

This year was all about getting together to rebuild relationships, make new friends, and find opportunities to advocate for our community. In this edition of the HAEA Youth Insider you will read about some of the exciting things that happened this year.

HAEA Youth Insider

It's been so good
to be together
again!



2023 US HAEA NATIONAL SUMMIT

If you couldn't make it to the 2023 National Summit, this is what happened:

The days were inspired by the acronym HAE: day one was about Health (H); day two focused on Advocacy (A), and, day three was about Empowerment (E).



Hey everyone! I'm Jazzy and I just wanted to share a little bit about my experience at the 2023 US HAEA National Summit Youth Programs. For those of you who were there, it was so good to see you, and for those who didn't make it, I hope to see you at a future

ARRIVAL DAY

We flew into the Orlando, Florida airport and got on a shuttle to the hotel. Then we checked into our room and got our swag bags. We enjoyed a group dinner and met some of the other people who were there. It was really cool to see some of my old friends and meet first-timers!



DAY 1

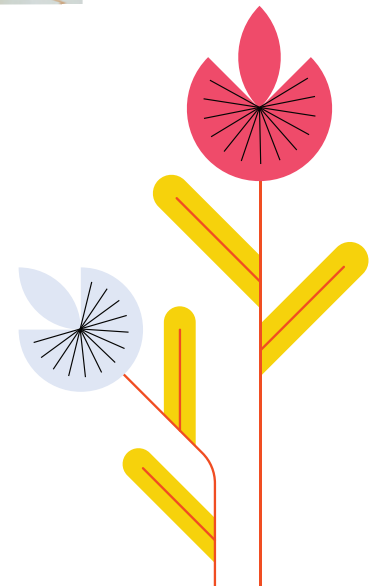
Day 1 of the program was all about Health and Wellness! We started the day with a cool icebreaker sharing our hopes and dreams for the future.

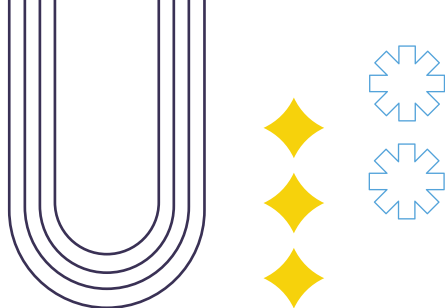
Then we divided into breakout in-the-now groups with the goal of encouraging us to live in the moment. Half of the group stayed inside for a street art themed mosaic making workshop and the other half of the group went outside to participate in lawn game challenges. I was in the mosaic workshop and I love the mosaic I created! It was really fun

and I loved being able to take my mosaic home and put it in my room.

After lunch, we participated in a mindfulness workshop and talked about techniques to help us better manage our mental health. It was actually really interesting!

That night we partied and danced at the #BeyondHAE Meet and Greet that was DJ'ed by one of the youth community members. The photobooth was a hit and we all took home photos from the event!





Day 2 was about leading HAE advocacy efforts! We started the day with an advocacy theme, learning about why it's important for young people to be involved in advocacy and communicate with our elected officials. Jess, from the HAEA, informed us about advocacy priorities for the HAEA and helped us write letters to our elected officials to ask them to support policy in favor of the HAE community. Over 66 letters were written and mailed to Washington, DC. We felt empowered and that we were able to make a difference!

After lunch, we played a Disney themed Hedbanz game. Then we worked in groups to come up with ideas to raise awareness about HAE on social media. It was really cool to explore the creativity and diversity of ideas from the group!

