



February 2017

Dear HAEi member organization,

As you may recall, the “Youngster Track” at the 2016 HAE Global Conference in Madrid was a great success. Since then a large group of youngsters have kept in touch via social media. It is wonderful to see how the youngsters enjoy the opportunity of having a truly global network of fellow HAE patients, with whom they can share experiences and ideas!

The Executive Committee of HAEi has therefore unanimously decided to arrange a “HAEi Youngster’s Summer Camp” in 2017 to further support and encourage our young patients in the global HAE community.

We are delighted to inform you that the first HAEi Youngster’s Summer Camp now is a reality, and will take place from Thursday 3 August until Sunday 6 August 2017 in Frankfurt, Germany.

We are asking you, as a HAEi Member Organization, to start recruiting youngsters to attend the Camp now. Each country can send up to 6 youngsters. We have space available for a maximum of 100 campers. Places will be allocated on a first-come basis, to the maximum registrations for your country. Please note that the 6 places for your country needs to also cover companions (see below) if the Youngster is between 12 and 15 years old.

***Who is eligible?***

- The youngster (and/or companion) must be member of the national HAE member organization, and must be able to communicate in English
- The youngster must be between 12 and 25 years old
- NOTE: a youngster age 12-15 is only eligible if they travel with a companion such as a brother/sister who will be at least 18 years old at the time of travel OR an adult care giver (parent/guardian/partner)
- 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 Companion must be a sibling/partner/parent 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 have enough HAE medication (acute therapy) to cover the entire trip
- Ideally, anyone with HAE who attends the Summer Camp is capable of self-administration



### ***Travel and accommodation***

HAEi will pay for:

- Round trip flight tickets for the youngster attending the camp, plus their companion as required (sibling/partner/parent or guardian) from their home airport to Frankfurt.
  - Arrival in Frankfurt on Thursday 3 August 2017 and departure from Frankfurt on Sunday 6 August 2017
- HAEi will also pay for transfers to and from Frankfurt Airport to the venue.
  - Note, HAEi will not pay for transfers to and from your home to your home airport
- Accommodation at the 4-star Hotel NH Frankfurt Mörfelden in single, double, or triple room for three nights.
  - For the youngster, plus their companion as required
- Meals as follows:
  - 3 August: Dinner
  - 4 & 5 August: Breakfast, lunch, and dinner
  - 6 August: Breakfast
- All scheduled activities during the Camp itinerary period
  - This includes sessions at the hotel and a possible excursion

There will be a registration fee per participant of EUR 75.

### ***Registration***

The registration web site for the 2017 HAEi Youngster's Summer Camp will go live on 10 March 2017. Please find link for the registration website below.

As part of the registration process, parents or guardians will be required to upload a 'Confirmation to Participate' document for their Youngster and/or the companion. This document will need to be signed by (1) themselves, and (2) the youngster's HAE physician (for youngsters with HAE) who confirms that the youngster with HAE is medically fit to travel to, and participate in, the Summer Camp.

A copy of this 'Confirmation to participate' will be forwarded to you as soon as possible. It will also be available to download from the registration website.

### ***Summer Camp Program***

We are still working on the final program for the Summer Camp, but are delighted to announce that the theme is, "Living with HAE." There will be plenty of time for our youngsters to network and create new friendships. HAE Expert Physicians will also be in attendance.

### ***Important dates***

10 March 2017 – Registration website will open for the 2017 HAEi Youngster's Summer Camp



10 April 2017 – If there is still available space on the Summer Camp – HAEi will promote the link to the registration website via HAEi social media

Since HAEi will not proactively be promoting the 2017 HAEi Youngster's Summer Camp (until 10 April 2017) – we kindly ask you to provide the below link to eligible participants from your country!

Link to the registration website: <http://www.trippus.net/HAEi-YoungsterCamp2017>

Please observe that the language for the 2017 HAEi Youngster's Summer Camp will be English. The participant must therefore be able to communicate in English.

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

Warm regards,

HAEi

A handwritten signature in blue ink, appearing to read "Henrik Balle Boysen".

Henrik Balle Boysen  
Executive Director