



Engaging with the media

If appropriate in your country, engagement with the media can be a powerful tool to help raise awareness of the 2020 **hae day :-)** and HAE. This section of the toolkit provides you with an outline and key template documents to support you in engaging with the media.

How-to guide for media outreach

The following are some of the main steps to follow if you decide you want to try and raise awareness of the **hae day :-)** as such or your specific 2020 **hae day :-)** event through the media in your country. We have included template materials for you to adapt – and translate if need be – for local use as you see fit.

A central element of your communications will be your key messages. Try to keep them at hand and use them if you can in your written material as well as when briefing speakers before interviews.

What to have ready – your press kit

Before contacting any media, it is important to consider the story elements you have to offer. Different media will be interested in different things, depending on their audience. As there are many awareness days, it may be quite challenging to interest the media in covering the one focusing on HAE. Making it as easy as you can for the journalists to bring the story, the better is your chance of interesting them in telling about the **hae day :-)** and HAE.

Supporting materials – often referred to as a Press Kit – help to get your message across to the media. Remember that it is important to present such material in a way that your audience can understand and should motivate them to take action, ideally beyond awareness building.

Key things to have ready to offer are:

- A written version of your story, e.g. your press release
- Facts and figures about HAE in your country and background to the disease



- Spokespeople to interview, for instance medical experts or members of your organization
- A HAE patient with a compelling story who is happy to talk to a journalist about his or her experience
- High resolution photos of a person with HAE during and outside of an attack
- High resolution logo for your organization
- High resolution logo for the **hae day :-)**

Some other preparation that you can do to support your messages is:

- Identify gaps or problems relevant to your organization
- Identify the steps that you need to take in order to raise awareness, generate support and catalyze action
- Summarize the work and projects that your organization has done and the future programs that you propose to improve the situation of HAE patients in your country
- Highlight success stories and stories of people who have benefited from the support of your organization.

Who to contact – preparing your media list

A good media list contains the names of media (newspapers, magazines, television news, online news sites, radio programs etc.) that you want to contact. Also, the list includes details of the journalists you should preferably contact, including their titles, phone number, email address etc.

When developing your media list, remember to always do your homework. Preferably, get a few copies of that particular paper, listen to the radio program or read the old articles on the particular website. Consider the stories you have read and see if health or awareness days are something they have covered before – and make a note of the department or journalists listed who have covered similar stories. If you cannot find this information, have a look for a health or news desk and try that first. There is usually a list of contacts within each printed edition, or listed on the media's website. Always try to find the right contact before you call to talk about your story.



Introduction to different types of media

Daily newspapers

These are the ones that you buy or have delivered on a daily basis. They will contain a variety of stories, typically national events/news, politics, crime, finance, health etc.

Depending on your country there may be broadsheet newspapers focusing on more “highbrow” stories and tabloid newspapers, which would carry more “every man” stories. These types of papers are going to be most interested in the biggest health stories, new data, new products, political decisions impacting on health, health scandal etc. As they focus on stories, which have a national interest, they may not feel a story on the 2020 **hae day :-)** will appeal to their readers. Unless you have high profile support for your event or a very compelling story from someone with HAE, they may not be interested.

The editorial board determines and writes the paper’s official position on various issues.

Some daily newspapers offer special sections on certain days of the week. These sections will have different contacts to the daily sections.

As the turnaround for stories in national daily newspapers is very quick, you should most likely plan on contacting these media close to the 2020 **hae day :-)** or your event (if on a different day that 16 May 2020). However, for the weekly specialist sections initial contact should be at least two weeks before your event.

Weekly non-national newspapers

These are usually local or regional newspapers, which strong focus on news of interest to their primary geographical area. They will have a smaller staff than the national papers and often one reporter will cover more than one area. As their focus is on things of interest in a local/regional area, they are more likely to be interested in the **hae day :-)** events being organized locally/regionally and could be a great way to raise interest in your event before it happens. They might also have a picture desk and be happy to send along a reporter and photographer to cover your event on the day.

As the turnaround for stories in these newspapers is longer than that of the daily newspapers, plan to contact them at least a week or two before your event.



Magazines

There are lots of different types of magazines, for instance women's interest, hobbies, culture, music, health, living etc. They will be published on a less regular basis than newspapers, e.g. weekly, monthly or even longer. As a result they will plan their issues weeks or sometimes months in advance. As a result they focus less on news events, as these can be out of date by the time they go to press. Instead they normally contain longer, more in-depth features on less time sensitive issues.

You should try to contact the magazines well in advance of your event.

Broadcast – radio/TV

Radio stations vary hugely in their focus and audience. A general broadcast station will usually have a mix of current/topical stories and programs and then feature stories or programs. It is a broadly similar approach for television news programs/channels. In the same way that there are national and local newspapers, there may also be national and local TV channels/programs or radio channels/programs that you can target.

