

November 2018

Dear HAEi Member Organization,

As you recall, the “Youngster Track” at the 2018 HAE Global Conference in Vienna was our first dedicated two-day youngster track and was a great success. At the end of the conference we proudly introduced the official HAEi Youngsters Community. It is wonderful to see how the youngsters appreciate and make the most of the opportunity of having a truly global network of fellow HAE patients, with whom they can share experiences and ideas.

The HAEi Executive Committee is truly moved by the passion and dedication of the youngsters and has unanimously agreed to keep supporting their future initiatives. Furthermore, HAEi is making a significant investment in helping the Youngsters Community develop the knowledge and skills to become global advocates. We believe that our youth is the future!

We are delighted to inform you, that the first HAE Youngsters’ Advocacy Workshop is now a reality and will take place from Thursday 25 July until Sunday 28 July 2019 in Atlanta, GA, USA. The two-day course will be held immediately prior to the 2019 US HAEA Patient Summit, and Youngster participants are then invited to join the US HAEA Patient Summit.

The HAE Youngsters’ Advocacy Workshop will be a fun, but intensive lecture- and project- based course that will train our Youth in the “art” of HAE advocacy. We are asking our Member Organizations to select Youngsters from your countries who, in your opinion, will most benefit from taking part in the HAE Youngster Advocacy Workshop. We are looking for **dedicated and determined Youngsters, who are able to both write and communicate in English** (intermediate to advanced level of language skills are preferred), who are motivated to (1) learn new skills, (2) be part of a team, and (3) have a passion for getting more involved in their local member organization.

HAEi will provide financial support for 40 International Youngsters who are selected to attend the workshop in Atlanta. We are asking you, as an HAEi Member Organization, to determine if there are Youngsters within your organization who you believe would fit the criteria we have outlined below. We would then ask that you share information about the Workshop with the candidate(s) you have identified. **Please NOTE that places are limited, and we anticipate that demand will exceed the places available. As a result, we will need to look at an allocation process which will take date/ time of preliminary application, as well as global representation into account.**

Which Youngsters are eligible?

- The youngster (and/or care-giver) must be member of the national HAE member organization.
- The youngster must be able to both write and communicate in English (intermediate to advanced level of language skills are preferred)
- The youngster must be between 16 and 25 years old at the time of the workshop
- The youngster must be a patient with a diagnosis of C1-inhibitor deficiency HAE type 1 or HAE type 2 only – as confirmed by a doctor’s letter
- The care-giver must be a sibling/partner/or guardian of a patient with a diagnosis of C1-inhibitor deficiency HAE type 1 or HAE type 2 only
- The youngster with HAE must be capable of administering medication on their own or together with an accompanying care-giver.



- It is **EXTREMELY IMPORTANT** and an **ABSOLUTE REQUIREMENT** that the youngsters travel with a sufficient quantity of HAE medication to cover their needs while they are away from home. Please **NOTE** there will be no emergency care or HAE medication available at the workshop venue.
- A valid passport as well as any required VISA and/or ESTA documentation must be obtained before HAEi will issue a flight ticket for you. Youngsters must prove their possession of a valid passport and VISA and/or ESTA no later than 1 February 2019 (otherwise HAEi will allocate their space to someone else). Any cost associated with a VISA and/or ESTA application will not be covered by HAEi.

This eligibility criteria is included as a check list at the end of this letter

Fees, travel and accommodation

There will be a **participation fee** required per Youngster and also per care giver (if required/ requested). The fee of **EUR 100** includes four nights' accommodation in a double or triple room, and the fee of **EUR 150** includes a four nights' accommodation in a single room at the 4-star Omni Atlanta Hotel at CNN Centre, as well as the following:

- Airfare from your nearest airport to Atlanta and back again
- Meals on the following days:
 - Wednesday – light dinner
 - Thursday – breakfast, lunch and dinner
 - Friday - breakfast, lunch and dinner
 - Saturday - breakfast, lunch and dinner
 - Sunday - breakfast
- Participation in the HAE Youngster's Advocacy Workshop (*Thursday and Friday*)
- Participation in US HAEA Summit (*Saturday*)
- Participation in the US HAEA 5K run/walk on Sunday morning (*optional*)

