

A Community
Advisory Board (CAB)
Newsletter
published by:

The Pediatric HIV/ AIDS Cohort Study

#### **INSIDE THIS ISSUE:**

From Our CAB Chairs	1	ł
Winter Wellness	<u>2</u>	
A Poem: A Poem of a Southern Texas Lady and Her Frying Pan	<u>3</u>	a v v
Recipe: Glühwein (Mulled Wine)	<u>4</u>	a s r a
Featured CAB Member: Queen K	<u>6</u>	t n
Recipe: Coquito	<u>7</u>	g
<b>Recipe:</b> Kim's Blue Heaven	<u>8</u>	
A Poem: Snowy Night	<u>9</u>	ł
PHACS Member Profile: Natalie Lewis-Vass	<u>10</u>	
Winter Activites: USC CAB MCA Spanish- Speaking CAB	<u>11</u>	
HECC Updates	<u>12</u>	
CAB Glossary	<u>14</u>	
CAB Word Search	<u>14</u>	
CAB Kids	<u>15</u>	
Word Search Answers	<u>17</u>	
Dates to Know	18	

Resources

<u>19</u>



#### From Our CAB Chairs

#### Kimbrae, PHACS CAB Chair

Hello again, everyone - I just wanted to touch base and see how you are doing during the Winter Holiday. I also would like to welcome our newest Spanish and HOPE CABs - welcome! I want you to remember during this season and time of the year to be a Hershey miniature. Some have nuts, some are just pure chocolate, some of them have coconut in it, and some are like me - a little bit of all of a mixture package. The reason why I use this examples is that it's a reminder that we are all different but yet still the same. Most of all, my Miniatures, I want you to remember (if no one ever tells you this year) that you are sweet, a little good for the heart, but most important that you are loved by your CAB Chair. Have a great, prosperous New Year!



## Exzavia, PHACS CAB Vice Chair Hey there, my fellow CAB members!



Hope you all are doing well and enjoying the holiday season. As we prepare to welcome 2024, I wanted to share some tips to help you stay healthy and happy during the winter months.

First and foremost, make sure to stay active! Even if you can't venture outside, there are plenty of indoor workouts to keep you feeling great. But, don't forget to get outside and soak up some fresh air and sunlight. It can do wonders for your mood and energy levels.

Eating well is also important during the winter months. Make sure to nourish your body with healthy and balanced meals to keep your immune system strong. It's easy to feel a bit lonely during the winter, so be sure to stay connected with your loved ones. Social interaction is crucial for our mental well-being.

Last but not least, make sure to practice some self-care. Take some time for yourself to relax and recharge with a warm bath, a good book, or some meditation. I hope these tips inspire you to take care of your mental and physical health this winter season. Let's kick off 2024 on the right foot!

## WINTER WELLNESS

How do you **take care** of your **mental** and **physical health** in the winter?

Making candles is extremely helpful and taking the garbage out daily helps me get guaranteed fresh air.

- Chitara





Spending time working on my ceramics helps keep me stay grounded in the winter.

Working with clay both gets my body moving and settles my mind, focusing my attention on only what is in front of me.

- Mandy

# A Poem of a Southern Texas Lady and Her Frying Pan

By Kimbrae

I have heard many stories of you from my grandmother and my mom. I was told you have many names such as a marital Peacemaker and the most prized possession a woman can have in the kitchen. I had a version of you once but I was such a young cook I did not know the type of Joy I could obtain from you so I destroyed our relationship and let the love rust away. I was later taught different things to do if I ever obtain you again and trust me it would be all out of love. I am making plans on one day having you in my life again and in my home. Mark my words, I will always make sure I get the best fire out of you. I know now that nothing can achieve the type of flavor that only you can give me. I promise if you give me the chance I will constantly season you with my love, never abuse you or misuse you. Most important I will take the wise words from my grandmother that if you are ever in my arms I will use you as a weapon for those who come against me. Also, I will make sure I make the best cornbread and fried steak that I ever can achieve with your help. So please allow me the love and patience of joining my team and being my prized possession. And you will be with me for the rest of our lives my cast iron skillet! Please come back into my arms.