DAY 2



Day 3 of the program focused on how to live a life with purpose: We worked together in teams to create care packages that would be donated to kids living with chronic illnesses. Each care package included an RC Race Car, a felt tie blanket, and a superhero cape. It was amazing to see everyone work together as a team to create these projects. There was really something for everyone in this activity. More importantly, with the care packages created, we brought smiles to 12 kids who got a reminder that they are not alone! As we wrapped up our experience at the end of the day, we came together for an open mic session that gave us

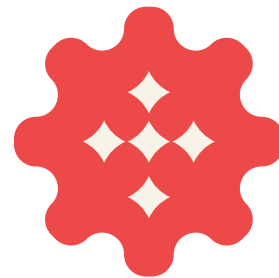


DAY 3

the opportunity to listen to our peer's stories and their experiences with HAE. It felt wonderful to get up and share my thoughts and feelings. The activity led us to experience a genuine and meaningful connection with my fellow youth community members.

The HAEA Summit is a rare event for a rare group of people that allows us to come together and build a community through our common experiences with HAE. Whether you have HAE, or have a loved one with HAE, this event truly showed us that we can find comfort and support in our journey.

WORDS OF WISDOM



We asked a group of HAEA Youth to share some words of wisdom that they wish they knew when they or their loved one was diagnosed. Here's their advice:



Rey

25 years

Diagnosed with HAE at age 10

Even if right now it feels like your HAE might stop you from doing what you love, keep going. You will learn to manage both. Your body, mind and heart will thank you. Also, practice self-care. You are not a burden. It's not anyone's fault. So, don't punish yourself with negative thoughts and habits. Reward yourself for your resilience.



Anna

18 years

Caregiver to her brother

One of the most important things is to have empathy. You may not have HAE yourself, but when someone you love does, try to put yourself in their shoes and think about how they might be feeling. Another important thing is to simply be there for them, both emotionally and physically. Try to lend a helping hand if they need it.



Brady

19 years

Diagnosed with HAE at age 12

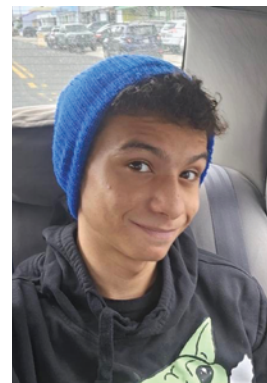
Share with the people around you so they understand and can support you. Breathe through it and calm yourself down during difficult times. You will make friends with people who understand what you're going through.

Angel

18 years

Diagnosed with HAE at age 3

Try not to worry. Life seems to give the hardest struggles and problems to the world's strongest people. It might be scary, and it might be tough, but fear not, because in a dark tunnel, there will always be light at the end. Keep going, you're a trooper, and remember, a lot of people love and care for you.

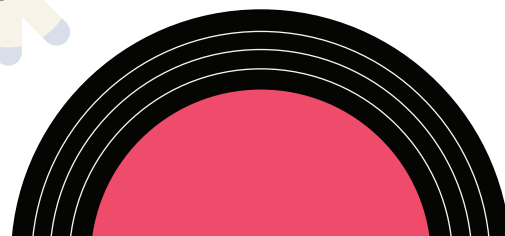
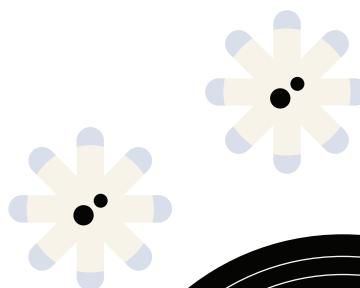


Peyton

14 years

Caregiver to his sister

Take time with your loved one and try not to bombard them with questions or your own needs while they are feeling stressed from an attack. Listen to them and their needs, it will allow you to help them feel better. And take time to simply make them happy.



BRADY CLUB



The Brady Club Kids hosted their first ever Cookies4HAE pop-up fundraiser at the 2023 HAEA National Summit!

The HAEA partnered with Cookies4Cures, a nonprofit organization that was founded by a passionate young girl named Dana who hosts cookie pop-up events to fundraise for rare disease research. Dana joined us in Orlando, Florida to teach the Brady Club kids about how to host a Cookies4HAE pop-up event, a fun and yummy way for kids to get involved in HAE awareness and fundraising.

