

MAY 2018

# YOUNGSTERS' VOICE



HAEi Youngsters' magazine · Issue 1

**Taking big steps  
together in Vienna**



**TAKE CONTROL OF HAE @ #haeGC18**



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Subscription: If you would like to see more from the youngsters have a look at the website [haei.org/youngsters/](http://haei.org/youngsters/)

Youngsters' Voice is created by the HAEi Youngsters community. HAEi is a global non-profit umbrella organization dedicated to working with a network of national HAE member organizations to raise awareness of HAE.



## DEAR HAEi YOUNGSTERS AND FRIENDS

Welcome to the first ever edition of Youngsters' Voice, the magazine created by the HAEi Youngsters community! Everything you read in this magazine has been prepared by youngsters from around the world. We hope it will provide inspiration and information that will help you take control of HAE! This magazine was launched at the 2018 HAE Global Conference (GC 2018), along with the HAEi Youngsters' website: [haei.org/youngsters/](http://haei.org/youngsters/)

We are very excited to share this incredible work with you.

The HAEi Youngsters community provides a fantastic opportunity for young people to find new friendships, experience new things and advocate for better quality of life for people with HAE. The inspiration for a youngsters' program came from our German friends at HAE-Vereinigung e.V and an active HAEi Youngsters Community now exists because of the hard work of the youngsters and the support of our member organisations around the world.

The Youngsters track at the 2016 HAE Global Conference in Madrid was the first time HAEi officially brought a group of young people together to share their experiences. A year later in August 2017 HAEi sponsored our first Youngsters Summer Camp in Frankfurt, Germany featuring a weekend of both fun and educational activities. We were thrilled to have 60 highly motivated youngsters attend the GC 2018, where they created this magazine and an incredibly useful website. Our HAEi member organizations and all of our stakeholders should be very proud that their support has created the opportunity for our HAEi youth to band together, share their stories, and form invaluable friendships.

Outside of events, the HAEi Youngsters also run an Instagram and Facebook group where they keep in contact all year round. In addition, Youngsters from different countries have been inspired to get involved in their country's member organizations.

The youngsters are the future of HAE advocacy. It's a very exciting time for the HAEi Youngsters community, you have already achieved so much in a short space of time, and we can't wait to see what you do in the next weeks, months and years!

Warm regards,

Tony  
President of HAEi

Henrik  
Executive Director





Vox pop about HAE

## **WE ASKED SOME YOUNGSTERS AT THE 2018 CONFERENCE A FEW QUICK QUESTIONS**

Are your usual attacks life threatening?

Yes 71 %

No 29 %

Do you have easy access to medication?

Yes 57 %

No 43 %

Can you do self-injection?

Yes 36 %

No 64 %

Can friends and family help you with the attack?

Yes 100 %

Are you excited that you are in the youngsters community?

Yes, of course 100 %



# HAE *life* hacks :-)

Tips to Take Control of HAE

## SPORTS

- gloves at the gym
- cool water on hands
- stop if your hands get red
- hydrate
- stay cool
- talk to your coach



## SCHOOL

- tell teachers and school principal
- advocate in school
- get help to not get behind
- class buddy to help you
- train school nurse to treat
- give school your meds



## TRAVEL

- compression tights
- keep meds in your carry on
- preplan
- wear loose clothes
- carry a note from your doctor
- check the weather



## H A E

## medicine

- prepare for your infusion, e.g. precut tape for after infusion
- use ice before injecting to numb
- use a stress ball to pump veins
- have someone with you during shots and a distraction
- place a pillow under your arm while infusing
- hot shower before meds or hot water bottle to help show your veins



## EVERYDAY

- wear wedges or platforms instead of heels
- avoid wrist pressure while typing
- take breaks

- keep calm
- support your siblings, friends, and family with HAE
- do what you love



**HAE** *can't* stop **YOU!**



MAY 2018



## RADIO ACTIVE YOUNGSTERS @ #haeGC18



As we start working on our community, we never forget to share our talents. Cool youngsters begin the session by playing music and singing along to Radioactive by Imagine Dragons – here performed by our HAE Youngsters.