## RECIPE: Glühwein (Mulled Wine)

By Claire Berman

When I was in my early twenties, I had the opportunity to live in Germany for two years – first during my junior year of college, and then for a year after college teaching English at a German high school. The weather in Germany was a lot like the weather in Boston – beautiful and mostly temperate for a few short months during the summer, and then cold, gray, and wet for long stretches of fall, winter, and spring.

I have always loved winter partly because of how home starts to feel cozier when you come inside to escape from the



cold darkness, and you can climb (and remain) under a blanket on the couch. Even so, one of my favorite parts of winter in Germany was held outdoors: the Christkindlmarkts, or Christmas Markets. Even though they are held outdoors, Christmas Markets in Germany embody the warmth of inside with beautiful soft lighting, lots of stalls selling unique home crafted goods and food, and most iconically, Glühwein. A hot mulled wine, Glühwein literally translates to "glow wine," which is a good description for the feeling you get after a glass or two.

Imagine that it's a chilly, perhaps even slightly wet evening in early December. You've bundled up to brave the weather and wander around the Christmas market with friends. You come to a Glühwein stall (one of many), and the inviting smell of cinnamon, cloves, and orange peel wafts over you. You buy a glass, which comes in a small mug decorated with a cozy winter scene, and you

stand around a small high top table with your friends, taking slow sips and letting the sweet mulled wine warm you from the inside out. Maybe you pair it with a snack, such as a package of hot spiced nuts or a Flammkuchen (a thin, crispy flatbread). When you're done, you return the cup to the stall – or you hang onto it as a souvenir. I had one from 2003 in my kitchen cupboard for almost two decades until it tragically broke last year! The recipe below is the one my German friend Esther wrote down for me when we were 21. While this is a classic outdoor drink in Germany, it is in fact perfectly acceptable to serve it indoors as well!



#### **INGREDIENTS:**

- 1 bottle dry or half-dry red wine
- 1 piece star anise
- One 3-inch cinnamon stick
- 10 whole cloves
- 1 orange
- Honey to taste

#### **INSTRUCTIONS:**

Pour the wine into a pot and add the spices (you can add the star anise and cloves in a spice packet to make it easier to remove them later).

Peel  $\frac{1}{2}$  - 1 orange and add the peel into the pot. Break up the rest of the orange and add it to the pot as well and stir.

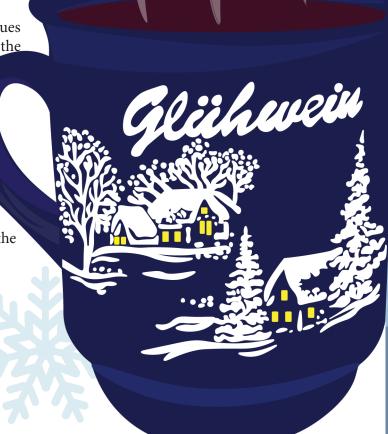
Cook over medium heat until it's hot but not yet simmering (this is important so the alcohol doesn't evaporate out!).

Turn down the heat to very low so that it continues to cook but not simmer or boil. Place the lid on the pot and keep it tightly closed for at least 10 minutes (or longer if you want the flavors to mix more). The most

Take it off the heat and add honey until it's the right level of sweetness for your own taste. You can either serve right away or return it to a low heat for longer if you want to keep it warm. When it's ready to serve, remove the spices, serve into mugs, and drink!

important thing is that it never boils.

