

A Community Advisory Board (CAB) Newsletter published by:

The Pediatric HIV/AIDS Cohort Study (PHACS) CAB

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## FROM OUR CAB CHAIRS

Kimbrae, PHACS CAB Chair

The sky's the limit but don't be the limit.

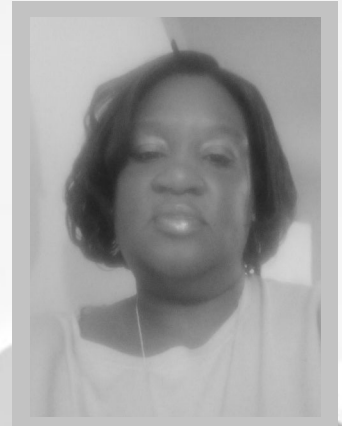
Greetings everyone from your CAB Chair! My article will be about never putting a limit on the impossible. We know that the whole body is like a machine that needs constant care and maintenance. If even a small part is out of place, injured, or hurt, then the whole body will not function properly.

I'm here to remind you that if we move forward with self-care, we also have to remind ourselves not to limit our spiritual care. We need to stay balanced. What that means is that sometimes we can be our biggest critic. When we are already at the mountaintop holding the trophy, we can bring ourselves down by thinking about all of the what ifs – What if I did this better? What if the world doesn't support me? What if the world doesn't love me? We can get in our own heads instead of just looking at reaching the stars and beyond.

I want you to know that your purpose is to be the best version of you. You deserve the best that the universe has to offer no matter what anyone says (including you!). Be mindful that there will be tough days. Know that although we can't change yesterday and that tomorrow hasn't come, we can put all our energy into every moment in the present. We should value every second and get the most out of life. When I say this, I'm not saying to live every moment as if it were rainbows and ponies. I'm saying that a good cry is okay if that's what helps you get to a good smile.

Learn how to accept that you are beautiful inside and out. Take the compliment; you deserve it. Most of all, remember that you can face any challenge even if you don't overcome it. It might not be done in a day. It might not be done in 50 days - heck, even 50 years! Enjoy the journey, not the battle.

I'm always here for support. Keep your head up because you never know who's looking behind you and admiring your strength!



Exzavia, PHACS CAB vice Chair

Happy New Year to my fellow CAB family and PHACS!

I hope that we all will have a prosperous year. I'm looking forward to what 2022 will bring us and hope that we can continue to accept and give knowledge as we have in the past.

Feeding the whole body can mean many things. For me, it means to push harder when you think you can't succeed.

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# FROM OUR CAB CHAIRS

## ( CONTINUED)



Feeding your whole body can sometimes feel like a fight for survival. I say this because sometimes life will bring many obstacles (COVID-19 for example). We are all hoping it will end. While COVID-19 has become part of our everyday surroundings, you may wonder how can you keep moving. I have continuously stayed focused on my goals and have accomplished more than I could have imagined despite the obstacles in my way.

“...I'm going to keep pushing for more.”

I share all of this with a sigh of relief, knowing that no matter how hard it got or will continue to get, I'm going to keep pushing for more. I just graduated with my Associate's degree and I'm going to continue on this journey until it's completed! Being told that things will be difficult might make you second guess yourself.

Feeding the whole body can mean many things. I figure you won't know unless you try. I will continue to feed my mind, spirit, and soul. Feeding the whole body is me not giving up and having a determined mind.



# MY SEARCH FOR HOLISTIC HEALTH



I am extremely pleased to be given the opportunity to submit an article for this particular newsletter, which as I understand is focusing on holistic health and wellness. As a Compliance Officer, I am often confronted with decisions on work flows that impact the quality of the work which takes place at the organization for which I work.