Scan with your smartphone  
– or click on the link to view the full video online  
[haei.org/youngsters/active-youngsters-haegc18/](http://haei.org/youngsters/active-youngsters-haegc18/)





*“Many small people, in small places,  
doing small things, can change the world”*

– Eduardo Galeano



## **UPLOAD, CONNECT, AND LEARN WITH THE YOUNGSTERS APP**

**How would you feel having an easier way to be connected  
with HAE youngsters from around the world?**

Here we have some ideas of how this amazing app will be a useful tool for you.

This app will be a great resource for you to:

- stay updated with news
- learn about where other HAE youngsters are around the world and communicate with other youngsters when you are close by
- learn about upcoming events and opportunities around the world.



**WE HAVE BIG PLANS, AND  
WE NEED YOUR HELP!**

Would you like to join us in developing this project? Send your ideas and feedback to us to help us create an app that meets your needs.

Reach out to Nevena Tsutsumanova by e-mail: [n.tsutsumanova@haei.org](mailto:n.tsutsumanova@haei.org)





WHY did you choose to take these photos?

### From the program: Friday, 18 May 2018

14:45 Selfie Scavenger Hunt (Downtown Vienna)  
(2:45pm) Nevena Tsarovska/Hannah Clarke

We had the opportunity to be creative and explore Vienna whilst taking themed selfies and photos to complete the selfie scavenger hunt.

Here you have the selfies of Noah, Kobe, Steve and Hayden from the HAEA (the HAE member organisation of the US).



View more selfies from other groups on our website:  
[haei.org/youngsters/selfie-hunt-vienna/](http://haei.org/youngsters/selfie-hunt-vienna/)





**B** **TYPICALLY FROM VIENNA**

*When in Vienna, a critical tourist attraction is the St. Stephen's Cathedral, so we thought it was necessary to make it a part of our selfie scavenger hunt.*

**I** **SPELL OUT HAEI**

*It's a bird! No, it's a plane! It's the YMCA! Nope, it's the HAEi Youngsters!*

**n** **Time**

*It's that time again! The HAEi Youngsters outside a clock shop in Vienna.*

**G** **MUSIC**

*Beautiful music drifting through the streets of Vienna led us to the Wiener Royal Orchester House.*

**O** **TAKING CONTROL**

*It's not cheesy to take control! Thanks to this local Vienna cheese store for letting us take an awesome picture!*



**B**

Again: Go to our website to see more selfies from other groups:  
[haei.org/youngsters/selfie-hunt-vienna/](http://haei.org/youngsters/selfie-hunt-vienna/)

**WILD CARD**  
*No horsing around for these HAEi Youngsters!*





## BEING IN A RELATIONSHIP WITH HAE

*The talk: how do you tell your partner you have HAE?*

*How are HAE patients' partners dealing with the disease?*

### Millen (19, Israel)

I have been with my boyfriend for 2 years now and we met when I finished high school. A few days after we met he saw online an interview about HAE that someone did on me. He read it and afterwards he decided to do some research online on HAE and after that he spoke to me about it. He was very understanding about it and he didn't freak out and afterwards he told his family about it. They are still really interested about it and they still worry about how I'm doing, if I can come visit, if I need to get medication or whether I need any help.

My boyfriend took it really well, and thanks to that positive reaction I'm confident about it. Before I got into this relationship I was really shy and when I would get attacks I was too shy to go anywhere but now it has changed because he was so accepting. And whenever I have an attack it's my boyfriend who takes me to the hospital so I can get medication and gives me a huge hug so I don't feel alone and as scared about it.



### Lars (18, Germany)

I met my girlfriend a year ago in a bar in my hometown and I've been in a relationship with her for more than a half a year now. Before I joined a national conference about HAE in Germany I told her about the disease. She was very interested and asked if I had any problems with it. Luckily, I haven't got a single attack yet, but I really appreciate her help and support and she knows that it can turn into a serious problem if I don't have my medication so she supports me in any possible way.

### Matan (19, Israel)

Since I'm really open about having HAE, my girlfriend knew about it before we got together. She didn't know many details, so once I got into the relationship I explained everything concerning HAE to her. When I explained it, she got worried but was very understanding about it. However sometimes it would interrupt our plans but we still had great time together.