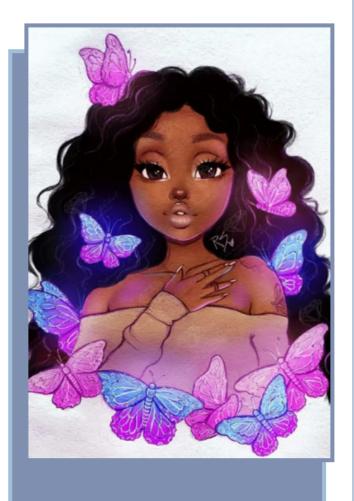
This recipe for hot, sweet, mulled wine is **perfect for winter.** Note that the end result still contains alcohol since it doesn't get boiled for a delicious non-alcoholic alternative for a winter drink, try this recipe for mulled apple cider!



#### Featured CAB Member: Queen K

Hello, I am a CAB member from Texas Children's Hospital, Site 19. I have been positive for 17 years, and I'm a mother of two. This journey has been a long but fulfilling one. I found out I was positive 17 years ago when I was pregnant with my first daughter. At that time, I thought my life was over. I felt as if I had no reason to live at all. But God placed me with the right people at the right time, and here I am: 17 years later, living my life to the fullest. I have been undetectable for 17 years and doing a lot of research and work that I love to do.

I have learned so much along the way from such a wonderful, great people, from doctors to nurses to friends - my butterfly sisters and all around wonderful people with beautiful souls. I really appreciate you guys and love each and every one of you, I don't know where my life would be without any of you guys. And now I am now using my diagnosis to help be the best Advocate I can be. I am doing this by representing Texas Children's/ Baylor Hospital as a PHACS and HOPE CAB representative. I decided to do this because I wanted my community to have a voice and also to be in charge of not only my healthcare, but my girls' healthcare. I am really shy about talking about my diagnosis because my family is not a safe space. There are only a few people in the world who truly know my status, and I am comfortable with that. And I also would like to tell those who are comfortable with not sharing their status because of stigma, discrimination, and just plain hate - it's okay, and you're not alone. Most important, it is your right and your choice. I also would like to thank Site 19 for making this a safe space for me to thrive and to have a voice, but still remain anonymous. I hope and pray that maybe one day, there can be a world where there is no stigma. but until then, thank you all for giving me this platform and using my choir voice to speak volumes to the healthcare world.





February 2024 | Volume 16, Issue I | PAGE 6 OF 19

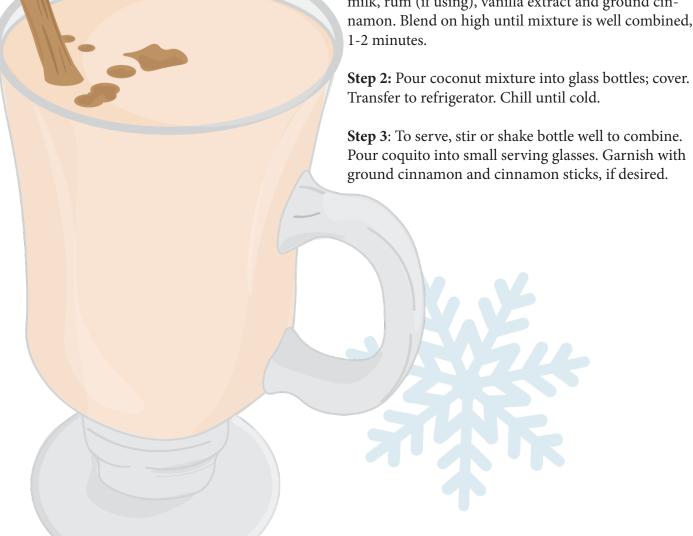
# RECIPE: Coquito Courtesy of Yesenia

#### **INGREDIENTS:**

- 1 can (13.5 oz.) Goya coconut milk
- 1/2 cup Goya sweetened condensed milk
- 1/2 cup white rum (optional)
- 1 tsp. vanilla extract
- 1/2 tsp. ground cinnamon, plus more for garnish if desired
- 2 cans (12 oz. each) Goya evaporated milk
- 1 can (15 oz.) Goya cream of coconut

