch the ground in search of bugs. The farmer and his children laughed. But a friend was undeterred. He again captured the bird, "Fly Eagle, Fly! You are not of the earth, but of the sky!" And he tossed the bird as high as he could. But the eagle merely glanced at the chickens below, stretched its powerful wings and glided to the ground to resume its scratching. The farmer shouted, "See, I told you it was a chicken." And he and his family roared with laughter. The friend returned home.

The farmer was jarred from his sleep the next morning by a knock on his door. When he opened the door and peered into the darkness, he saw his friend and moaned, "What are you doing here so early in the morning?" The friend replied, "I want to show you something. Bring your funny bird and follow me." The farmer reluctantly fetched the bird and followed. In the cool morning darkness, they climbed the steep trail to the top of the mountain where the farmer had originally found the eaglet. Just as the sun was about to rise, they reached a ledge of rock near the summit. The friend then took the bird and gently set it down on the edge of the ledge so the bird faced East. He spoke softly and firmly. "Look at the sun, O Eagle, and as it rises, rise with it. You belong to the sky, not the earth. Fly, Eagle, fly!" Just as the sun broke the horizon across the river valley below, dazzling them in its warm glow, the eagle gazed at the rising sun, raised its head, stretched its wings, and slowly leaned over the ledge. Then, feeling the updraft of a wind more powerful than man or bird, it swept up, soaring higher and higher in the brightness of the morning sun, never again to live among the chickens.

Submitted by: Kimbrae Sanders



Kimbrae Sanders' Pecan Surprise

Ingredients:

- ⅔ cup butter (room temperature)
- 2 ½ cup white sugar
- 2 eggs
- 2 tbs vanilla extract
- 2 ⅔ cup flour
- 2 ½ tsp baking powder
- 1 tsp salt
- 1 ½ tsp cinnamon
- 1 ½ tsp milk
- 1 cup chopped pecans

Directions:

1. Preheat oven at 375° degrees.
2. Combine and beat butter and sugar, then add eggs, milk, and vanilla.
3. Combine and beat flour, baking powder, cinnamon, and salt in a second bowl.

NOTE: If you prefer, you can add the pecans to the dry ingredients, or you can add them after rolling out the dough in step 6.

4. Slowly combine bowls until well mixed. You may need to add a little more milk if your dough is too dry, that's okay!

5. Place down parchment paper, trust me you will thank me later, this will help with an easier cleanup. Lightly dust the parchment paper with flour and then place down the dough and roll it out.

6. Now this is something that I do – place each pecan after I roll the dough because it ensures that every spot of dough has pecans.

7. After the pecans have been added to the dough, place it in the refrigerator for 20 - 30 minutes.

8. Cut out shapes and bake for 5 - 8 minutes. Baking time depends on how hot your oven gets, as well as the climate and humidity you're baking in.

9. Let cool before enjoying!

Most of all I would love to see pictures in our next newsletter of someone making my cookies. This is my recipe, so if you decide to sell them, I want a cut...lol enjoy PHACS family!



PHACS MEMBER PROFILES

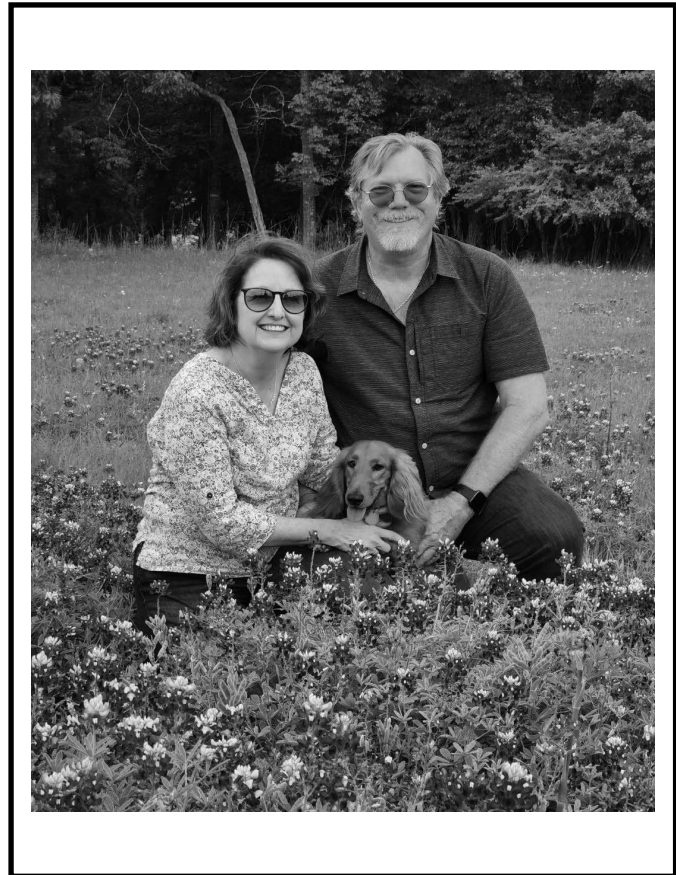
Mary E. Paul, MD

Hi, CAB members. I am the PHACS PI for the Baylor/Texas Children's Hospital PHACS site in Houston where my role is to:

- Provide oversight for all aspects of conducting the studies in the PHACS including regulatory, training, conducting the studies, and participating in site visits and meetings.
- Inform CAB members about studies and get feedback about study design and goals. Relay information about new developments in aspects of care and prevention.
- Contribute to the science of PHACS studies as a member in the Women's Health, Adolescent and YA Health and Behaviors, and Cardiopulmonary Working Groups and the Sleep Task Force.
- Contribute to the development of rules around operations and to review manuscripts as a member of the Publications Committee.

I joined PHACS when it first launched in 2006. In the last 16 years, collaborations and discoveries have informed and enhanced the way I provide care, treatment, and prevention and resulted in new areas of exploration.