**Roei**  
(24, Israel)



On my third date with my girlfriend, we were having dinner and the minute after we got our food I felt that my throat started swelling up. That being a really serious attack, I had to leave so I partly explained what the disease is like to her and I told her I had to leave. Just after that, she got to my place to see how I was doing and she saw me injecting the medication and asked me about it. So I tried to not make it a big deal, and I talked jokingly about it but she was still concerned about my health and how this disease affects my life. I remember that once when I was having a really bad attack, she got really worried about it and she started crying and asked me if our lives were always going to be like that. It was then me trying to calm her down, and from that moment she became more relaxed about it and now she spoils me each time I have an attack.

**Sofija**  
(20, Serbia)



It actually took me long time to tell my partner I have HAE but that was only because at that period of time I didn't have attacks often. My partner was a little bit scared for me, but after explaining how it works and that I have medication for it they understood it was not as scary as it might seem.



# COOL INFOGRAPHIC ABOUT HAE

An easy to understand infographic to explain Hereditary Angioedema (HAE), common triggers and an action plan for children. You can print it out and use it at schools, extracurricular activities and summer camps.

I made it for my little sister when she transitioned to a new school.  
 – Isabel, 18, Costa Rica/USA

## HEREDITARY ANGIOEDEMA

### ANGIOEDEMA HEREDITARIO

**Name:** \_\_\_\_\_  
**Cell :** \_\_\_\_\_  
**Home:** \_\_\_\_\_  
**Emergency Contacts:** \_\_\_\_\_

Triggers  
 Symptoms

**If Dizzy:**

- Sit down/Stop activity
- Drink water/tea, give salt snack

**If Hands or Feet:**

- Sit down/Stop activity
- Drink water/tea, give salt snack

**If Stomach:**

- Call Parents/Emergency Contact

**If Throat:**

- Call Parents and Medical Professionals

**DOWNLOAD AND PRINT**

[haei.org/youngsters/cool-infographic-about-hae/](http://haei.org/youngsters/cool-infographic-about-hae/)





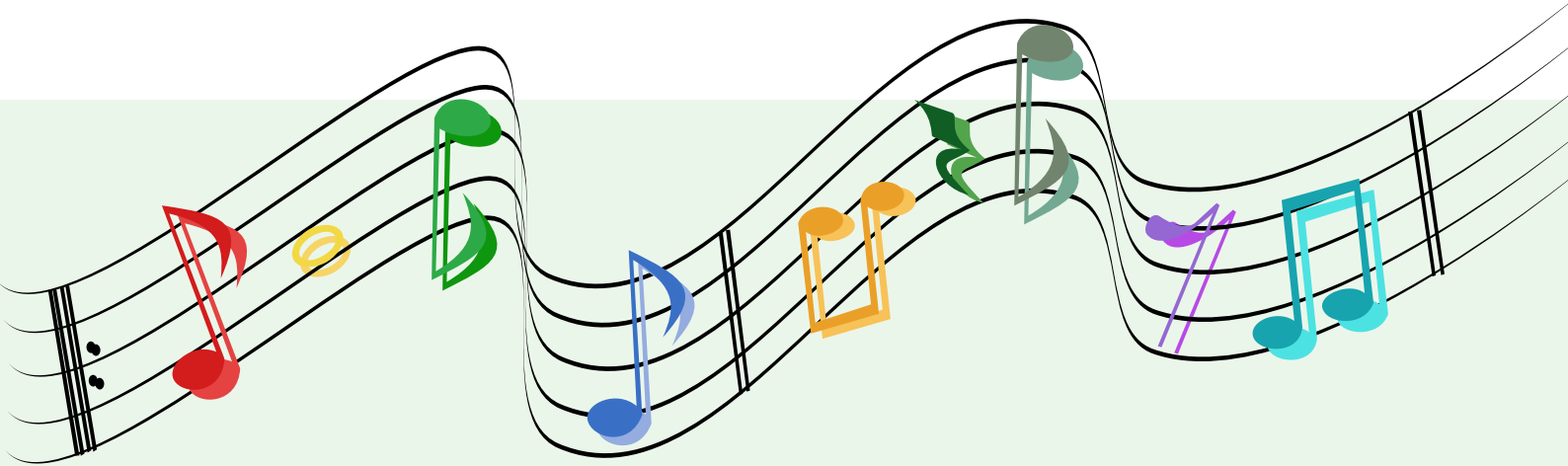
# ARTISTIC EXPRESSIONS OF HAE



– Emma Parker, 11, USA

## EMMAS POSTER

Most people think HAE is something to be afraid of. I see it as a way to be different. I created something where you can say how you feel about HAE, what you do for it and how you advocate for yourself.