#### **INSTRUCTIONS:**

**Step 1:** In bowl or blender, add evaporated milk, cream of coconut, coconut milk, sweetened condensed milk, rum (if using), vanilla extract and ground cinnamon. Blend on high until mixture is well combined,



## **RECIPE:** Kim's Blue Heaven

By Kimbrae

#### **INGREDIENTS:**

- A bag of frozen blueberries
- A container of fresh blueberries
- A bottle of blueberry juice
- A bottle of your favorite vodka (2 ounces per drink/serving) skip this if you'd like to keep it non-alcholic

• Sprite or 7 Up (optional)

The back story of my blueberry surprise recipe. (I'm playing with the name of the drink!): I was at one of my first PHACS retreats and the hotel gave the participants two free drink coupons. I was already in my room but I had many phone calls to come to cocktail hour and use my drink coupons. When I got there, I saw one of our previous family members M (she is no longer with us because she moved on to a new job). M was talking about how she was almost kidnapped by her Uber driver! And we are all convinced it was a body in the trunk! So of course my interest was peaked to hear the end of the story, which included her pulling pieces of hair out and stuffing it in the backseat just in case she came up missing. (She was okay and today this is one of our favorite stories to laugh about.)

When I went to the bar they told me they did not do cranberry vodka they only do their signature blueberry vodka. I am not a regular drinker, but it was disgusting.

So I decided to take it and make it my own.

#### **INSTRUCTIONS:**

**Step 1:** Gather ingredients. Rinse and dry one container of fresh blueberries.

**Step 2 :** Take your serving glass and fill with equal parts fresh blueberries and frozen blueberries. The reason for the frozen berries is they take the place of ice which can melt and dilute the alcohol and flavor of the drink. Add the berries to a blender. Top the berries off with blueberry juice (about 1/2 a cup) and 2 ounces of vodka. Mix well.

**Step 3:** Pour your concoction into your glass. For kids or a non-alcholic option, skip the vodka and top the slush with a soda of your choice. For a less slushy consistency, add more juice (more like a drink on the rocks).

I guarantee this new version of fruit and vodka will bring you into the 20th century of cranberry and vodka! You might never go back.

# **Snowy Night**

## by Mary Oliver

Last night, an owl in the blue dark tossed an indeterminate number of carefully shaped sounds into the world, in which, a quarter of a mile away, I happened to be standing. I couldn't tell which one it was the barred or the great-horned ship of the air it was that distant. But, anyway, aren't there moments that are better than knowing something, and sweeter? Snow was falling, so much like stars filling the dark trees that one could easily imagine its reason for being was nothing more than prettiness. I suppose if this were someone else's story they would have insisted on knowing whatever is knowable - would have hurried over the fields to name it - the owl, I mean. But it's mine, this poem of the night, and I just stood there, listening and holding out my hands to the soft glitter falling through the air. I love this world, but not for its answers. And I wish good luck to the owl, whatever its name and I wish great welcome to the snow, whatever its severe and comfortless and beautiful meaning.

## **PHACS Member Profile:**

Natalie Lewis-Vass, MPA (she/her)



Hi, CAB members! I am the Senior Project Manager for the HOPE study (Health Outcomes around Pregnancy and Exposure to HIV/Antiretrovirals). I provide day-to-day oversight of HOPE study operations and manage the study's administrative and financial management. I also work to support and promote the study's engagement with the HOPE CAB.

I was raised mostly in Vermont by a single mom but moved to Istanbul, Turkey and Nairobi, Kenya during high school for her job. I returned to my home state for college and attended the University of Vermont to study Political Science with minors in German and Sociology. Thanks to my mom, I have been passionate about expanding and improving access to reproductive and sexual healthcare from an early age. In college, I worked on campus at the Women & Gender Equity Center and became involved in multiple clubs to help to

improve resources and advocate for all students. After graduation and before joining the HOPE study in September 2023, I worked in New York City for four years at the Guttmacher Institute supporting research focused on abortion, contraception, and pregnancy. While working, I also went to graduate school at New York University to receive my Master's in Public Administration, focused on non-profit management and policy.