As I started my career at Baylor/Texas Children's Hospital (TCH), I was site co-investigator for the landmark PACTG 076 trial, which showed that use of zidovudine in moms and babies could dramatically decrease transmission of HIV. Since then, I have led local efforts to ensure that pregnant women with HIV and their infants receive appropriate care. As a pediatrician member on the Texas HIV Medication Advisory Committee from 2000-2018, I advocated for prioritization of care of women, adolescents and children in Texas. As leader of the TCH Ryan White grant, I have maintained funding from HRSA for case management services for families affected by HIV at TCH for 20 years.



Another role has been to mentor learners. An association with the Baylor Pediatric AIDS Initiative (BIPAI) and with Fogarty Fellows allowed me to work with foreign learners both in the US and abroad and resulted in travel to African countries including South Africa, Tanzania, Lesotho and Equatorial Guinea. From my initial trip in 2011, the accomplishments of colleagues in Africa who have comparatively fewer resources have astonished me. These collaborations have been uplifting and inspiring.

Other contributions to learners include that I am an editor of Pediatric HIV sections in the electronic reference series, "Up-To-Date" which reports an overall reach of over 1.9 million clinicians. As a co-chair for the Panel that produces the Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection, I lead the "Drug Subgroup". The Pediatric Guidelines has had 111,086 page views worldwide in the last year.

As a trials unit, we have contributed to trials resulting in advancements in treatment and prevention. For example, most recently, we have conducted the IMPAACT 2017 trial that resulted in FDA approval of use of the injectable Cabenuva for treatment of HIV in teenagers. Many teens report that having two injections every 2 months is a great improvement over taking oral medication daily.

Outside of my work, I enjoy traveling and spending time with family. While raising two children, I learned a love for baseball and am very proud to be living in the city of the current World Champion Astros baseball team. My love for babies and children is about to be rewarded with a first grandchild due this summer.

Over the years, my work has changed from caring for many children born with HIV to now caring for youth with newly acquired HIV or with perinatal HIV who are aging into adulthood. Despite many successes during my career, there is still much work to do. I am so fortunate to be aligned with the PHACS Network and CAB to continue to move the needle forward to improve treatment and prevention in the future.

Theresa Aldape, LMSW

First and foremost, I would like to thank the PHACS CAB Leadership for inviting me to share a little bit about myself and my work as a social worker at Texas Children's Hospital (TCH) in the Allergy, Immunology and Retrovirology (IAR) Section.

I am a native Houstonian and have lived in Houston all of my life. I am proud to be Mexican American, bilingual, and from one of the original neighborhoods in Houston named Magnolia. I attended Catholic elementary, middle, and high school. My father died at an early age and my mother worked tirelessly so my brothers and I could attend Catholic school and complete a higher education.

I have always loved sports, especially baseball and softball. I played softball for many years. I am a huge Houston Astros fan. I enjoy reading novels and spending time with my family and friends. My husband is the #1 supporter of my career in medical social work. To work in the healthcare profession, I truly believe we must have the full support of our family to be successful.

My passion for social work began when I was a sophomore at Mount Carmel High School. My best friend, Helen, and her mother invited



me to meet and spend time caring for a young lady who was in a tragic car accident in Mexico. She came to Houston and was admitted to the Rehabilitation Unit at St. Dominic Center near the Texas Medical Center. In high school, my service project was at a nursing home. The role of the students was to brighten the lives of patients. I remember making sure the patients had pitchers of fresh ice water,

magazines, and books. We read with the residents and engaged them in conversations about their interests and family members.

I attended Texas Woman's University in Denton, Texas, completed my internship at St. Paul Hospital in Dallas, and received my undergraduate degree in social work. After graduation, I returned to Houston and started my first job at Ben Taub General Hospital (BTGH) as a pediatric social worker from 1984-1988. While working full-time, I attended the University of Houston and graduated from the Graduate School of Social Work in 1988.

In the mid to late 80s, children were being admitted and later diagnosed with HIV at BTGH and TCH. Dr. Celine Guerra Hanson and Dr. Howard Rosenblatt from the Immunology and Allergy Department at TCH/BCM met with the families to discuss their child's diagnosis. Young children often had failure to thrive, pneumocystis carinii (PCP), and other opportunistic infections. The healthcare team members provided emotional, medical, psychological, spiritual, and social support for the children, adolescents, and their families.

While at BTGH, I was recruited by Dr. Hanson to work at TCH in the Department of Allergy and Immunology. Dr. William T. Shearer received funding to begin the first pediatric clinical research studies at TCH/BCM. Our team continued to provide medical and social services to patients at BTGH, Jefferson Davis Hospital (JD) and TCH. Children of all ages were seen in the hospital or clinic because of their ongoing infections and later diagnosed with HIV. We provided education, support, financial assistance with housing, utilities, funerals, and transportation for medical and research visits. Dr. Hanson and the entire HIV team began having holiday parties and various other social gatherings for children and families to meet each other and gain support from each other. In 1996, the AIDS Foundation Houston approached TCH to partner and begin the development of the first camp for children with HIV in Texas. I am honored to have been part of the team of physicians, nurses, social workers,

child life therapists, pharmacists, dietitians, and volunteers at Camp Hope in Manor, Texas and now at Camp for All in Brenham, Texas. The camp provides a recreation and supportive environment for children and adolescents with HIV. The campers are from Texas Children's Hospital, other nearby hospitals and cities, and also from Florida. It was wonderful being involved in camp and seeing the happiness the week long camp brought to so many children. They met new friends who were living through similar experiences. This continues to be the highlight of the year for so many of our young patients.

The Community Advisory Board at TCH/BCM began in 1991 at the suggestion of William T. Shearer, MD, PhD. He began the HIV clinical trial group at TCH for all children in Houston, other surrounding cities, and states. Our CAB has impacted science by advocating for the inclusion of the community at all levels of leadership. Families from around the world have a direct impact on the development of new and upcoming studies about the effects of HIV, mental health aspects related to the care of their children living with HIV and the development of medications that are tolerable and accessible to all.