## SWOLLEN NATION ARMY MUSIC VIDEO

The Red Polkadots made a parody of 'Seven Nation Army' by The White Stripes. The purpose of the song is to show we take control and we recognise there are difficulties in everyday life but we can take control.

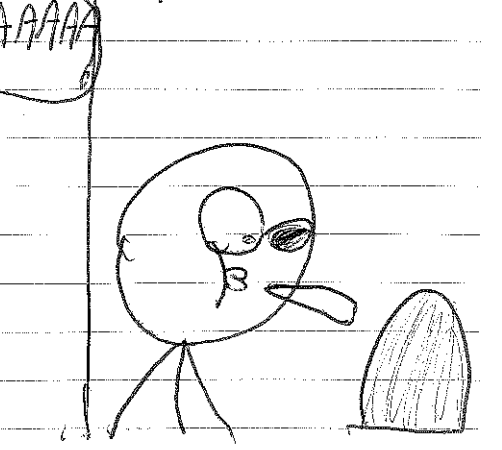
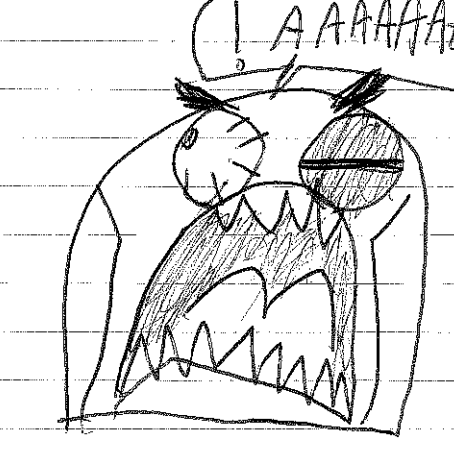
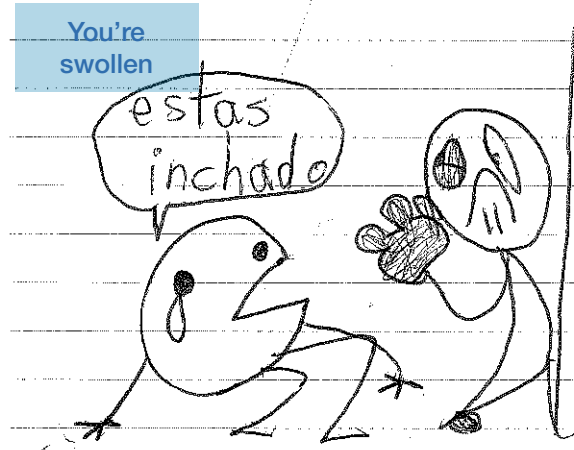