I was drawn to HOPE and PHACS because of the network's clear commitment to community-driven research that makes a positive impact. I have learned so much in my first few months of work and I feel so lucky to be a part of this community.

### Winter Activites: USC CAB

#### MCA\* Spanish-Speaking CAB at University of Southern California

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

#### By Guadalupe

In Los Angeles, CA, every year, for 18 years, the Annual Women's Conference on HIV/ AIDS Treatment has been held. All women living with or affected by HIV/AIDS are invited to this conference to obtain current information on treatment and other aspects of HIV/AIDS.

Last December, more than 150 women gathered to listen to and participate in this conference. Lectures were offered in English and Spanish, as well as bilingual lectures. The Spanish Community Advisory Council (CACE) of the Center for Infectious Diseases and Virology for Mothers, Children and Adolescents/Adults participated in the planning and organization of this event. In addition, there were presentations for attendees, such as Emotional Empowerment in Women in their BioPsychoSocial Environment and a panel on the Pod Cast "Confessions" which deals with how women living with HIV have coped with this disease.



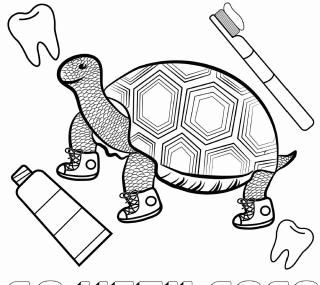
Community events like this are important for the population living with HIV/AIDS because it is a reference point to obtain up-to-date information regarding the disease.



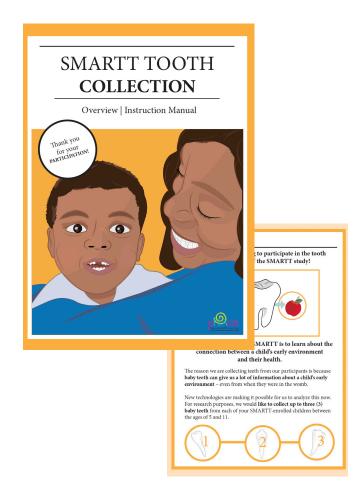
## **HECC Updates**

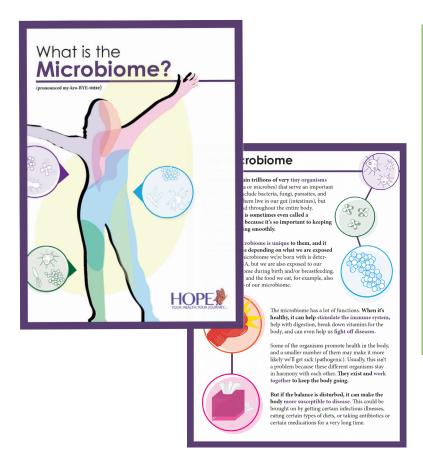
It's been an exciting fall and winter at the Health Education and Community Core (HECC)-our roster of creative projects and community collaborations continues to expand! This fall, we successfully launched Go with Coco, PHACS' first activity and coloring book for 5-, 7-, and 9-year olds in SMARTT featuring a tortoise named Coco. Now, our team is developing a new installment of the Coco series. This time, our beloved tortoise embarks on an adventure to visit the tooth fairy. With the SMARTT protocol beginning to collect baby tooth samples from participants, these new coloring pages will help kids learn a bit of the science behind teeth. Like the original Go with Coco, the new pages will be translated into Spanish (the Spanish version will feature Ratoncito, the tooth fairy character in many Spanish-speaking countries). The coloring pages will accompany a designed brochure for parents that explains the reasons for tooth collection and provides step-by-step instructions on how to submit tooth samples for the study. All tooth collection materials will be available for digital download and print later this year. You can see a sneak peak of the coloring pages in this edition's CAB Kids on page 15!

