

# Welcome to the Brady Club

LET'S LEARN ABOUT HAE!

Brady the Bear wants to help you understand more about HAE.

Most of the medications used to treat HAE attacks require you to use a needle to inject the medicine. Sometimes you have to go to the doctor to get your medicine and sometimes you and your parents, or a nurse can do it for you at home. It's normal to

be a little scared of needles, but it's important to remember to be brave like Brady the Bear when you have to get medication to treat your attacks.

There are many things you can do to be less scared when you have to get your HAE medication. You can listen to your favorite song, watch a fun show on TV or on your iPad, hug your favorite teddy bear, or just remind yourself that the medicine is going to make you feel better. If you have to go to the doctor when you have an attack, make sure to bring a yummy snack, your favorite blanket, or even your iPad to help the time pass.

Let's learn about HAE! Brady the Bear knows a lot about HAE and he wants to help you understand more about what HAE is and how it works.



Hereditary is something you get from your mom or dad like your hair or eye color.



Angio means there is something missing in the protein of your blood (C1-INH) and just like you need protein to eat everyday your body needs all kinds of different proteins. When one is missing or not working correctly, your body will react and not work the same as someone else's.



Edema is a medical word that means swelling.



#### ALWAYS REMEMBER, KNOWLEDGE IS POWER!

The more you know, the quicker you can act to make sure you don't get too sick from your HAE! If a part of your body starts to feel funny and you think it might be a swell, make sure to tell an adult right away so they can help you.

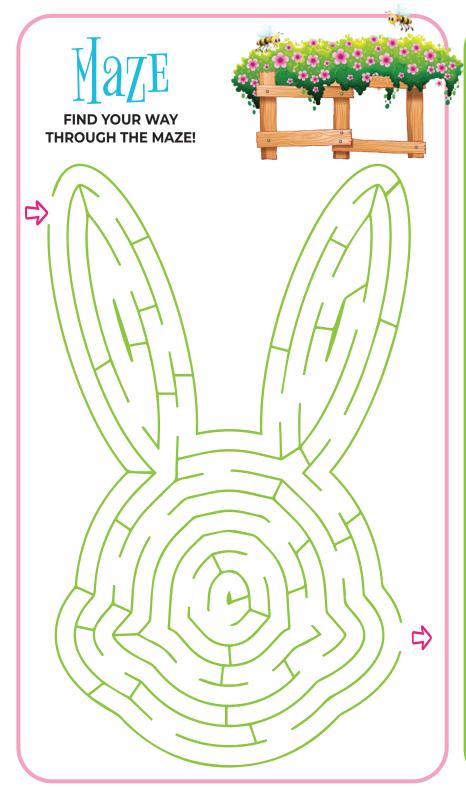
## Did you know?

HAE - related swelling is NOT the same as swelling caused by allergies and cannot be treated as an allergic reaction. This means that swelling caused by a bee sting or a food alergy is not the same as HAE swelling.



great, find two and you're on a roll, but can you find all seven? Only time will tell!





# Make us Laugh!



Q: What do you call a cold dog sitting on a bunny? A: A CHILLI DOG ON A BUN!

Q: What do you call a pig who knows karate?
A: A PORKCHOP!

Q: How can you tell if the ocean is friendly?

A: IT WAVES!

Q: What kind of tree can you grow in your hand?

A: A PALM TREE!

### Have you downloaded the Brady Club Mobile App?

Search for the Brady Club in the app store and look for Brady the Bear on the icon.



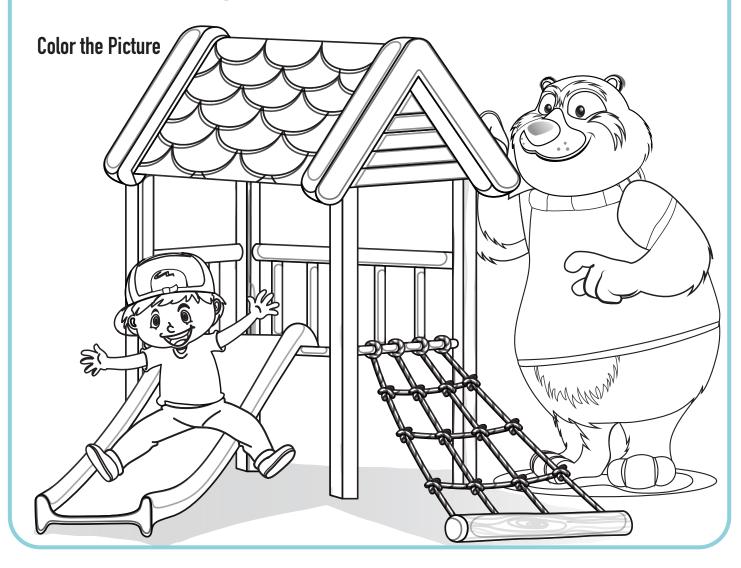


SEE YOUR JOKE IN THE NEXT BRADY (LVB ACTIVITY BOOK!

Send a joke or a riddle, along with your name and age to lisa@haea.org

The Brady Club app - now available on IOS and Android

# Imagine the Possibilities



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### HAE Words

Work hard to find the hidden words! To learn more about the meaning of these words, log-in to the Brady Club and click on HAE Words.

FLOWER
SPRING
BUTTERFLY
SALINE

NEEDLE

GAUZE



## Meet Brady's Friends

Brady would like to introduce you to some of his friends. Submit your story and you could be featured in the next Brady Club Activity Book! You can receive a free Brady Club t-shirt\* when you submit your own story and photo. Visit the Brady Club and click on Submit Your Story. Then, you can click on the Storybook to read stories that have been submitted by other kids just like you!