As a human being, I am also frequently confronted with decisions that may impact the quality of my life. This is something that I in fact think about frequently, having undergone many life changing and often tragic events- just as I am sure many of the readers may have experienced. In 2008, I was severely burned and injured in a house fire. I escaped via a 2<sup>nd</sup> story window, but not before enduring burns over 28% of my body and critical smoke inhalation. The fall itself caused me to shatter my right leg femur and hip. I was not expected to survive the first few nights and underwent respiratory arrest two times. Suffice it to say, I survived and not only survived, but thrived. That had been the worst time of my life, until my husband unexpectedly passed away last year just ten days before Christmas, leaving me with two very young children.

Once again, I was faced with critical decisions that I had to make both for myself and for my children, and I knew that the health of my children was dependent on my ability to survive, not only in a physical sense but in an emotional and psychological sense. Dealing with young children is difficult as many

can attest, but dealing with them under the weight of intense grief and the upending of all that you thought was permanent and lasting is nearly debilitating.

However, I share these stories because I did in fact pull my life together after both events, and it is my desire to share some of the tools that I have learned on this journey. I desire to share some things that carried me not only through horrible experiences, but also in my everyday life.

"once again, I was faced  
with critical decisions  
that I had to make both  
for myself and for my  
children, and I knew that  
the health of my children  
was dependent on my  
ability to survive, not  
only in a physical sense  
but in an emotional and  
psychological sense."

My search for holistic health started when I was still in the hospital after the fire, and could not walk at all because of my leg and hip. I was stuck in a bed and could not move,

because the skin grafts had to heal and every bit of movement would cause intense pain. I finally had been released from the intubation tube and thus from the drugs that initially kept me unconscious. I decided that I needed to change my life and more than that, my perspective on life. To me, this is what everything -- and the key to mental health -- is about: perspective. Perspective is the way in which we interact with and interpret the events in our lives.

I changed my perspective and with it, the way in which I view my world and myself. Changes to my perspective did not come easily and essentially, and if you are someone who leans toward negative self-talk or negative outlooks, changing perspective may take some initial significant effort. But it is not impossible, and it is worth the efforts. A typical human has approximately 70,000 thoughts a day. Of these thoughts, only 5,000 are new. The remaining 65,000 are thoughts that we have had before, and many times these are on a loop. Things such as "I am not good enough, I need XXX in order to be happy, good things never happen to me, I don't deserve X or X will never happen to me..." can get stuck unconsciously in our brain wiring and actually interfere with the way in which we view ourselves and the world.

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# MY SEARCH FOR HOLISTIC HEALTH (CONTINUED)



How did I stop these thoughts? Here are a few tools:

## GRATITUDE AND POSITIVE AFFIRMATIONS

Spend at least five to ten minutes a day proactively thinking about what you are grateful for. Find a positive affirmation and say it to yourself, even if you don't believe it. Things such as, "I am good enough, I deserve to get what I want, I am good at what I do and this will lead to me getting what I want." Over time, these new thought patterns will begin to overtake the old thought patterns and instill a new way of viewing yourself and your surroundings.

## MEDITATION

Many people feel that meditating is a waste of time, or that it is some silly practice that "new age" people use to relax themselves. In fact, the true practice of meditating is actually the act of sitting and listening to, observing, and allowing yourself to acknowledge all of the thoughts that come into your head. If you spend time doing this, you can actually find those unconscious thoughts and address them head on. It is ok if you hear negative self-talk when listening to your thoughts, but the idea is to learn compassion for yourself and release them. Or, at least acknowledge that they are there and learn to replace them with more affirmative, positive thoughts. Over time, you will learn to better listen to your internal dialogue even when not in active meditation, and this will allow you to "catch" yourself in the midst of negative self-talk and thus learn to control it.

## JOURNALING

Learn to write down the things that you are seeking in your life. Also write down your thoughts in free writing fashion. Learn to understand how you think and what you think about most often. Finish every journal entry with an intent to make changes in your life that will increase the possibility of good things happening. The law of attraction is a powerful force in life, and by putting thoughts to paper, you can better focus on what truly makes you happy and what you are actively thinking.

## VOLUNTEERING TO HELP OTHERS

One of the best ways to care for your own mental health is through volunteering to secure the health of others'. This does not necessarily require that you sign up for a soup kitchen or volunteer at an established charity, although these things are extremely rewarding. Instead, this can be as simple as asking someone how their day is and mean it. It might be reaching out unexpectedly to a friend to ask how they are doing. Little and unexpected acts of kindness to others has been proven to increase our own sense of self-worth.