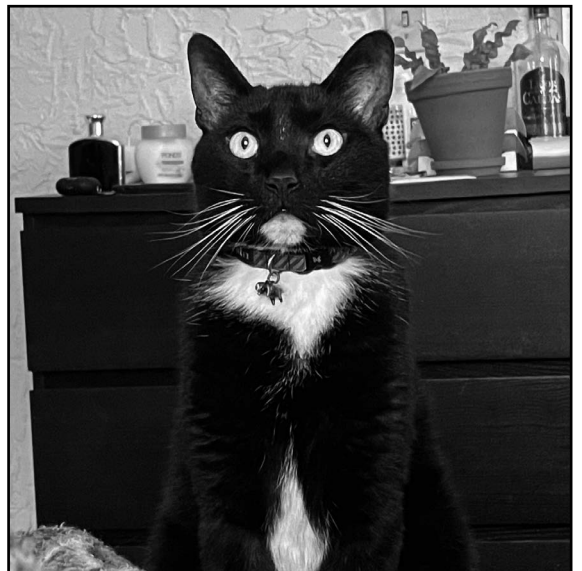
Dr. Mary Paul is the Chief of the Retrovirology Section and oversees the HIV research Clinical Site at TCH/BCM. The entire HIV research team at TCH continue to work daily to continue seeing patients on IMPAACT, PHACS, HOPE, TERBO, ATN and other studies. New studies will be open for enrollment in 2023. We have overcome so many changes to our daily lives because of COVID-19 and are prepared for the new year.



PHACS PETS

Some of the traditions of our PHACS pets include dressing up, napping, and supervising the cooking of latkes.

Clockwise from bottom left:
Cooper, Harvey, Mac



Submitted by: Sharon Hwang, Eduardo Vergara, Amanda Flores

The Third Night

By: Claire Berman

My Mom's love language is food. The fourth of nine children, she grew up in a Catholic family in a suburb of St. Louis, Missouri, where I was born. As she and her siblings went on to have families of their own, our extended family's numbers grew exponentially. My Mom will say she doesn't know how to cook for one person, only for forty.

My Dad, on the other hand, was a Dodgers-then-Yankees-hat-wearing, bagel-loving Brooklyn Jew. My Mom's "in" to his culture was in learning its food, harnessing her skill at gathering family and applying it to her husband's holidays, especially Passover and Hanukkah. I only came to understand as an adult that for most Jews, Hanukkah is a fairly minor holiday. This was because in my family, it was anything but that. Our Hanukkah party was one of the most important rituals of our year.

We played games of dreidel with pennies and chocolate gelt. We read the story of the holiday for the kids, of the Festival of Lights and the miracle of the oil lasting eight days instead of one. But the highlight of the party was the food. My Dad would play Cat Stevens in the kitchen as he shaped and fried enormous latkes, and my Mom would produce a feast of kugel, blintzes, stollen, soup—and challah. By the time I woke up on the morning of the party, she would have already been in the kitchen for hours, shaping and braiding challah dough and rotating loaves in and out of the oven. Two at a time, a well-oiled machine. As two loaves cooled on a wire rack, their braids a rich, smooth golden brown, the next two were puffing in the oven. She made a variety: some with raisins, some with sesame seeds, and some plain. As each family departed into the cold winter air at the end of the night, my Mom would hand them a full loaf of challah bread to enjoy the next morning.

My Dad's menorah is bronze, a gift from my Mom for their first Hanukkah together in 1979. It holds a marriage's worth of wax from melted miracle candles. He sat at the head of our table each year, his large hands fumbling with the candles. He lit the server first, then used it to light the wick of each other candle representing one night of Hanukkah. He recited the Hebrew prayers of his childhood from an open book in front of him. "Baruch atah Adonai"... As one of the only Jewish people in our suburban Midwestern town, inviting our friends and family into his traditions meant a lot to him. Performing these rituals was his way of staying connected to his own upbringing and especially to his parents who had passed away.

In 2017, a few days before Hanukkah began, my Dad collapsed with sudden cardiac arrest. He spent five days unconscious in the Intensive Care Unit (ICU). During those ICU days, we kept his large, bronze menorah on the plastic hospital tray. On the third night of Hanukkah at sundown, at the time when he would normally light the menorah, he passed away.



Sometimes, it is in the repetition of ritual that you can keep something alive. In the days that followed, we decided we needed to go ahead with our annual Hanukkah party. My Mom produced her usual feast for several dozen people, and our party for a minor Jewish holiday that my Dad had presided over my whole life went on. We ate the same food we always had: stollen, blintzes, noodle kugel, soup, the latkes, and of course, challah. Its airy, egg-rich flavor pulled us into the past even as it grounded us in the present.

My younger brother lit the bronze menorah, and he stepped into our Dad's place of reading the Hebrew prayers. The kids played dreidel with pennies, we peeled foil from chocolate gelt, and there was a lot of laughter even amid our tears. The party felt both familiar and entirely new. Our Dad was so freshly gone, but so inseparable from and present in what we were doing. Every year since, we have continued to celebrate Hanukkah, and now, my niece and nephews help light the candles. I think about how they are extensions of him, learning the same rituals he did as a child and eating the food that has carried us in this tradition. A through-line connecting the generations.

In traditional Judaism, it is the mother who passes Jewish status on to her children. My mother grew up Catholic, but she is still half the reason I feel Jewish, at least as much as my Brooklyn-raised Dad who played stickball in the street as a child, had a bar mitzvah, and whose father worked his entire life in a Jewish deli. My father gave us the DNA that stretches backwards through our eastern European Ashkenazi ancestry, and my Mom brought the flavor of Judaism into our lives. Together, they created a ritual that has endured.