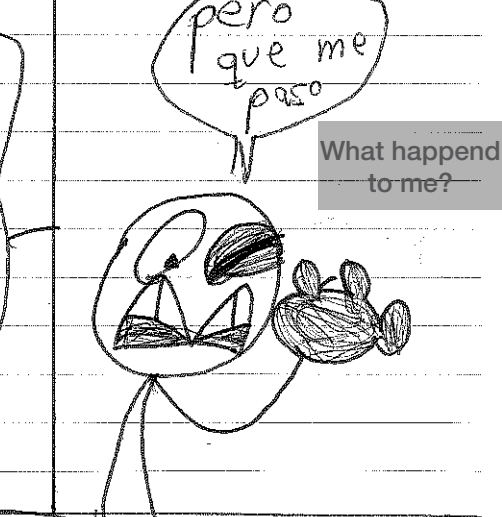
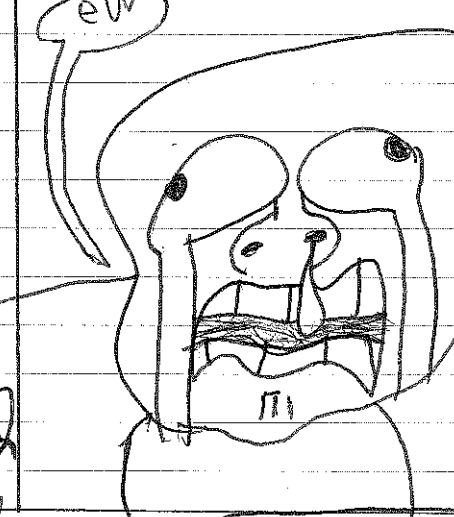
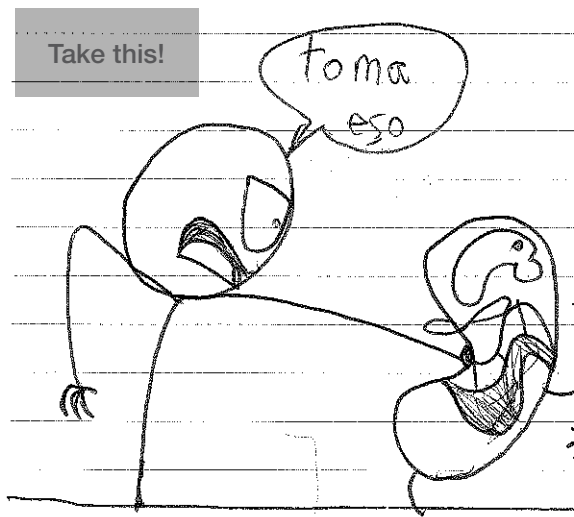
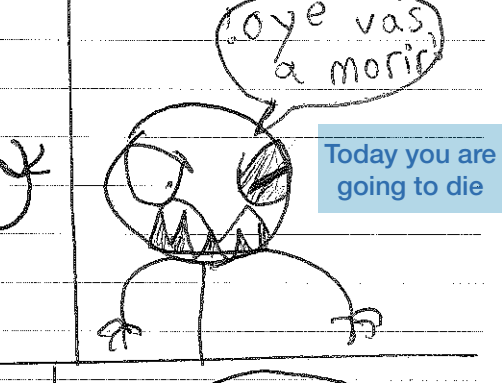
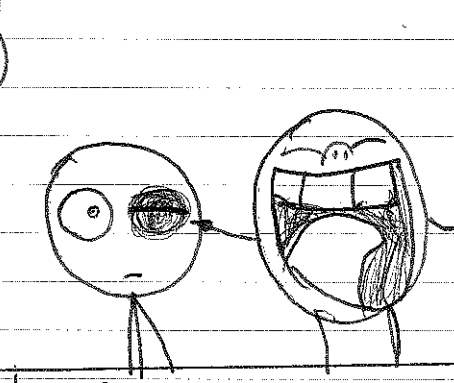
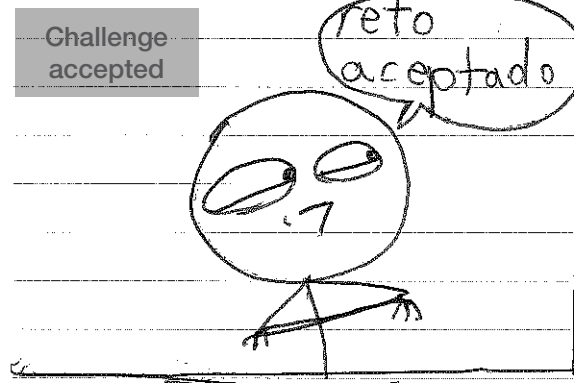
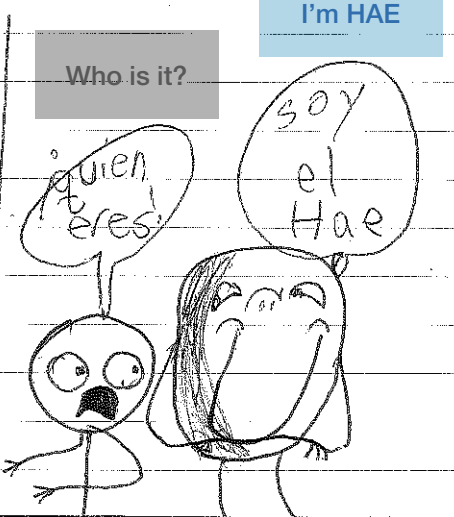
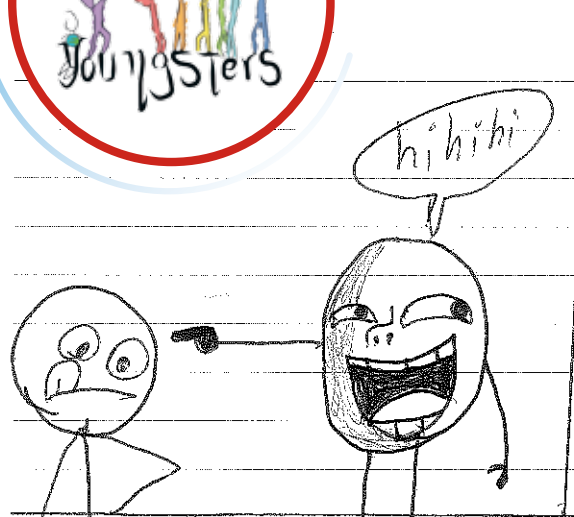
Lyrics:

*You know we swell a lot  
Our disease ain't gon'na hold us back  
We're gonna pay'em all  
Millions of dollars just to find a cure  
And we hurtin' every day & night  
because we swell a lot  
Back and forth with IV's in the hospital  
And the message from the H.A.E. is to take control*

### LISTEN FOR YOURSELF

[haei.org/youngsters/swollen-music-video/](http://haei.org/youngsters/swollen-music-video/)

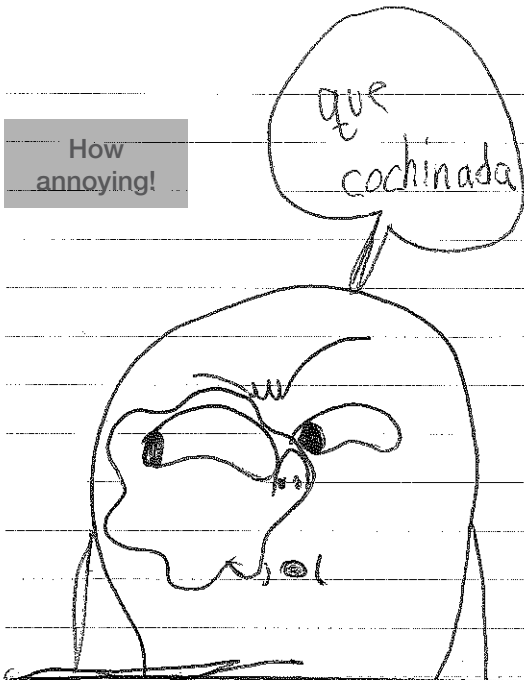
Credits:  
Jack Chacon  
Camren Parker  
Luke Granat







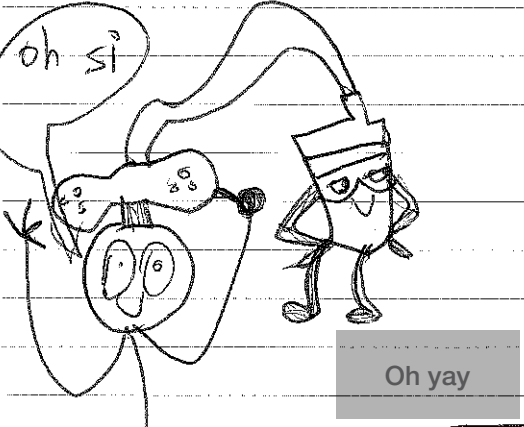
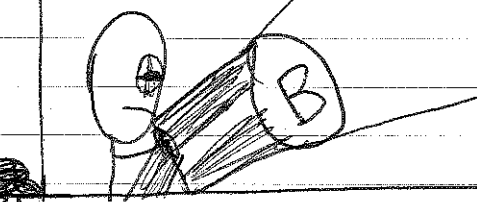
How annoying!



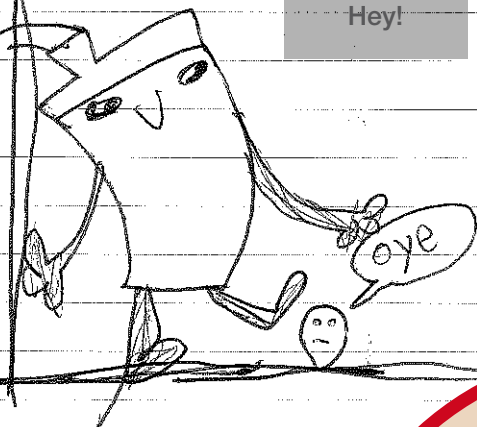
I can't take anymore



MEDICINE ARRIVES



Hey!