These are just a few of the ways that I have learned to confront and handle negative emotions and self-talk. I need to keep remembering that more than half of being happy lies with my ability to react with positivity to the things outside of my control, and this starts with self-care in the mental health department. I used to feel like it is selfish to take time out of my day to care for myself, especially with young children, but by making myself a priority I began to develop into a better person for the sake of all of the individuals in my personal life.

(Submitted by: Colleen)

# FEEDING THE WHOLE BODY

WE ASKED CAB MEMBERS AND PHACS STAFF MEMBERS TO TELL US ABOUT HOW THEY *FEED THE WHOLE BODY*. WE FOUND THAT OUR NETWORK HAS ALL SORTS OF INCREDIBLE WAYS OF NOURISHING THEIR MIND, BODY, AND SPIRIT! THE FOLLOWING ARTICLES CONTAIN IDEAS, TIPS, AND RESOURCES FOR FEEDING THE WHOLE BODY.



## FEEDING THE EMOTIONAL AND INTELLECTUAL SELF

MANY CAB MEMBERS AND PHACS STAFF FEED THEIR EMOTIONAL AND INTELLECTUAL SELVES THROUGH READING! PLEASE SEE A LIST OF CAB AND STAFF-RECOMMENDED AUTHORS AND BOOKS BELOW INCLUDING QUOTES FROM CAB MEMBERS AND STAFF:



**No Mud, No Lotus: The Art of Transforming Suffering** by Thich Nhat Hanh

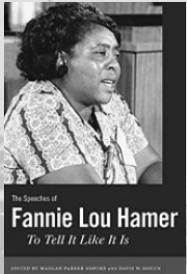
**Being Peace** by Thich Nhat Hanh

“Anything by Thich Nhat Hanh is wonderful. His book “Being Peace” was my entry into meditation and mindfulness back in the early 90s. His writing is so simple and yet so profound.”

(Continued on [page 6](#))

# FEEDING THE EMOTIONAL AND INTELLECTUAL SELF (CONTINUED)

**The Long Shadow of Little Rock: A Memoir** by Daisy Bates



**The Speeches of Fannie Lou Hamer: To Tell It Like It Is** by Maegan Parker Brooks

“Something that I have been doing as of late is centering voices from the past. People may not think how it translates to today, but it really does. They have wonderful stories that actually make me feel like I can still push forward in the 21st century, even though they're not from my time. I like reading the voices of people from the past and people from other experiences and other cultures, who may have some wisdom in how I interpret it for modern day.”

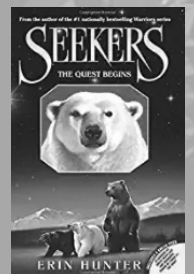
**30 Days of Self-love: A workshop for gay men** by Stephan G. Dahl, PhD



The **Harry Potter** Series by J.K. Rowling

“I am rereading Harry Potter and I read it, when I was a kid and I find that absolutely the most comforting thing to reread.”

**Seekers, The Quest Begins** by Erin Hunter



**Healing After Loss: Daily Meditations For Working Through Grief** by Martha Whitmore Hickman

“This book has daily meditations for each day of the year. It's not specifically religious so everybody can bring to their own belief system to it.”



# FEEDING THE SOUL SHORT READS

A collection of short reads I pick up whenever I can't fall asleep or need a pick-me-up!

## SHORT STORIES

**Someone Who Will Love You in All Your Damaged Glory** by Raphael Bob-Waksberg

A humors and heartfelt collection of short stories about love. A particular highlight is the love story told from the perspective of their dog.

**The House on Mango Street** by Sandra Cisneros

Beautiful and poignant vignettes about a young Latina girl growing up in Chicago. The writing is lyrical and descriptive, reading like a dozen beautiful poems.