Kids who were registered for the Brady Club programs met Dana, who shared all of her secrets on hosting a successful cookie pop-up event. Brady Club kids got to participate in a cookie baking demo from the hotel Executive Chef, Candice Wells, where they decorated their own cookies.

On Friday evening during the welcome reception, the Brady Club hosted a Cookies4HAE pop-up event where summit attendees had an opportunity to enjoy delicious cookies in exchange for a small donation. The event was a wild success!

Are you interested in hosting a Cookies4HAE pop-up fundraiser? Contact Lisa@haea.org for more information on how you can get a copy of our Cookies4HAE Guidebook.



HAE YOUTH ADVOCACY

October is HAE Youth Advocacy Month!

Advocacy Paves the Way for Change!

Why should young people be involved in legislative advocacy?

Youth involvement in legislative advocacy can convince policymakers to consider the HAE community's unique experiences and needs.

REPRESENTATION:

Young people represent a significant portion of the population, and their voices and perspectives should be heard and considered in the policymaking process.

DIVERSE PERSPECTIVES:

Young people bring diversity to the table. Youth involvement brings new viewpoints and creative suggestions that can lead to innovative solutions and better access to care for all people with HAE, creating a better future for the HAE community as a whole.

ACCOUNTABILITY:

When young people are involved in the legislative decision-making process, policymakers are held accountable to the needs and concerns of young people, ensuring that policies are inclusive and equitable.



Make a Lasting Impact in the HAE Community!

Join the HAEA Youth Advocacy Network

The Youth Advocacy Network is a branch of the HAEA's Grassroots Advocacy Network that offers youth focused training and advocacy opportunities for teens and young adults. The Youth Advocacy Network amplifies our collective voices by rallying young people between the ages of 12 and 25 to become active players in communicating the needs of the HAE community to elected representatives.

Receive practical training and real world advocacy experience.

Each year, HAEA Youth Advocacy Network members will be invited to join two virtual youth advocacy training workshops, and one in-person advocacy training event. Youth Advocates will also be invited to join our annual Capitol Hill event. Each event will inform and educate young members about important issues impacting the community and how they can take action to make a difference.

Use the QR code to sign up for the HAEA Youth Advocacy Network





Hey guys! My name is Ally and I'm a caregiver to my little brother, Jack. This year, I was given the incredible opportunity to take part in the launch of the HAE International LEAP program, which was created to educate youngsters on how to become effective advocates for our community.



LEAP PROGRAM

Ally talks about her experience and why she went to Dubai to join the HAE International LEAP Program.

In April, I traveled to Dubai with youngsters from over 20 countries, where we got amazing in-person education on everything from social media advocacy to speaking and presentation skills. After an adventure filled weekend I went home to start my 12-week online training. The goal was to come up with an advocacy project while working hand in hand with our personal Member Organizations. Each week, we watched and reviewed educational videos and articles, followed by small assignments. With these tools I learned how to create my own website, conduct a professional interview, and write educational articles.

I'm now working alongside our member organization to launch a resource to aid people in becoming the best caregivers they can be for their loved ones while also making sure they're taken care of mentally as caregivers. I'm indescribably thankful for my opportunity with the HAEi LEAP program and I can't wait to see what other youngsters create!



The #BeyondHAE Podcast expands with new video episodes!

You can now WATCH new episodes of the BeyondHAE podcast! Video episodes are available on spotify and on our IGTV channel at HAEAYouth.

We release a new episode every month! Find us on all major podcast platforms, including iTunes



LISTEN TO OUR PODCAST



ACCESS HERE

Have you checked out our blog?

The HAEA Community blog hosts a collection of stories from HAEA community members who share a unique aspect of their HAE journey. You will find a diverse mix of stories waiting for you to read, and we are always looking for new features. Use the link to access the blogs and our writers' interest form.



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