The approach here is a mixture of the approach for daily newspapers and magazines. If you are targeting a national news program follow the daily newspaper approach. If you are targeting a local news program, a non-time sensitive program or a news channel use the local newspaper approach.

Medical media

There may also be specialist medical publications targeting physicians, nurses, and other healthcare professionals. These types of publications often focus on new data, or changes to health law/political approach and management strategies. If you are interested in targeting medical publications it might be worth discussing this with your doctor and nurse to hear what specialist medical magazines they read and if they have a copy you could see.

Online media

As online outlets are not working to a print or broadcast deadline, they often publish more content on a more frequent basis. Have a look online at what sites have covered an awareness day or health story in your country and build a list of contacts for those sites.



Pitching your story

Always prepare what you are going to say to the journalist before you actually contact them by email or phone. Think about the reasons you are contacting them: who, what, why, where, when, how.

Focus on what makes the **hae day :-)** important for their audience *now* by including timely information about an upcoming event or activity surrounding the awareness day or tying the story into current events and media trends. It is also important to think like the journalist's readers, listeners or viewers while crafting your pitch. Look for trends or themes in previous coverage and capitalize on those in your pitch.

Once your media list is completed, simply start making phone calls and/or sending out emails. If calling, ask whether a reporter or editor who specializes in health issues is available. If not, ask to speak to a reporter or editor specialized in human-interest stories.

When in contact with the right person, make a passionate appeal that your story is of great value to all readers/viewers – and do not forget to highlight the 2020 **hae day :-)** as a global HAE education and awareness effort.

Keep an active outreach list

Each time you speak to or exchange emails with a journalist, take thorough notes and keep them all in one place. A spreadsheet is a useful tool to use to track them. This will help you stay organized and you will always know where you stand with an opportunity. It will also remind you of the last correspondence so as not to follow up with a journalist too frequently or infrequently.

Spokespeople and interviews with patients

Often with health stories, journalists will ask to speak to a spokesperson to get a first-hand account of what it is like to live with or treat a particular condition. This is even more valuable in the case of a rare disease when not many people may have heard of it. Make sure you prepare to offer spokespersons in advance of talking to any media. That will really help you in getting coverage for your story.

If you are able to offer a case study, it will be really beneficial to share an overview of their personal story with the journalist to secure their interest.



Different types of spokespeople:

Physicians/nurses

A medical expert who can provide insight into the clinical diagnosis and management of a particular condition would be a great spokesperson for the media. Consider physicians with whom you already have a relationship, and one that treats HAE and is an advocate for HAE and/or rare disease awareness. Begin well in advance by reaching out to such nurses and physicians to gauge their interest in participating. Once they have confirmed their interest, let them know that you will be in touch to set up media interviews upon securing them.

Patient organization representatives

These are often interviewed to give the point of view on behalf of patients, and what they are looking to achieve for patients through the work of their organization.

Patients or caregivers (often referred to as a case study)

Journalists often want to interview someone who has the condition to hear first-hand what it is like to live with the disease, the impact it has had on the individual and those around them, and how life has changed with medical treatment or to call for action to secure medical treatment.

When thinking of people you could contact to be a case study, there are a few key points to bear in mind:

- ***Type of story:*** It is important to know that most journalists will want the story to be dramatic. If you think about the personal health stories you have read in the paper they tend to focus on a dramatic or very bad experience, which has been turned around with the right management – or with a call to action to secure a treatment to potentially positively change that individual’s life.
- ***Exclusivity:*** Most likely the journalist will prefer to speak to a case study exclusively – he or she wants to know that this particular story has been given to no one else. If you are only able to find one or two people who have a dramatic story and are willing to share this with a journalist, you may want to be



selective in whom you offer this to.

- **Approval:** Nothing that is said to a journalist is ever off the record, and it is unlikely that you will be able to see the article to approve it before it goes into print.

When you have secured media interest for an interview, we suggest you look at the tips for preparing for an interview in the next section. And do share these with the spokesperson before you put them in touch with the journalist, talking through them carefully.

Tips for the one being interviewed

Before and during an interview:

- Ask the reporter what he or she is looking for you to contribute, who else has been or may also be interviewed, and whether your interview will be live or taped.
- Prepare what you want to say – be sure of the details of the story you want to tell.
- Be prepared to speak in terms that the journalist and readers will understand, avoiding complicated medical language.
- Double check facts/timings/key details of your story before you do the interview.
- Think about what are the three points you really want to make – this is an important opportunity to deliver your message (you can use the key messages as the basis for this). Do not worry about sounding repetitious.
- Remember that it is fine to ask to do an interview at another time if it is not convenient – give yourself time to prepare.
- Practice out loud before you speak to the journalist.
- You are not likely to see or hear the story before it is written or aired.
- If you get a question you are not prepared for, stop to think through carefully what you want to say. It is quite all right if you do not know the answer to a question – then say so. It is okay to offer to answer any follow-up questions by phone or email.
- If you are unsure of an answer or think that the journalist is referring to information you feel is incorrect, do not hesitate to suggest the HAE International website at www.haei.org for additional information.
- It is quite all right to not answer a question if you do not want to – try not to be led into giving an answer. Ask the journalist to repeat the question if necessary.