## POETRY

**Devotions** by Mary Oliver

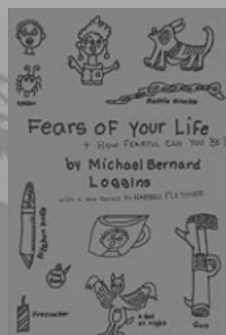
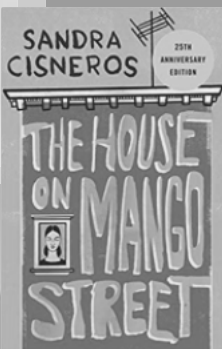
A selection of poems from her entire life's work. Mary Oliver weaves descriptions of nature's beauty and the universal truths of humanity like no other.

## ZINE

**Fears of Your Life** by Michael Bernard Loggins

An honest and endearing collection of one man's fears. A beautiful reminder that we are all more alike than we think!

*Submitted by: Mandy*



# FOOD FOR THE SOUL

MANY CAB MEMBERS AND PHACS STAFF FEED THEIR BODIES AND SOULS BY COOKING AND BAKING! SEVERAL CAB MEMBERS EXPLAINED THAT COOKING AND BAKING CAN BE THERAPEUTIC AND USE THESE ACTIVITIES FOR SELF-CARE. PLEASE SEE A LIST OF CAB AND STAFF-RECOMMENDED COOKING RESOURCES:

“I wanted to talk about recipes because I think I like the idea of indulgent and healthy. I think there's a lot of emphasis on healthy food, all the time. Which is important, but I also believe, you know, ice cream is good for the soul and good for the mind, and so I think, to include both in your life is a really good idea.”



**100 Techniques: Master a Lifetime of Cooking Skills, from Basic to Bucket List** by America's Test

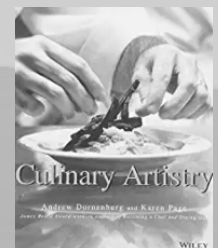
**The Science of Cooking** by Stuart Farrimond



**Ratio: The Simple Codes Behind the Craft of Everyday Cooking** by Michael Ruhlman



**Culinary Artistry** by Andrew Dornenburg



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# SELF-CARE CORNER

DURING THE FALL 2021 VIRTUAL CAB RETREAT, CAB MEMBERS SHARED ABOUT THE IMPORTANCE OF SELF-CARE. ONE CAB MEMBER NOTED THAT “YOU CAN’T CARE FOR OTHERS IF YOU DON’T CARE FOR YOURSELF, TOO.” THE CAB WANTS TO REMIND ALL MEMBERS OF THE PHACS NETWORK TO TAKE CARE OF THEMSELVES SO THAT WE CAN ALL CONTINUE TO DO THIS AMAZING WORK TOGETHER. PLEASE SEE SOME SELF-CARE RECOMMENDATIONS FROM CAB MEMBERS AND STAFF BELOW:

Coloring Hair

Sleeping

Taking Baths

Decorating (and Re-Decorating!)

Grounding/Earthing

Chiropractic Care

Watching TV

Card Making

Self-Care Subscription Boxes

Puzzles

Low-Impact Exercises, Stretching\*

Yoga\*



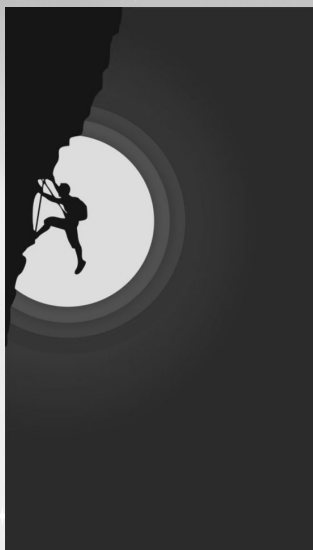
*\*Be sure to check with your medical team before starting any exercise or yoga routine. Remember, you know your body best. If something doesn't feel right, do not do it. If it does not feel good (specifically sharp pain or discomfort) then take note of that and stop the movement.*

# ADRENALINE!

Feeling the  
adrenaline in my  
body is feeding my  
body with life!



