



Getting involved

- roles of HAEi and the national organizations

The annual **hae day :-)** is coordinated by HAEi on a global level and the national organizations on a national level. Anyone is welcome to take part, including (but definitely not limited to) patients, caregivers, researchers, clinicians, the general public, companies, Ministries of Health etc.

Below is a description of the key principles of the **hae day :-)** as well as the role of HAEi and that of the national organizations.

The role of HAEi

HAEi is fully committed to the **hae day :-)** and will provide the following support before, during and after the 2019 **hae day :-)** activities:

- International coordination of the **hae day :-)**
- Decisions on international dates, themes and content
- Management of graphic properties (logo, visuals, etc.)
- Development and management of the website at www.haeday.org
- Development and management of the **hae day :-)** social media platforms including Facebook, Twitter, and YouTube
- Development of the **hae day :-)** toolkit with communication tools to spread awareness
- Gathering and sharing steps walked by HAE patients and others on the **hae day :-)** website
- Evaluation of results and analysis at international level
- Distribution of regular updates about the **hae day :-)** to the HAE community and the national organizations.

The role of national organizations

We hope that all the national organizations will participate in the **hae day :-)** in whatever way they can. There are no specific activities that we are asking you to conduct; it is entirely up to you to decide what activities are most appropriate in your country and to match the resources available to you. For example you may only wish to highlight the



hae day :-) to your membership or you may wish to extend your activities to fundraising events or media engagement.

Getting involved

Anyone is welcome to take part in the 2019 **hae day :-)** and we have provided the list below as inspiration for a variety of activities you might want to consider, from small to large. Also, do not forget to check in with your country group to see what they are organizing – you may be able to get involved too.

- Alert your colleagues, friends, family or organization membership that the 2019 **hae day :-)** is coming up
- Register your steps via www.haeday.org
- Talk to your country media (see the document “Engaging with the media “)
- Co-ordinate collection boxes for donations in support of the **hae day :-)**
- Organize a meeting for your members
- Implement a letter/email campaign to local or national policy and decision makers
- Organize a meeting with your local and national authorities/MEP/Minister of Health
- Organize events for the **hae day :-)** e.g. sponsored walks, tea party, sports events
- Recognize HAE advocates, patrons or caregivers with an award
- Hold a competition centered on the **hae day :-)** be it photo, art, essay writing, etc.
- Collect HAE stories via video camera and post them to your site
- Hold a silent auction via your website.

Your **hae day :-)** team