



Approaching hae day :-) activity

This toolkit has been designed to support you in preparing for the **hae day :-)** in 2019. Below are some of the key steps that will help you in developing your approach to the day. We focus on specific activities in more detail in other parts of the toolkit and provide template documents which you, if need be, can translate and adapt to help you in your efforts.

The toolkit is available for you to use as you like. Whether you decide to work with all of it or just one or two sections we hope that it will help you effectively shape the activities in your specific country.

This toolkit is provided in English. However, if it is relevant in your country you are more than welcome to translate the toolkit so that you can share it more broadly with your members. Also, you are very welcome to share your translation with other national organizations speaking the same native language as you.

1. Take the time to read the entire toolkit

You may not need to use all the contents but it will be helpful to read through the entire toolkit in order to get an overview of the contents and support materials. The toolkit provides background information on HAE, and explanations to the need for the **hae day :-)** as well as details regarding the role of HAEi, suggestions of ways of getting involved, and other initiatives.

2. Focus on your success

We appreciate that being able to implement activities for the 2019 **hae day :-)** will take time, and that you may have limited resources, or have a very specific need in your country. Before you begin planning any activities, consider what your specific objectives for the **hae day :-)** are in your country and what you realistically can achieve with the resources you have available. For example, you may want to focus on the fundraising component of the **hae day :-)** and concentrate on organizing a single fundraising event. Or, you may wish to focus on awareness raising through the media.

3. Raising awareness – consider your target audience

It is worth considering where you could make the biggest impact in your country. A complex health problem such as HAE needs to be supported with the collective work of



many sectors and partners. Although important to raise as broad awareness about HAE as we can, there may be groups of people who already have a level of understanding of HAE or rare diseases that you could target specifically this year. For example, targeting healthcare professionals or advocacy groups who support rare diseases with HAE information on the 2019 **hae day :-)** may be more successful than targeting the general public. They may also be happy to lend their support to your campaign. As the **hae day :-)** grows from year to year, you will be able to broaden your audience accordingly. Here are some target audiences to consider in your activity:

- Regional and national government leaders and policy makers
- Civil societies and groups
- Patients and their families
- Health and medical professionals
- General public.

4. Consider local activity – make sure to cover off the basics

Within the toolkit we have suggested some ideas for local events and activities. Please do not think you have to do them all, they are merely an inspiration so you can decide which ones may be most appropriate for your organization and target audience. Consider how these activities match your specific objectives for the 2019 **hae day :-)** whether you have the resources and how you are going to measure your success.

Do not forget to make sure your membership contact list is up-to-date and you have the contact details for the HAE physicians in your country. Remember to alert your membership and physicians to whatever **hae day :-)** activity you are planning as early as possible, so you can secure support and involvement for when you need it. You will find template emails to do this in the toolkit.

5. Consider how you can work with the media in your country

Read through the guidance and the template materials that have been provided in the section “Engaging with the media”. These are available for you to tailor as you like, translating and distributing to the key media in your country, where appropriate.

6. Make the most of the hae day :-) website and social media

- Walk for HAE awareness and encourage your members to do likewise at www.haeday.org
- ‘Like’ the **hae day :-)** Facebook page at www.facebook.com/haeday



- Visit the **hae day :-)** Twitter profile at www.twitter.com/haeday
- Share the website, Facebook and Twitter links as broadly as you can
- Feel free to use the material at www.haeday.org.

7. Funding for your activities

We welcome all national organizations who wish to participate in the 2019 global awareness day. However, please only undertake activity that you have the resources to support. You should carefully consider the resources that you have before you plan or commit to any activity. Please ensure that the funds that you have or will generate will more than cover the cost of any activity that you plan. It will be the national organizations' responsibility to cover any additional expenses. Unfortunately HAEi is unable to contribute any funding to your local **hae day :-)** activities. Please track your expenses carefully to ensure that you are able to cover the costs of your plans.

8. Follow-up

We would love to hear from you after your 2019 **hae day :-)** activity has taken place. Please share your successes with HAEi at s.bjerre@haei.org. and we will include information in upcoming issues of the HAEi magazine and elsewhere. Any photographs would be very welcome too and can be mailed to HAEi at the same address.

9. Use the HAEi media platforms

HAEi is active on a number of media platforms. Please feel free to interact with us here:

- www.haeday.org and www.haei.org
- www.facebook.com/haeday
- www.twitter.com/haeday
- www.youtube.com/haedaychannel

Your **hae day :-)** team