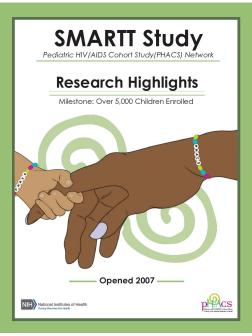
The HECC is also rolling out several other resources to support participants. First is a handout on the microbiome. After we heard from site staff about requests from HOPE participants to define what the microbiome is and why it is relevant to participants, the HECC worked closely with the Community Task Force, HOPE and PHACS CABs, and PUG to develop a brochure outlining the science behind certain specimens requested at study visits (like saliva or vaginal swabs). The HOPE Microbiome brochure is available on the PHACS website, and versions for SMARTT and AMP Up will be available this spring.



# to visit the Tooth Fairy!







Last year, the SMARTT protocol reached a huge milestone by enrolling its 5,000th child participant into the study. To celebrate the SMARTT study, which opened in 2007, the HECC is developing a brochure highlighting its major scientific findings. Created for our sites and participants, the brochure celebrates our network's collective effort in improving the living of those living with or affected by HIV. The brochure will be made widely available later this spring.

This winter, our community groups had an exciting opportunity to share their thoughts and perspectives with the National Institutes of Health (NIH). NIH requested community input about priorities in research around women living with HIV from people with lived experience. Members of the PHACS English and Spanish CABs and the HOPE CAB held discussions and completed a written survey to share priorities they would like to see shape the research in the future. This was a great opportunity for community members directly influence the science, focusing on the goals and collective good of the community.

Finally, the HECC is also working on completing new designed lay summaries of four recent PHACS publications, as well as developing our first animated lay summary of another publication with a voiceover recorded by one of our Community Task Force members! We are working on a soft launch of the new Project Positive website resource for PHACS and HOPE participants. We are also writing a paper describing the HECC model, and we hope this can help other research networks expand their own community engagement efforts. Stay tuned for updates on these projects later this year!

As always, this is just a small fraction of the work accomplished by the collective effort of the HECC. We are truly thankful for our participants and community group members: without you, these accomplishments would not be possible.

February 2024 | Volume 16, Issue I | PAGE 13 OF 19

## CAB GLOSSARY

**Arm:** The treatment or placebo group in a clinical trial may be referred to as an "arm" of the study.

**Incidence:** The rate at which, or how quickly, NEW cases of a disease are happening.

Example: In one single day, the daily **incidence** of COVID-19 infections was 30,900 in Italy. This means that on that day, there were 30,900 NEW cases of COVID-19. This number does not count the total number of people who already had COVID-19 before that date.

**Prevalence:** Refers to the proportion of the population affected by a disease at a particular point in time (like a camera snapshot).

Example: The **prevalence** of COVID-19 infetions was 500,000 in Italy on a certain date. This means that on that day, there were 500,000 cases of COVID-19, including any new cases that happened that day. This number includes everyone who had COVID-19 at that moment in time.

**Peer Educator:** A person who provides information and training to a person with a similar background or characteristic.

Check out PHACS' new glossary of terms with pronunciation guides!