- Remember that everything you say may be used in the interview so avoid saying anything that you do not wish to read or hear at a later date.
- Always tell the truth – and remember that sarcasm as well as disparaging comments about others and negativity in general may backfire.
- Most likely the journalist will be friendly but keep the relationship polite and professional at the same time.
- Remember that every HAE story is compelling and unique. Tell your story. Be confident – you are the expert.

After the interview:

- When the article is printed, the interview aired etc., do make sure to send an email to the journalist. A small word of thank you will help you and your organization to be remembered favorably the next time a media opportunity comes along.

Monitoring and reporting media coverage

Once you have confirmation from a journalist that he or she will cover the 2020 **hae day :-)** or your event, try to find out when it might be printed/broadcast or posted online. You can monitor for the publication of the story with internet-based tools such as Google Alerts (instructions to set up alerts can be found at www.google.com/alerts). Receiving an alert will give you the opportunity to see the coverage – and to check for and possibly correct any inaccuracies very shortly after the story is published. Also, if you have created a good contact with the journalist, do indeed ask for information on the date of print or broadcast.

HAE International would greatly appreciate that any media coverage in your country regarding HAE, your event or the 2020 **hae day :-)** be sent to h.boysen@haei.org. To help spread awareness of HAE and the 2020 **hae day :-)** all coverage will be shared on our Facebook page as well as on www.haeday.org.

Template media documents

In the following we include a set of templates that you can use when communicating with the media. They are all meant as guides – please feel free to edit as you see fit.

(A) Save the date

This can be used with your media and any other contacts you want to alert to the **hae day :-)** and/or your event. There is space for you to incorporate details about



your plans to celebrate the day, and to include quotes from local spokespeople. We have included some points for you to consider when including quotes.

(B) Press release

This can be used with your media and any other contacts you want to inform of the **hae day :-)** and/or your event. There is space for you to incorporate details about your plans to celebrate the day. It will be important to incorporate relevant local patient and physician quotes. We have included some points for you to consider.

(C) Letter to the Editor

A “Letter to the Editor” can be an alternative and useful form of communication with a media, providing the editor with an opportunity to publish the letter in full in the publication (unlike press releases or media alerts which are used as a prompt and a resource for a story). The content can be more informal and personal in tone which in the case of an awareness day or campaign can help to encourage support.

(D) HAE disease fact sheet

A fact sheet can be used to support the content of a press release. It provides more detailed background information to add to the journalist’s understanding of the disease area and situation. It can be sent out accompanying a press release or as additional material later on.

The fact sheet provided to you contains up to date global information on HAE. However, it will be more useful to your media if it also has content that is relevant to your country. So if you are able to include national or even regional statistics, you should. Placeholders have been left in the document for you to insert this information.

Please note that the fact sheet information should to be appropriately referenced.

(E) Talking points

Talking points provide preparation and support for you and your team in advance of any contact that you might have with a member of the media, a third party or partner. They outline the key points about the **hae day :-)** so that you can be sure to communicate what matters at every opportunity.



You should make sure that you and your team are very familiar with the talking points and have them to hand at all times during the build up to and on the 2020 **hae day:-)** and/or the day of your event. You should add some national or even regional information to the talking points so that they are truly relevant. There are placeholders for this.

(F) hae day :) Frequently Asked Questions

This document can be used either directly by yourself to answer any questions from the media or it can be shared with journalists or other contacts where appropriate.

(G) HAE Frequently Asked Questions

This document can be used either directly by yourself to answer any questions from the media or it can be shared with journalists or other contacts where appropriate.

High-resolution photographs

Photographs can provide a powerful support to a story and journalists are likely to request them, so it is useful to have them available. They must be relevant to the story, of interest to readers and of good enough quality to print (1+ MB).

Whilst it will be helpful to have a supply of photographs to send to journalists if they request them, it is also recommended that you pick one or two to send with the press release to support the story from the start. You may already have your own supply of good quality relevant photos that you can offer to the media. Otherwise it is worth sourcing or generating some in advance to have available.

Please note that if your images feature recognizable persons, you must ensure that you have their permission to distribute them, making them aware of where and how they are likely to be published.

Should you not have any photos it might be beneficial for you to visit www.haeimages.com, the HAE Image Repository of the US Hereditary Angioedema Association. Please note that use of any image acquired from this website must be accompanied by the recognition statement "Reprinted with permission of www.haeimages.com".



Your **hae day :-)** team