Raisin Challah

Ingredients:

- 1 cup lukewarm water, divided
- 6 teaspoons (more or less heaping) of active dry yeast
- 6 teaspoons sugar, divided
- 4 – 5½ cups of unbleached white flour
- 2 teaspoons of salt
- 3 eggs
- ¼ cup oil (at room temperature)
- 1½ cups of seedless raisins (either use baking raisins, or soak regular raisins in hot water for 20 minutes or so, and then drain)
- Egg glaze: (1 egg + 2 teaspoons of water)
- Sesame seeds



Directions:

1. Preheat oven to 400 degrees F. Pour ½ cup of warm water into medium sized bowl. Sprinkle yeast and 1 teaspoon of sugar on top. Let stand about 3 minutes, then stir to dissolve yeast completely. Set bowl in a warm place for 5 minutes or until mixture doubles in volume.
2. In a large mixing bowl, combine 4 cups of flour with salt and remaining 5 teaspoons of sugar. Pour in yeast mix, remaining ½ cup of water, eggs and oil. Beat until smooth.
3. Turn dough onto floured surface and knead until smooth and elastic, using remaining flour as needed. Place in a greased bowl, cover with saran wrap, and let rise until double in bulk.
4. Punch down dough and knead in raisins. Divide into five pieces and roll each into 18-inch lengths. Braid first three (starting in the middle of the braid, and then working from the middle towards both ends) and pinch together at both ends. Arrange the braided first three on a piece of parchment paper laid on top of a cookie sheet. If you don't have parchment paper, grease the cookie sheet first, and then lay the braid on top of that. Twist the remaining two lengths (again starting from the center), and place on top of braid. Pinch the ends of the twist together with the braid. Let rise in a warm spot for 30-45 minutes.
5. Brush with egg glaze and sprinkle with sesame seeds (if desired). Bake in preheated 400° oven for 5 minutes. Without opening the oven, reduce heat to 375° and then bake 25–30 minutes more, until brown and crusty. Be careful not to burn the loaf. The timing is iffy, so keep your eye on it after the first 20 minutes. If you have access to an instant read thermometer (a small device, not the big thing we use to check meat), you can tell that it is done if it has reached an internal temperature of anywhere between 190° and 210°.

Yield: 1 large loaf (or 2 smaller loaves). If you make 2 smaller loaves, cut the dough into ten pieces, not five.

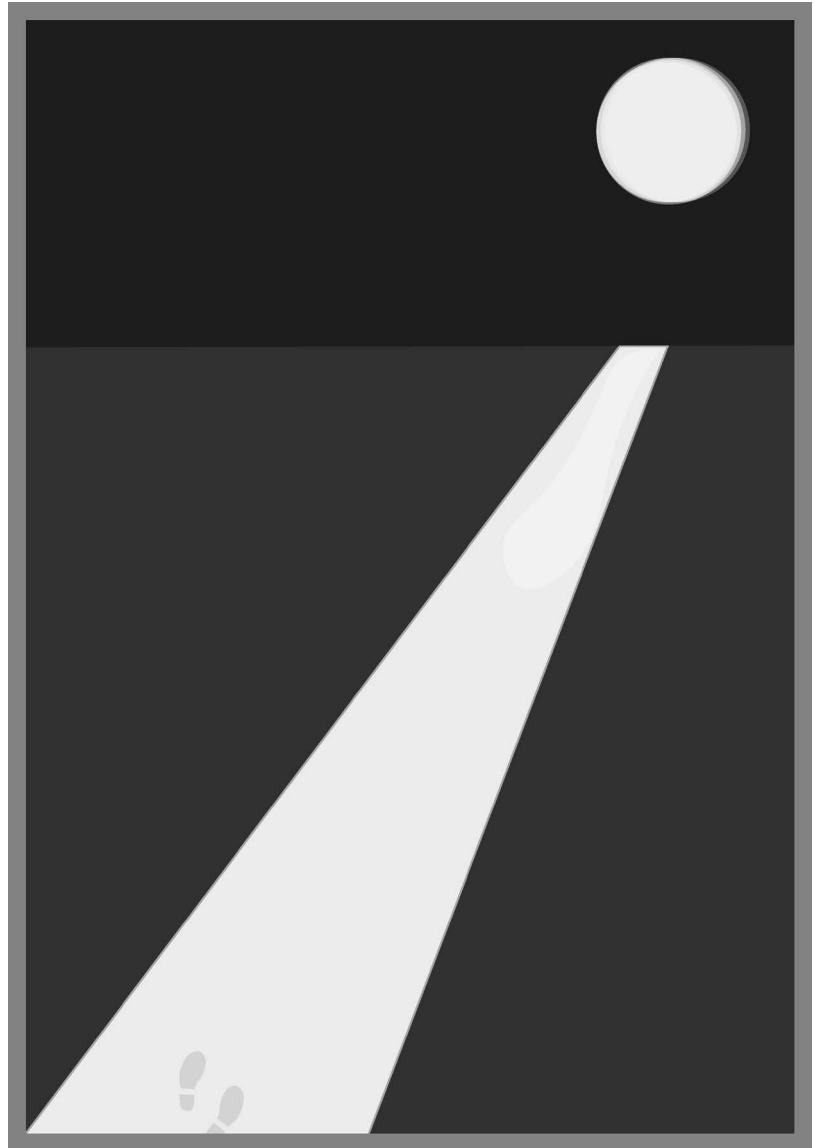
*The kitchen should be draft-free. Makes a very light bread. Wrap tightly in saran wrap once thoroughly cool.

Submitted by: Claire Berman

The Journey

By Mary Oliver

One day you finally knew
what you had to do, and began,
though the voices around you
kept shouting
their bad advice —
though the whole house
began to tremble
and you felt the old tug
at your ankles.
“Mend my life!”
each voice cried.
But you didn’t stop.
You knew what you had to do,
though the wind pried
with its stiff fingers
at the very foundations,
though their melancholy
was terrible.
It was already late
enough, and a wild night,
and the road full of fallen
branches and stones.
But little by little,
as you left their voice behind,
the stars began to burn
through the sheets of clouds,
and there was a new voice
which you slowly
recognized as your own,
that kept you company
as you strode deeper and deeper
into the world,
determined to do
the only thing you could do —
determined to save
the only life that you could save.