#### **CAB WORD SEARCH**

٧	M	G	Ν	С	Υ	Ν	Υ	J	S	L	L	Α	С		Ν	1	L	С	W	T	D	Е
L	Κ	G	R	Ν	Е	V	1	T	С	Е	F	F	Е	Н	G	L	Υ	U	R	D	Υ	T
G	0	T	K	С	Z	В	1	D	٧	D	F	Ε	D	U	С	Α	Τ	0	R	S	T	0
F	Т	R	В	M	D	S	U	D	G	Ρ	T	Α	Α	В	U	F	R	L	Z	Α	Χ	Ν
٧	F	Е	M	Ε	Ī	Е	M	В	U	S	R	G	G	J	В	Ν	J	С	M	L	S	0
D	L	Α	В	0	R	Α	T	0	R	Υ	С	0	L	Е	T	M	J	Ρ	S	Α	F	Н
0	Т	T	L	Χ	В	R	Ν	В	R	Α	W	С	G	V	Q	S	J	Е	Υ	R	С	٧
0	L	M	J	Е	С	G	G	Α	K	J	L	J	R	R	K	Ν	W	T	Υ	I	Z	R
L	D	Е	В	L	В	K	С	Ρ	G	R	U	Α	J	ļ	Е	L	V	D	Ν	V	В	R
В	0	Ν	Q	Χ	В	U	J	Υ	Α	T	G	L	L	F	R	S	Е	Е	Κ	D	M	K
S	В	T	Υ	G	T	Е	Κ	M	С	D	R	Α	D	Ν	Α	T	S		Ν	S	J	D
T	Е	U	0	T	1	L	S	Ν	Ρ	1	В	M	Ρ	T	1	L			L	Ρ	J	K
0	С	U	S	M	Υ	D	T	Ν	Χ	Α	0	K	Υ	D	V	В	Α	R	0	С	Z	
0	Α	V	0	0	Z	В	Н	M	Е	С	Ν	Ε	D	l	С	Ν	-	S	V	Ν	Q	L
L	L	W	Н	T	Ν	Ρ	S	D	Н	Χ	I	G	U	J	Α	Ρ	L	С	W	Ρ	M	W
Ν	Ρ	С	Α	R	M	Α	Κ	Κ	F	]	Κ	D	S	F	Р	Ε	Ε	R	Χ	L		Р