## UPCOMING EVENTS



**February 7:** National Black HIV/AIDS Awareness Day

**March 10:** National Women and Girls HIV/AIDS Awareness Day

**March 20:** National Native HIV/AIDS Awareness Day

**April 10:** National Youth HIV & AIDS Awareness Day

**April 18:** National Transgender HIV Testing Day

**May 18:** HIV Vaccine Awareness Day

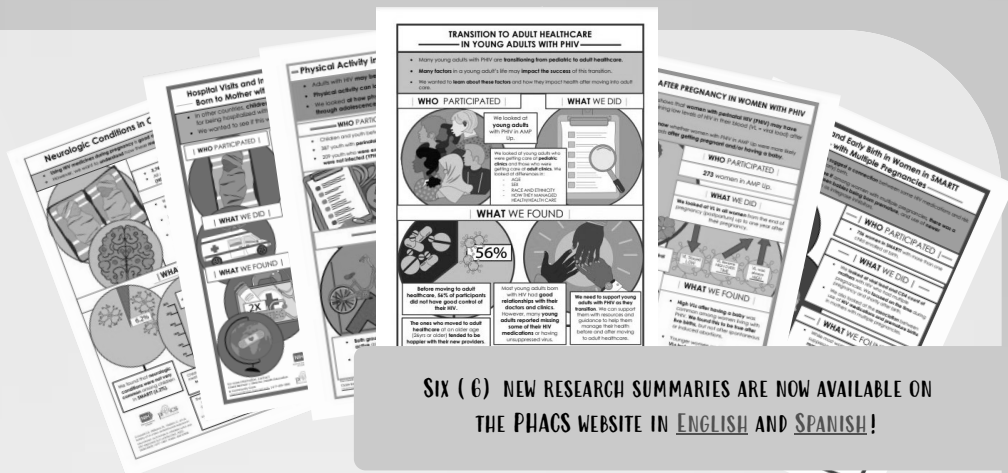
**May 19:** National Asian & Pacific Islander HIV/AIDS Awareness Day

**May 24-25:** PHACS Spring 2022 Network Meeting

**June 5:** HIV Long-Term Survivors Awareness Day

**June 27:** National HIV Testing Day

# HECC UPDATE



SIX ( 6 ) NEW RESEARCH SUMMARIES ARE NOW AVAILABLE ON THE PHACS WEBSITE IN [ENGLISH](#) AND [SPANISH](#)!

The Health Education and Community Core (HECC) is in full swing! Since the July newsletter, the HECC has worked a variety of research and creative activities. Some of our research activities included:

- COMPLETED 2 CAPSULE REVIEWS
- COMPLETED 3 CONCEPT SHEET REVIEWS
- ADDRESSED MANY RESEARCH PROJECT QUERIES ( SEE BELOW)

Part of the HECC's mission is to identify and address information gaps in PHACS to support our participants, staff, clinicians, and researchers. The Project Queries listed above spanned a range of topics, including: working to identify appropriate racial justice measures in PHACS; producing a HOPE logo and project slogan; designing icons for each PHACS Working Group (WG) and Task Force (TF); facilitating the Fall 2021 Virtual CAB and PUG retreats; drafting the PHACS Community Engagement Policy; designing and disseminating six (6) research summaries; creating recruitment video stills for the AMP Up Hearing grant application; designing and drafting new banners for the PHACS website (coming soon!); providing TF feedback for the AMP Up Series surveys; providing TF feedback from the SMARTT maternal substance

use questionnaire; creating legal releases for HECC creative projects; and developing PHACS certificates of appreciation. We look forward to even more of these in 2022!