Birthday Cake

By: Amanda Flores

I have always struggled with the idea of celebrating my birthday. Having been born in the throes of a snowstorm the day after Christmas, I was used to feeling swallowed up by a month saturated in sacred traditions. A time when homes are filled with towering trees of pine and adorned with precious glass bulbs taken from their basement cocoons only once a year, and golden menorahs sit on mantles burning the candles of dozens of generations from before, the idea of celebrating my existence felt almost laughable. Who was I to take time away from this busy month to mark another rotation around the sun? What would jamming striped candles into a Stop & Shop sheet cake and inevitably spewing rainbow wax droplets across thick vanilla frosting* do? Why do we feel the need to celebrate birthdays?

A week before my twenty-fifth birthday, I was in one of the lowest places of my life. Feeling stagnated in my career prospects, relationship prospects, and generally lacking in having any “major boxes checked,” I looked gloomily on to the “prospect” of “celebrating” my birth. That time of year had also taken on an undertone of mourning. Over the years, I had come to lose some of the most important people in my life during the winter months. It was hard not to see the snow flurries as gentle reminders of those I loved and lost.

Needless to say, I was in no mood to accidentally choke myself on the elastic of a party hat, when my best friend called me one evening. As usual, she jumped into the call mid-conversation.

“Now I know you don’t want to celebrate your birthday or are not excited about your birthday... blah blah blah. But we need to do something. It can just be small. We can watch a movie at my place, have some champagne, and take cute pictures. Just you, me, and a cake. We need to celebrate you. Okay?”

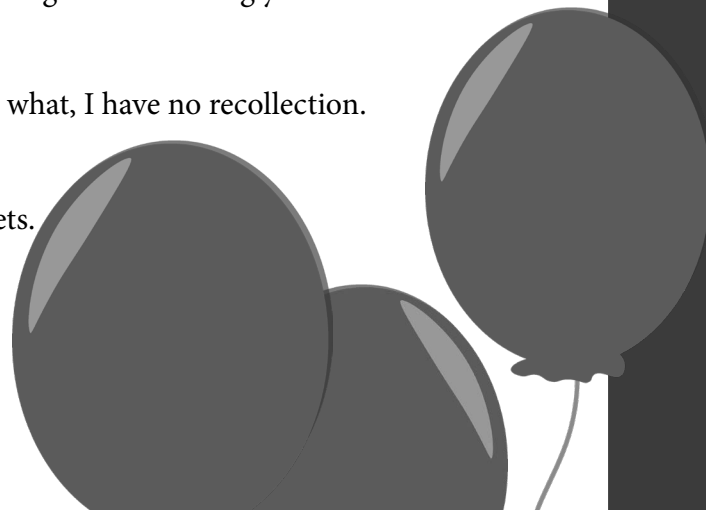
Minka was usually right. Her quick wit, compassion, and uncanny ability to be “right” about many things were major catalysts for our friendship of nearly two decades. I paused but eventually, hesitantly said:

“Okay fine. Yes...”

“Okay! Bring your red dress! You can bring sweats to change into but bring your red dress for pictures.”

As per usual, we went on to chat for another two hours. About what, I have no recollection.

* To this day, I maintain that the best frosting is the thick, plastic-like stuff found on sheet cakes at your local supermarkets.



On December twenty-sixth, I showed up on Minka's doorstep, red dress in hand but feeling low. She gave me the biggest hug. Enthusiastically ushering me in, she welcomed me into the warm apartment she had filled with some of my favorite things: chocolate cake with vanilla frosting, champagne, and Doritos. Her infamous set of party speakers, which had made appearances at all major post-college events, was blasting our latest sound obsessions. She hugged me again and said:

“Okay, let's get the pictures out of the way. No one will ever know it was just you and me. And one day, you'll look back and see how different you were, how you didn't know a damn thing.”

I nodded, warming up under the glow of her energy.

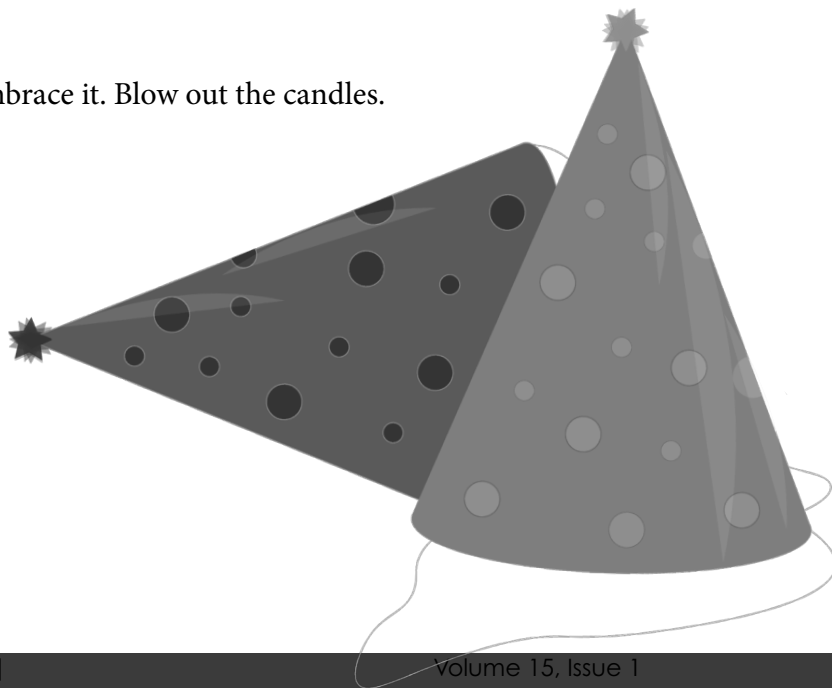
“And then let's get into our PJs. And eat cake and do whatever you want!”