Costs not included in the participation fee*:

- Transportation from your home to your departure airport and back
- Cost for VISA and/or ESTA application
- Travel insurance (with sufficient health care covering)
- Train transportation from your arrival at Atlanta Airport to downtown Atlanta (the one-way ticket price is USD 2.50)
- Other meals, activities, and pocket money.
- **Please NOTE:** If the youngsters decide to extend their stay in Atlanta – additional hotel nights and meals are also not covered by HAEi

*Other cost items may apply

Preliminary application and subsequent full registration process for the workshop

Youngsters from your member organization, who meet the criteria and would like to join the Advocacy Workshop will be expected to complete a preliminary application no later than 10 December.

Here is the link for the preliminary application: <https://haehost.org/application/>

On 12 December, HAEi will contact you with a list of Youngsters representing your member organization that have applied. At this point we will also provide the number of places available for Youngsters from your country. We ask that you validate the list of Youngsters from your country and confirm which Youngster's you believe will best benefit from taking part in the workshop.

When HAEi receives confirmation of the youngsters you have chosen from your country, we will send a message of acceptance together with a link for registration. The registration will be open **from 21st December**



2018 until 5th January 2019. We will send a waitlist message to the youngsters we are unable to confirm immediately.

As part of the registration process, parents and/or guardians of all participants below the age of 18 will be required to sign a digital consent form for their youngster and/or care-giver.

HAEi will be promoting the HAE Youngsters Advocacy Workshop on social media and will direct all enquires for participation, to the Youngster's country member organization.

Advocacy Workshop Program

We are still working on the final program for the advocacy workshop. Participants will be informed as soon as the program is online.

Important dates: Note, timings are based on the time in Central Europe

- 5pm Monday 10th December – the application link closes
- Wednesday 12th December – You will get a list of those from your country that have applied, and will be asked to validate this and select the Younger's for the number of places available for your country
- Sunday 16th December – Last day for confirming, which youngsters from your country should participate
- Friday 21st December 2018 – Full registration for the 2019 Youngsters' Advocacy Workshop will open

We ask you to discuss this exciting initiative and provide the application link to your choice of eligible motivated youngsters from your country as soon as possible.

Should you have any questions or comments, please do not hesitate in contacting us.

Warm regards,
HAEi

Henrik Balle Boysen
Executive Director



Eligibility criteria check list, to be used in the selection process:

Eligibility criteria checklist		(✓)
The youngster (and/or care-giver) must be a member of the national HAE member organization.		
The youngster must be able to both write and communicate in English (intermediate to advanced level of language skills are preferred).		
The youngster must have an interest in learning new skills in advocacy and working as part of a team towards a common goal.		
The youngster must be between 16 and 25 years old <u>at the time</u> of the workshop.		
The youngster must be a patient with a diagnosis of C1-inhibitor deficiency HAE type 1 or HAE type 2 only as confirmed by a doctor's letter.		
The care-giver must be a sibling/partner/or guardian of a patient with a diagnosis of C1-inhibitor deficiency HAE type 1 or HAE type 2 only		
The youngster with HAE must be capable of administering medication on their own		
It is EXTREMELY IMPORTANT and an ABSOLUTE REQUIREMENT that the youngsters travel with a sufficient quantity of HAE medication to cover their needs while they are away from home. Please NOTE there will be no emergency care or HAE medication available at the workshop venue.		
Adequate travel insurance is a mandatory requirement when traveling to the USA. We will need to see a proof of travel insurance before any flight ticket will be issued.		
A valid passport as well as any required VISA and/or ESTA documentation must be obtained before HAEi will issue a flight ticket for you. You must prove your possession of a valid passport and VISA and/or ESTA no later than 1 February 2019 (otherwise HAEi will allocate your space to someone else). Any cost associated with a VISA and/or ESTA application will not be covered by HAEi.		