A Maternal Stress Supplement to the SMARTT study was funded in August of 2021. The COVID-19 pandemic has caused many people stress, anxiety, and depression. Furthermore, the combination of COVID-19 and structural racism has deeply impacted Black, Indigenous, and other people of color in the US. The study will look at individual characteristics (online survey), community factors (geocoding), and personal lived experiences (qualitative interview). The HECC assembled a team of six (6) of our existing Task Force (TF) members to serve as the primary TF for this supplemental funding. To date, the TF and the HECC has reviewed and given input on the quantitative survey, provided guidance on themes/topics for the qualitative component, and provided feedback on the geocoding component. Additionally, by recommendation of External Advisory Board (EAB) member, Dr. Amani Allen, the team has held several discussions aimed at developing a definition of "structural racism" derived from the lived experiences of participants and staff in PHACS. This is an incredibly important task that will help guide future PHACS research questions around racial justice.

The first report on HIV/AIDS was on June 5, 1981. In honor of this important anniversary, the HECC is planning to launch a multimedia

project examining the evolution of pediatric HIV/AIDS over the last 40 years with historical, cultural, and personal lenses. This may include digital/short videos, photo series, poetry, and historical timelines. Filming kits and guides were sent out to three (3) PHACS sites. These sites have been filming stories with their site CABs. The HECC is in the process of developing a website to house media from this project and future HECC creative projects.

We look forward to working with the TF, CAB, and the PUG on these exciting HECC tasks. CAB and PUG members, thank you for everything you do for the community and for PHACS!

*Submitted by: Megan and Claire*

# CAB GLOSSARY

**Class (of medicine):** A group of medicines that work in a similar way to treat a disease or health problem.

**Data Analysis:** Studying and interpreting a set of information. Studies like PHACS use data analysis to understand the outcomes of the study.

**Food and Drug Administration (FDA):** The agency responsible for ensuring the safety and effectiveness of medicines, vaccines, and medical devices approved for use in the US.

**Open to Accrual:** A protocol is open to accrual when it has been approved and clinical site(s) can start enrolling participants.

**Standard of Care:** A treatment plan that experts agree is appropriate, accepted, effective, and widely used for a given disease or condition.

**Undetectable Viral Load:** A viral load test that shows the amount of virus in the blood sample is too low for the test to detect it. The goal of all antiretroviral medications is to help people achieve an undetectable viral load.

## MAD LIB!

**Instructions:** Play this mad lib with a friend! One friend acts as the “reader” and asks the other to fill in the underlined blanks with nouns, adjectives, and verbs. The reader inserts the words into the blanks and then reads the story aloud. Feel free to get silly!

It was a very eventful day at (PHACS site). The day started off normally, but all of a sudden there was a big boom outside. A huge spaceship appeared! Everyone at the site (verb, past tense)!

The site staff grabbed (noun) to help protect the participants.

When the doors of the spaceship opened, a (adjective) Martian family came out with their sick baby. They asked the site staff for help. The site staff had not had a Martian patient before, but realized that candy, cookies, and (noun) made the baby better.

The Martian parents was so grateful to the site staff that they showered the staff with (noun). They also gave (noun) to all the children in the hospital. But, the best gift of all was a selfie they took with their (noun). The selfie was so (adjective) that the site staff were able to hang in the clinic lobby for the whole world to see, so that they could share their story on how (PHACS site) saved a Martian baby.

Submitted by: Kimbrae



# GOALS FOR 2022

During the Fall 2021 Virtual CAB Retreat, CAB members talked about what they hope to get out of future retreats and future CAB meetings in 2022. Below is a list of CAB ideas. Join us on our upcoming PHACS CAB Zoom call to brainstorm more ideas for 2022 (the CAB call schedule may be found on the [PHACS website](#)).