We took the pictures. And cut the cake. Minka insisted on singing me happy birthday. I laughed. All these things felt trivial, but we did them anyway. Just the two of us. I continued to bend under Minka's cheer. We stuffed our faces with chips and cake, watched music videos, danced and sang together, and even visited our old high school IM website. As the afternoon blended into the evening and then late evening, I felt a genuine hum of happiness. I fell asleep, tummy full of sugary frosting, content on her couch.

My life completely changed in the months following our “celebration.” A job opportunity presented itself, pivoting my career in an unexpected and wonderful direction. With the support of others and professional guidance, I began rebuilding my mental and physical health. By the fall, I felt firmly rooted in my independent feet – grounded and optimistic, for the first time in a long time.

I have finally warmed up to celebrating my birthday. Much like Minka said, I look back at those photos and see someone in state of change, someone who had no idea about the opportunities to come. As humans, we are constantly growing and evolving. This growth can be hard to see sometimes, especially when it can't be measured in numbers or the check marks defined by society. But birthdays, much like many traditions, are a stance of hope. We preserve the past, reflect on the past, and wish for a brighter and fuller future. It's a way to mark who you are now because you may be a very different person in another 365 days.

Embrace it. Blow out the candles.



HECC UPDATES

It's been a busy and transformative time for the Health Education and Community Core (HECC). Although we still miss Megan Reznick, who departed from PHACS this summer, we've seen some outstanding individuals step into greater roles here at the HECC. Mandy Flores was promoted to Creative Project Manager, focusing on expanding her leadership role within the HECC, managing our suite of creative projects, supporting Task Force outreach, and acting as the new national PHACS CAB liaison.

Eduardo Vergara was also promoted to Senior Research Study Coordinator at PHACS. In addition to working with Mandy as the co-facilitator for the national CAB and supporting research-oriented tasks, he is helping to spearhead efforts to expand the role and influence of Spanish-speaking participants. Karim Bermudez has long since been a vital figure in the HECC, juggling many logistics of our national CAB and Task Force. Recently, she has expanded her role at the HECC, consulting on projects, supporting Task Force outreach, and translating many network materials into Spanish - greatly expanding accessibility across the network.

Sharon Hwang was promoted to Program Manager for PHACS Cores, and in the HECC, is focusing on tackling research-oriented tasks. Recently, Sharon collaborated and led the development of the latest issue of "Just the PHACS," a quarterly email digest highlighting recent publications and news. Renee Smith also continues to dedicate time graciously to the HECC. She has been lending her insight and expertise across various research-oriented projects, including HECC capsule and concept sheet reviews and plain language summaries, clinical reviews, and using her local site CAB knowledge to help inform the HECC's community engagement work.

The whole team continues to be guided by Claire Berman, the Director of the HECC. In addition to juggling various creative and research-oriented community projects and motivating and encouraging individuals inside and outside of the

HECC with great compassion, she recently presented the HECC's community engagement work to nearly fifty researchers and clinicians from the German Centre on Child and Adolescent Health.

This fall and winter, the HECC worked on a variety of projects, including:

- The development of 3 brand new designed lay summaries.
- The premiere of "Through Your Eyes," a short film about the passionate people who make up PHACS
- A new edition of "Just the PHACS," the quarterly email digest on PHACS publications.

How Much Tenofovir Do Babies Absorb During Pregnancy?

- Many pregnant people living with HIV take antiretroviral therapy (ART), which is good at preventing their baby from getting HIV.
- There can be some health concerns when babies are exposed to ART in the womb, so looking at the drug's safety is important.
- Previous studies have only measured a baby's exposure to medicines at a single point in time. Our study used a new approach for measuring how much of the medicine tenofovir a baby had absorbed over the entire pregnancy.

WHO PARTICIPATED

- 103 mother-baby pairs in the US and Puerto Rico who were enrolled in SMART (Surveillance Monitoring for ART Toxicities).
- The mothers had all taken tenofovir during pregnancy.
- All mother-baby pairs donated hair samples (around 100 hairs from the head) at the time of birth.

WHAT WE DID

- We used special lab tests on the hair samples.
- That test **estimated how much tenofovir the baby had absorbed from its mother over the whole pregnancy.**

WHAT WE FOUND

- We found high amounts of tenofovir in the babies' hair. This meant they had absorbed a lot of the medication during pregnancy.
- Some babies had lower amounts of tenofovir. The babies tended to be those who:
 - Were delivered early.
 - Were delivered via C-section.
 - Were born to mothers who took tenofovir only in the first trimester.
- We the test we used was reliable in showing how much tenofovir was absorbed over the whole pregnancy, not just a single point in time.
- While we learned that babies absorbed their parent's medication while in the womb, we need to conduct further research to determine if there are positive or negative outcomes on the child's health.
- We recommend studies around the world adopt our approach to test the safety of other ART medicines during pregnancy.

For more information, contact Claire Berman | Director, Health Education & Community Core | cberman@phacs.org | 410-754-1900

JUST THE PHACS
Quarterly Digest • October 2022 • Issue 7

WHAT'S NEW IN PHACS?
Welcome to Just the PHACS, our quarterly digest! See below for our latest publications and other happenings in PHACS.

RECENT PUBLICATIONS
(OCTOBER 2021 - AUGUST 2022)

The CAB and PUG have continued to meet on a monthly basis and have been instrumental in guiding the HECC's projects, including lay summaries, visual artwork for the network, and a new website for participants to be launched this year called "Project Positive". They are looking forward to holding their first in-person retreats in nearly four years this spring. This past November, the HECC presented at the virtual PHACS Fall Leadership Retreat. With the assistance of community members, Claire and Mandy presented on the numerous projects and successes of the collective efforts of community members, participants, researchers, and clinicians. The attendees were very enthusiastic about the community's accomplishments, with many citing their irreplaceable role in the network.