Hi my name is Lisa. I am 5 years old in this picture. My favorite thing to do is go to the beach. I really don't like vegetables. I think a superhero is someone who is there when you need them. When I want to grow up I want to be a teacher.



Hi, my name is Hazel. I am 3 years old. My favorite thing to do is to go on holiday (vacation). I really don't like naps. I think a superhero is someone who flys! When I grow up I want to be a witch.







Hi, my name is Amelia. I am 6 years old. My favorite thing to do is play with my friends. I really don't like hamburgers. I think a superhero is someone who takes care of me like my mommy and daddy. When I grow up I want to be an artist.

\*one t-shirt per child

### Did You Know?



The US Hereditary
Angioedema Center is
now seeing kids ages
eight and older. If you
would like more
information about how
to make an
appointment with a
specialist at the
Angioedema Center, please
contact Troyce Venturella at
troyce@haea.org.



Spring time has arrived and this means that it's the perfect time of the year to plant a garden. Complete the story on the right by choosing a word for each of the blank sections. You will be asked to choose a noun or an adjective for each blank word. A <u>noun</u> is a person, place or thing. An <u>adjective</u> is a word that you use to describe something. Once you fill in all the blanks, go back and read your spring garden story!

#### **FIND 5 DIFFERENCES**





Planting a vegetable garden is not only fun, it also
helps save
You will need a piece of land. You
may need a to keep the
and out. As soon (noun/s)
as Spring is here you can go out there with your
and plant all kinds of
Then in a few months you will
have vegetables and big
flowers.



Have you been trying to think of a way that you can make an impact in the HAE community?

#### SPREAD AWARENESS!

Starting on Feb 28, you will be able to order a copy of Nico's Lunchbox for your child's school library! How incredible will it be knowing that there is a book in the library about a child with HAE?! As part of the 2020 HAE Day awareness campaign, the HAEA is offering to send a FREE copy of Nico's Lunchbox to your child's school library (US members only). https://www.haea.org/autoforms/f/101

#### RAISE MONEY FOR HAE RESEAR(H TO FIND A (URE

Do you have fun MAKING cookies?!

Join the Cookies4HAE team to host a cookie pop-up between February 28 and May 16 and help us raise money for HAE research! Find our Cookies4HAE video tutorial on YouTube by searching for Cookies4HAE. You can also email lisa@haea.org to recieve a step-by-step guide to hosting your event.

# Stories From Brady's Friends

Hi. My name is Avery and I am almost eight years old. My older brother, Jack has HAE. He loves to play basketball and I



love to play basketball with him. It's sad to see him have HAE. The attacks are one of the worst parts of HAE because they hurt and they make his skin swollen. It looks really painful and I feel bad for him. When I was four years old, I learned how to help with his medicine. I help to mix his medicine and sometimes push the saline into his IV. I also help sort Jack's medicine supplies into kits when they come. It makes me feel like a nurse and it feels good to help him.

It's also fun to do things to support HAE like marching in the St. Patrick's Day parade and going to HAE races. When I get older, I would like to do more to help HAE patients. Writing about HAE made me think about bringing Nico's Lunchbox into school and reading it out loud to my class. I am excited to tell my teacher all about it.

Advocacy Stories

#### RAISING AWARENESS IN (IN(INNATI

The Mallory family has been part of the Cincinnati Red's Opening Day Parade for decades. Each year they polish up their antique firetrucks and secure their HAE awareness banner from one end to the other, making sure that everyone watching them pass by learns about HAE. Over the last three years, the Mallory Family has been excited to welcome young kids affected by HAE to join them for this fun and exciting event. This is just one fun way that a family has turned a local tradition into an opportunity to raise awareness about HAE.

Cincinnati Reds Opening Day kicks off the first day of baseball season and is a 100 year old local holiday. People gather downtown by the masses. The day starts with the parade followed by the Reds Opening Day baseball game. Local school bands play and march, local business create elaborate floats, and the Mallory Family has had their restored fire trucks in the parade since the 1990's. When Abby was diagnosed with HAE, Mike and Missy wanted to bring more awareness to the Cincinnati community about HAE, thus adding HAE banners to the firetrucks. Each year all of the local news stations show the Mallory firetrucks on TV. The trucks are beautiful, sirens blowing, and huge HAE banners for all to see.

The preparation for the parade starts long before the parade does. The Mallory Family takes the trucks out for test drives to make sure the restored trucks are up for the voyage downtown. Missy, Stephen, Oliver and Abby hand wash the trucks a few days before the parade, and once again on site the morning of the parade. Then its decorating time, The Miller and Mallory families (Maggie Miller, Mike's sister and her family attend the Opening Day parade every year as well. Maggie also

has HAE). Streamers are flowing, tons of balloons, and the HAEA banners are placed on the trucks for all to see!

Oliver and Abby love attending the parade! They both love to ring the bells, and hit the trucks sirens, watching the crowd cheer for them driving by!

"Waving to all the people watching us, is the best!" says Abby. Abby enjoys riding in different places on the truck, inside the cab, and also in the back of the truck. While, Ollie loves to hear the sirens blowing, he likes to ride in the back on top by the huge Red's flag that flies on top of one the trucks.

"I love hanging out with the other kids from the HAEA! They are all pretty cool!" says Ollie. Ollies likes to show all the other kids all the places that make noise on the firetrucks and where they can stand during the parade. Ollie likes to walk around and see all of the other floats before the parade begins.

And, of course, it is not Opening Day, without enjoying a Cheese Coney, or two!