Increase recruitment for the PHACS CAB, recruit new members

Check in with each other throughout the year

Develop site CAB resources/toolkit

Participate in more advocacy activities

Do more collaborative/creative projects together

Channel the energy from our virtual retreats to our in-person time together

Share activities we're doing locally in our communities and in our CABs

Share vision boards

Add time and space for mindfulness on our CAB calls

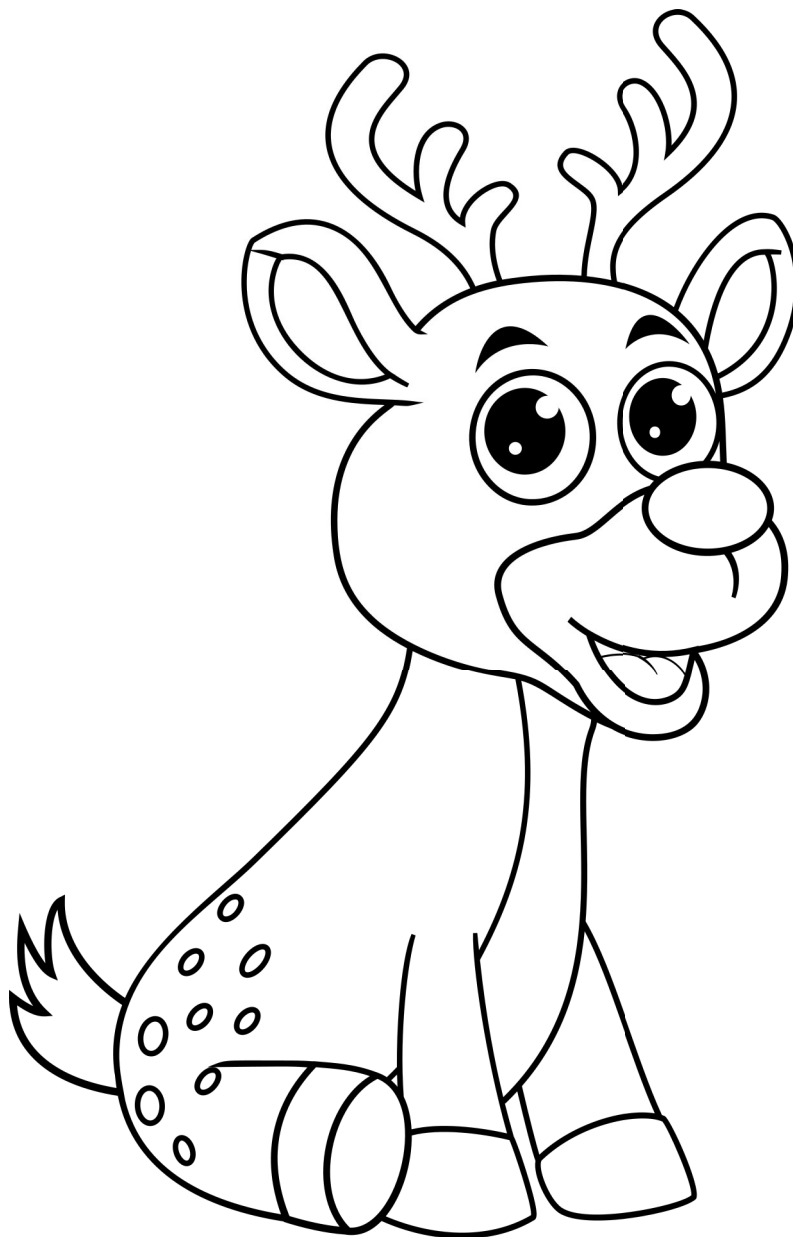
Play story building games

Encourage the CAB to develop presentations for researchers

Have more dance parties :-)

# 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.





# RESOURCES

**NIMH: Caring for your Mental Health:**

<https://www.nimh.nih.gov/health/topics/caring-for-your-mental-health>

**Outdoor Afro:**

<https://outdoorafro.com/about-us/>

**How to Meditate:**

<https://www.nytimes.com/guides/well/how-to-meditate>

**40 Positive Affirmations to Add to Your Daily Rotation:**

<https://www.oprahdaily.com/life/relationships-love/g25629970/positive-affirmations/>

**Recipes for Healthy Kids: Cookbook for Homes:**

<https://www.fns.usda.gov/tn/recipes-healthy-kids-cookbook-homes>

**Yoga vs. HIV, AIDS:**

<https://www.yogajournal.com/poses/positively-healing-2/>

**Please send all questions, comments, and suggestions for the CAB Newsletter to Megan Reznick  
([MeganReznick@westat.com](mailto:MeganReznick@westat.com)).**