This past December marked the end of the first 2-year term for the PHACS Community Task Force. After numerous submissions and interviews, a second cohort was instated in January. Some familiar faces will continue their work on the Task Force, serving a second term, while five new members joined from across the country. This new cohort will attend an orientation in February and will serve until December 2024, continuing to provide input and guidance into all of PHACS' research proposals and creative resources.

**A special thank you
to the participants and
community members that
make our work possible!**

**Please send all questions, comments, and suggestions for the CAB Newsletter to
Mandy Flores (aflores@hsph.harvard.edu)**

CAB Glossary

National Institute of Mental Health (NIMH):

Provides national leadership dedicated to understanding, treating, and preventing mental illnesses through basic research on the brain and behavior, and through clinical, epidemiological, and services research.

Antibody:

A protein produced by the immune system that recognizes and fights infectious organisms that enter the body. Each antibody is specific to a particular infectious organism (such as HIV antibodies or measles antibodies).

Horizontal Transmission:

HIV transmission from one person to another, except in the case of mother-to-child transmission (called vertical transmission).

Confounding Factor:

An unmeasured third variable that could influence both the cause and effect in a research study. Without accounting for them, they can introduce bias into the study.

Concept Sheet (CS):

A full proposal for a research study, expanded from a brief capsule.

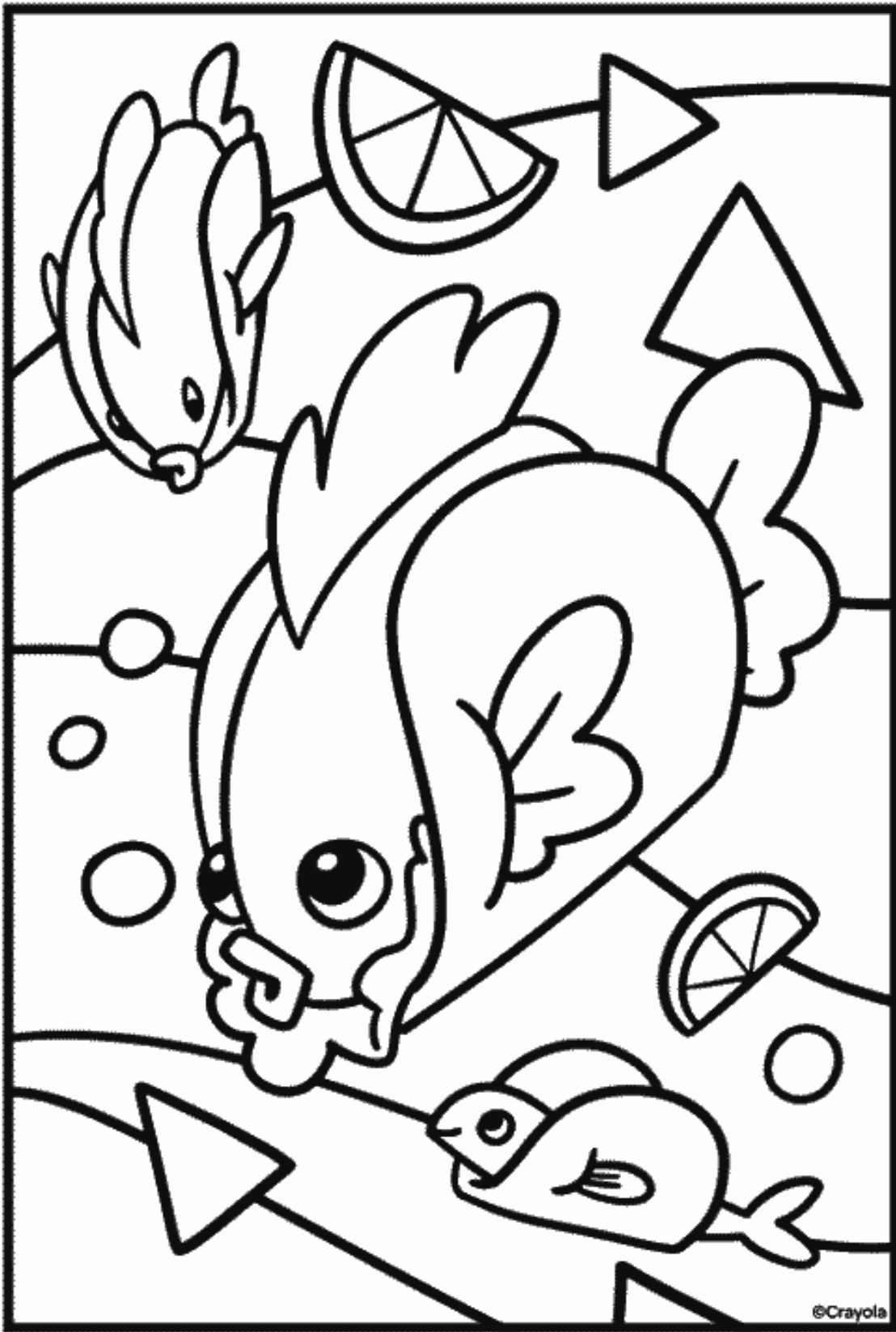
Word Search

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ANTIBODY BEHAVIOR BRAIN CHARACTERISTIC CLINICAL	CONCEPT CONFOUNDING EPIDEMIOLOGICAL IMMUNE PROTEIN	RESULTS TRANSMISSION TREATMENT	ANSWERS ON PAGE 21
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CAB KIDS