HAE IS DEFEATED



Oh yay

Fin

CARTOON MADE BY Gustavo Nieto, Mexico





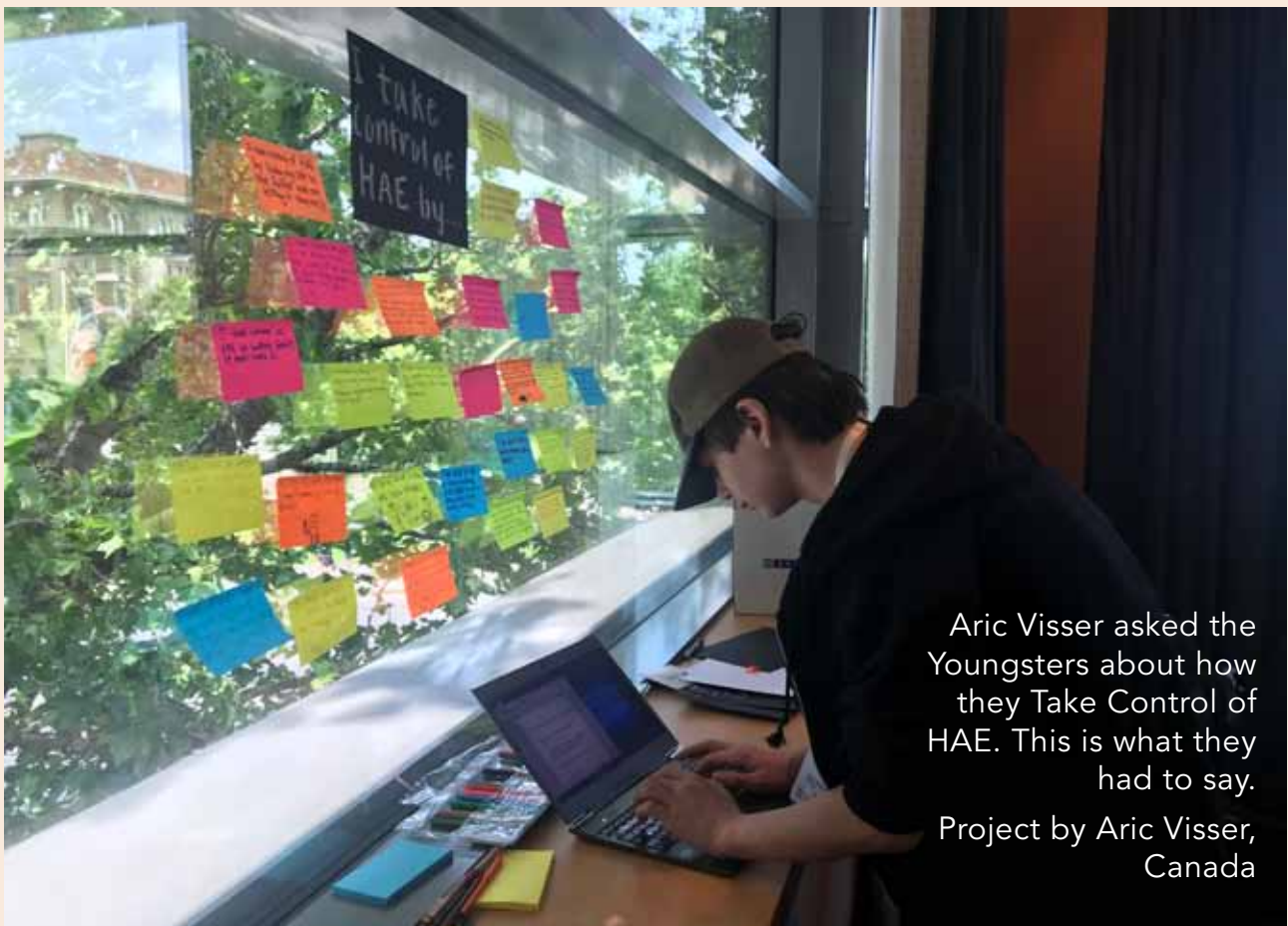
## I TAKE CONTROL OF HAE BY ...