ARM
BLOOD
CLINICAL
EDUCATOR
EFFECTIVE

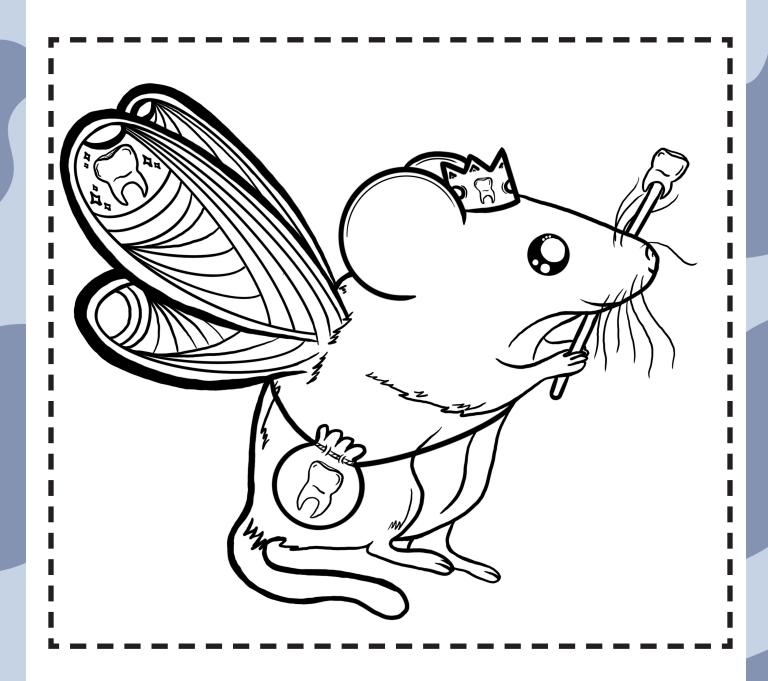
INCIDENCE LABORATORY PEER PLACEBO PROGRESSION STANDARD TREATMENT VIRAL

ANSWERS ON PAGE 17

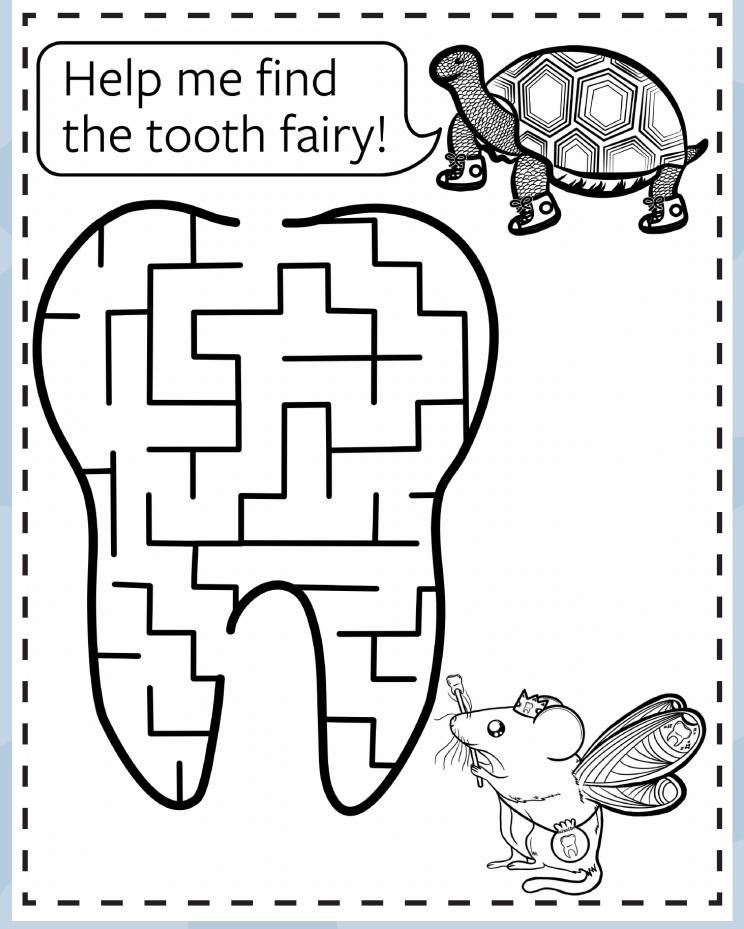
February 2024 | Volume 16, Issue I | PAGE 14 OF 19

## **CAB KIDS**

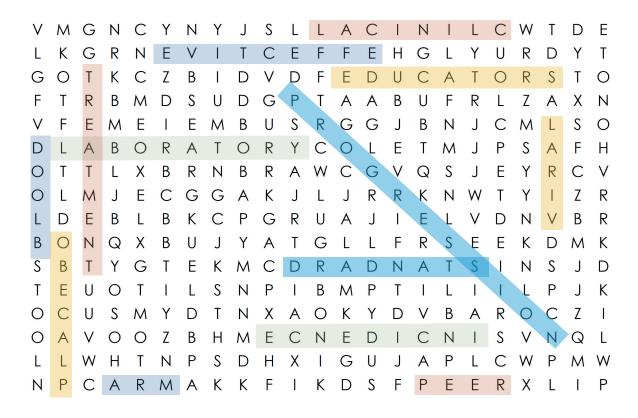
**INSTRUCTIONS:** Cut along the dotted line to remove the CAB Kids coloring pages.



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



## **WORD SEARCH ANSWERS**



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

February 2024 | Volume 16, Issue I | PAGE 17 OF 19

## **DATES TO KNOW**





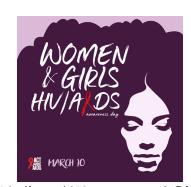
National Black HIV/AIDS Awareness Day

February 7



HIV Is Not a Crime Awareness Day

February 28



National Women and Girls HIV/AIDS Awareness Day

March 10



National Native HIV/AIDS Awareness Day

March 20

## **RESOURCES**



## Happify (App) <a href="https://www.happify.com/">https://www.happify.com/</a>

A free app avalible on the App Store and Google Play. The app offers a **variety of science-based activites to help cope** with stress, negative thoughts, and practice mindfullness through meditative practicies.



# The Free Mindfulness Project

https://www.freemindfulness.org/

A collection of free resources, including **guided meditations,** meant to support individuals for stress reduction through **mindfulness practices** 



## Therapy for Black Girls (Podcast)

https://therapyforblackgirls.com/podcast/

A weekly podcast focusing on mental and physical health, as well as **personal growth and development.**