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



©Crayola

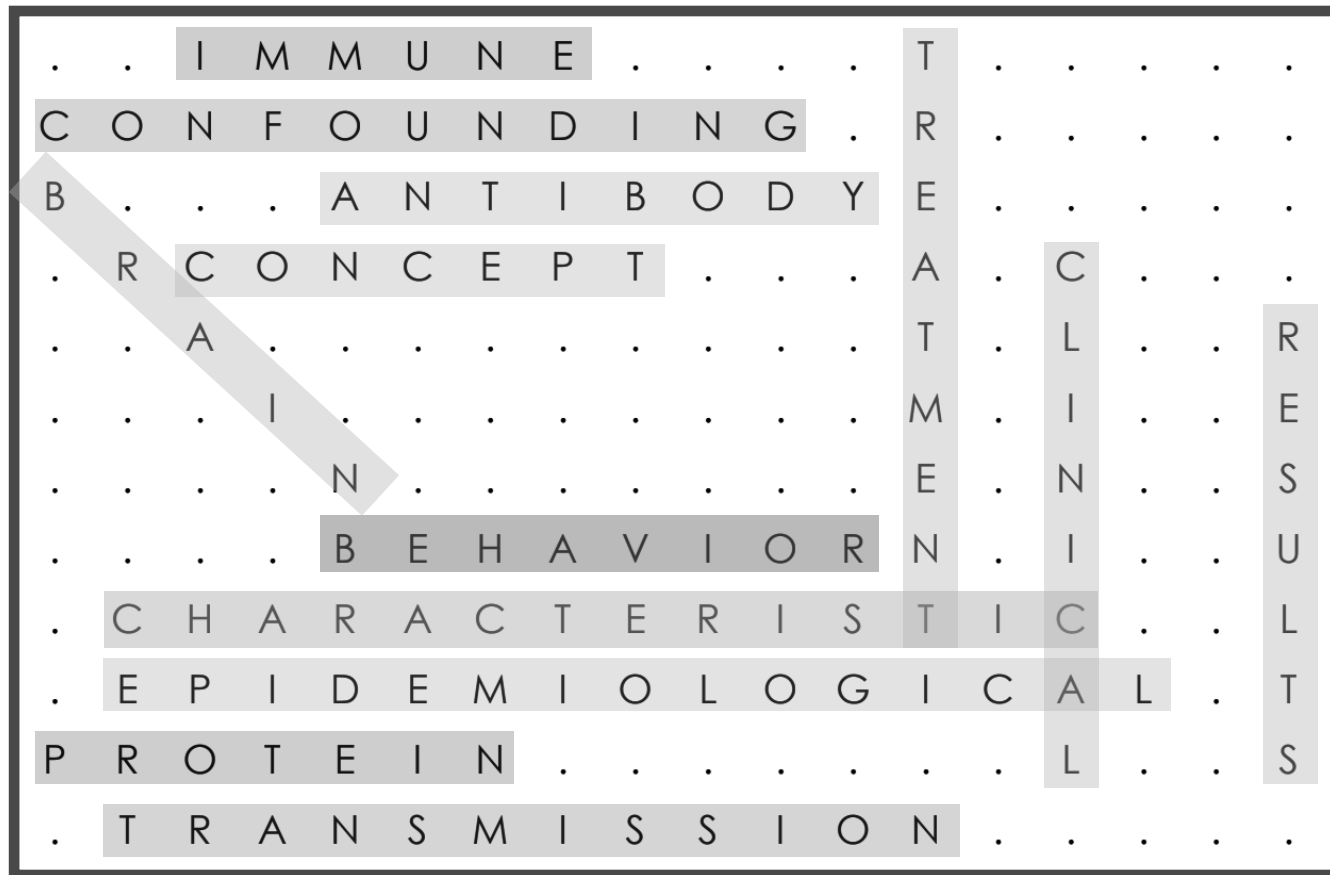
CAB KIDS

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



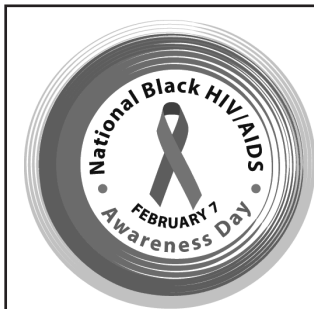
Word Search

ANSWERS



Please send all questions, comments, and suggestions for the CAB Newsletter to
Mandy Flores (aflores@hsph.harvard.edu)

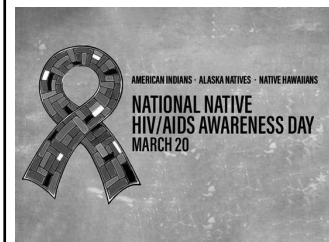
UPCOMING EVENTS



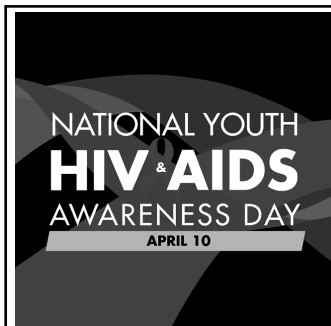
National Black HIV/AIDS
Awareness Day
February 7th



National Women
and Girls HIV/AIDS
Awareness Day
March 10th



National Native HIV/AIDS
Awareness Day
March 20th



National Youth HIV/AIDS
Awareness Day
April 10th



National Transgender
HIV Testing Day
April 18th



National Asian and Pacific
Islander HIV/AIDS
Awareness Day
May 19th

RESOURCES

THE LOVELAND FOUNDATION

Provides financial assistance to Black women and girls seeking therapy nationally.

<https://thelovelandfoundation.org/therapy-fund/>

PSYCH CENTRAL: 8 WAYS TO LIVE WITH A CHRONIC ILLNESS

Navigating mental and emotional health.

<https://psychcentral.com/blog/8-ways-to-live-with-a-chronic-illness#5>

NIH: I'M SO STRESSED OUT! FACT SHEET

Feeling overwhelmed? Read this fact sheet to learn whether it's stress or anxiety, and what you can do to cope.

<https://www.nimh.nih.gov/health/publications/so-stressed-out-fact-sheet>

THE ARTIDOTE

Personalized notes with inspiring thoughts, vulnerably honest stories & beautiful artwork—delivered directly to your inbox.

https://newsletter.theartidote.org/gentle_reminders

