

Cure HHT Social Media Toolkit

HHT Awareness Month

June 2018



About this Toolkit

This toolkit is created to help those interested in sharing information about HHT through social media, particularly through Facebook, Twitter and Instagram. We at Cure HHT created tips and tricks to help users with their posts, as well as establish best practices for spreading awareness about this disease to the public.

Who Should Use this Toolkit?

HHT patients, families, friends, healthcare professionals, support groups (both national and international) and other organizations that align with the mission and values of Cure HHT.

What is HHT Awareness Month?

HHT Awareness Month is an annual observance held throughout the month of June. It is intended to raise awareness of HHT, or Hereditary Hemorrhagic Telangiectasia, across the world.

Aspects of HHT Awareness Month include sharing educational resources, hosting and supporting community events, creating legislative and advocacy opportunities, as well as celebrating Global HHT Awareness Day on June 23rd by taking steps to cure HHT.

Cure HHT collaborates with the HHT community both virtually and in-person to unite the thousands of people who are impacted by this disease to heighten the visibility of a disease that is unknown, yet affects many across the world.

HHT Awareness Month & HHT Global Awareness Day: What to Post, How to Post & When!

Why Post?

The more we talk about HHT, the more people will recognize the importance of this disease. Awareness leads to screening and testing for HHT, which could lead to a positive diagnosis. In a way, awareness is saving lives of those who have HHT, but who never knew it!

What to Post:

During HHT Awareness Month, we encourage users to post, share, retweet and like posts about HHT. Whether it is a post about HHT facts, a story about someone with HHT, a community event to empower others who have HHT, or a question about HHT, sharing information about this disease matters!

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Social Media 101:

Social media presents an opportunity to reach audiences both near and far, and social media has the ability to connect people across cities, states, ocean and continents. When posting and sharing on social media, it is important to be mindful of the audience and the methods of sharing content (text, photo, video, etc).

When creating a post, it is a good idea to first think of what you want the goal(s) and objective(s) to be of the message, what you are trying to achieve and how you measure your success. These don't need to be very elaborate or detailed, but thoughtful posts go a long way when sharing important messages.

And finally, keep it simple and fun! The messaging and content should be meaningful to you. If it isn't genuine, chances are you and your audience will not be engaged. But if you can be yourself, your voice and words will carry well beyond feeds, walls and hashtags.

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How to Post:

Posting on social media about HHT can be easy! We encourage users who post about HHT for the first time to spend a few minutes drafting and reviewing their post.

Pro tip: typing your post on a Word doc or in an email is a simple way to check your messaging, scan for any grammatical errors, and review what you wish to send before actually doing it!

When posting about HHT for **HHT Awareness Month**, we suggest using the following hashtags:
#takestepstocurehht hhtawarenessmonth2018 #curehht

When posting about HHT for **Global HHT Awareness Day** on June 23rd, we suggest using the following hashtag:
#takestepstocurehht

Be sure to tag Cure HHT in your posts! To tag our organization, simply use the "@" sign and type Cure HHT.

When to post:

There is no golden hour for social media posts, so post at a time that works best for you!

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Communicating About HHT: Best Practices

HHT can be complicated, confusing, overwhelming, scary and sad. Your audience may be well versed about what HHT is, but we suggest explaining what this disease is in simple terms. As you know, HHT affects everyone differently and while tragedies do occur in HHT patients, many can live healthy and fulfilling lives through management and treatment.

Here are a few sentences we use to describe this disease to the public:

HHT is a genetic disease that affects the formation of blood vessels in different parts of the body, including the nose, skin, lungs, liver, gastrointestinal tract and brain.

HHT, or Hereditary Hemorrhagic Telangiectasia, is a genetic disease that impacts blood vessels, and can lead to bleeding in various parts of the body.

HHT is a disorder that affects blood vessels, causing frequent and severe nosebleeds and creating arteriovenous malformations (AVMs) in internal organs that can be at risk to bleed. HHT has impacted millions worldwide, but is very difficult to diagnose. And, HHT never skips a generation, so child of an affected parent has 50/50 odds to inherit this disorder.

Feel free to copy and paste these sentences in any of your posts!

Facebook & Twitter: Best Practices

- Keep it short!
- Add photos or videos to boost posts and have your posts stand out
- Use a conversational tone
- Explain WHY the content of your post should matter to your audience

The Dos vs. Don'ts for Posting on Social Media:

Do:

- Talk about your experience with HHT
- Share your story through videos and photos
- Tag Cure HHT in your posts & use hashtags

Don't:

- Post with slander and offensive/profane language
- Post any inappropriate or illegal activities
- Reveal confidential information (especially medical information!) about someone if they have not given their consent

Final Words of Advice:

We understand everyone has different viewpoints and opinions. Feel free to express yourself, we just ask that you be respectful of others.

Remember – the Internet is forever! Don't post anything that you don't want to be available indefinitely.

Thank you for participating in HHT Awareness Month through social media!
Together, we can make a difference in the lives of those impacted by HHT