- By living my life to the fullest and not letting it stop me!
- By helping family if they need it.
- By going around Vienna and taking pictures.
- By teaching everyone I know about it.
- By doing things I love!
- By advocating on behalf of my sister and step father.
- By living the most normal life I can. Also, living life without the fear of a swell.
- By traveling around the world and exploring new cultures, HAE doesn't stop me!
- By supporting my sister and helping her during attacks.
- By trying to inform people about it, then maybe a day will come when there will be a worldwide plan for HAE patients and make many lives easier.
- By trying to live a normal life and making the best of it.
- By not letting it stop me to do things i really want, im trying to treat the attacks as soon as possible so I wont suffer.
- By traveling and seeing new things, I met new people. I see everything is possible by doing things like that anyway so I can control it, HAE can't stop us!
- By raising awareness in my school, theatre, dance, voice and acting classes!





- By helping my mother and sister get through their tough times. While I live a full life and never let HAE run my life :D.
- By drawing personal growth from the condition.
- By living my life to the fullest and helping other patients reach their goals!
- By being able to treat myself, this gives me a new perspective on life and makes it easier for me to do what I love! HAE cant stop us!
- By listening to music, taking pictures and drawing, and sometimes I do it at the same time.
- By advocating and educating people about the disease and by supporting my sister and mom.
- By not cutting my wings and being able to dream along with having HAE and not letting it set limits to myself.
- By everything that brings pleasure like music, walk on travel, doing nothing with my friends.
- By not letting it stop me and using it as motivation to work even harder to achieve my goals
- By always telling my friends that I feel like an attack coming
- By trying to live my life as normal as possible. I try not to let it control me or my life
- By living a full life and pursuing my dreams. HAE cant stop me!



Aric Visser asked the Youngsters about how they Take Control of HAE. This is what they had to say.  
Project by Aric Visser, Canada



# INTERVIEWS ABOUT HAE - IN SPANISH

**We asked these two questions:**

1. What does living with HAE mean to you?
2. What is important in this conference for you?

**Bresia, Perú**



**Antonio, Spain**



**Hector, Venezuela**



**See OUR ANSWERS HERE:**

[haei.org/youngsters/video-interviews-es/](http://haei.org/youngsters/video-interviews-es/)

TIP: You can add subtitles in your own language on Youtube





# ARTISTIC EXPRESSIONS OF HAE



## YOUNGSTERS FROM AROUND THE WORLD

### Ilke Irem Kurt

My name is Ilke Irem Kurt and I'm 17. I'm from Istanbul, Turkey. I'm not a patient. I'm here for my best friend and my dad. I try to support them.

### Elgin Tezcan

Hi! My name is Elgin I'm 16. I'm from Izmir, Turkey. I got diagnosed in 2010. I have Type 1 HAE. Singing, dancing and doing sports are the things I like most. I often have difficulty doing these things because if I have stomach pain or swelling, it's harder to dance and play.

### Paige Rockwell

My name is Paige Rockwell I'm 13. I got diagnosed in September of 2015. I'm from the USA in North Carolina.

### Sophia Andrade

Hi! my name is Sophia Andrade and I'm from Connecticut, USA. I was born in Bristol, CT and have lived there my whole life. I have Type 2 HAE but that doesn't prevent me from living my life. I love music and iced tea and Dunkin'. I love the sunshine and the beach and anywhere warm.

### Natalie Dersch

I'm Natalie Dersch. I am 16 years old, from Illinois and I play soccer. My identical twin sister has HAE Type 3. I remember going through everything trying to diagnose my sister. Whenever she goes to the ER I make sure they keep me updated. Having a twin with HAE is hard. It's hard to watch her go through everything alone.

### Maddy Dersch

Hi, my name is Maddy Dersch, I am a 16 year old from Illinois. I live near Chicago and I love to visit the city. I was diagnosed with HAE Type 3 in April 2017. I try to live my life as normally as possible, I really enjoy listening to music and reading. My favourite bands are Panic! At The Disco and Twenty One Pilots. My favourite book series is Harry Potter.

### Diego Lopéz

Hi, I'm Diego I am 15 years old. I was born in Chile and I'm an inventor, I like to make robots and other things to help people. To pass the time I like to do great things like graffiti, draw, parkour, etc...



# STAY CONNECTED!

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