



#LetsTalkAboutHD



Huntington's Disease
Society of America

HD

HUNTINGTON'S DISEASE AWARENESS MONTH TOOLKIT

MAY 2023

[HDSA.ORG/LETSTALKABOUTHD](https://hdsa.org/letstalkabouthd)



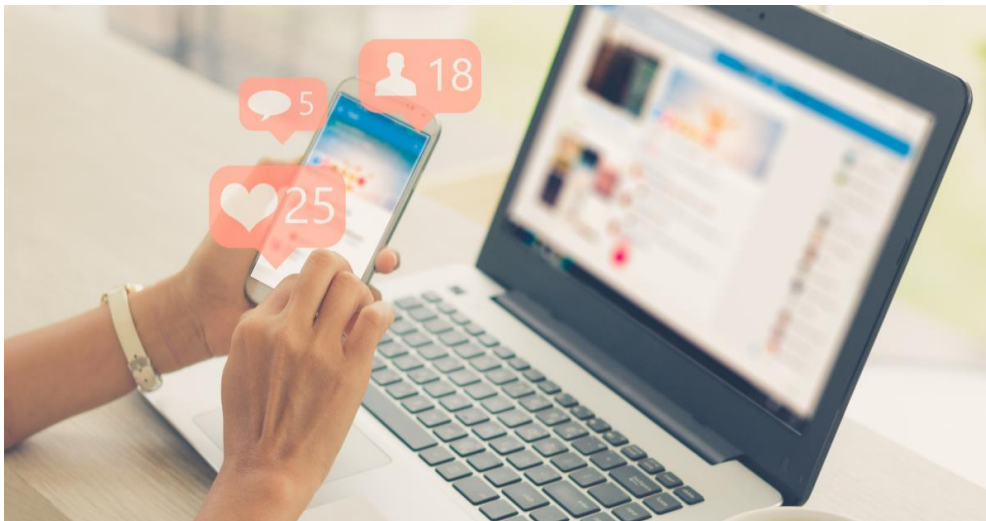
OVERVIEW

#LetsTalkAboutHD is a social media initiative during Huntington's Disease Awareness Month to encourage families to share their experiences with HD throughout the month of May.

Use #LetsTalkAboutHD to educate the world about the devastating impact that HD has on families. You can post videos, photos or written stories – HD impacts every family differently and it is time the world talks about Huntington's disease!

CAMPAIGN GOALS

- Build awareness by getting people talk about HD on social media
- Engage people outside the HD community
- Inspire everyone to get involved with HDSA





KEY MESSAGES

Below you will find key facts & messaging about HD & HDSA.

- Huntington's disease (HD) is a fatal genetic disorder that causes the progressive breakdown of nerve cells in the brain. It deteriorates a person's physical and mental abilities, usually during their prime working years, and has no cure ...yet.
- Every child of a parent with HD has a 50/50 chance of inheriting the faulty gene that causes Huntington's disease.
- Today, there are approximately 41,000 symptomatic Americans living with Huntington's disease and more than 200,000 at-risk of inheriting HD.
- The symptoms of Huntington's disease are described as having ALS, Parkinson's and Alzheimer's diseases –simultaneously.
- HD manifests as a triad of motor, cognitive, and psychiatric symptoms, which progressively get worse over time.
- Help us pass the HD Parity Act to waive the two-year Medicare waiting period for people with HD. Learn more at [HDSA.org/takeaction](https://www.hdsa.org/takeaction).
- The Huntington's Disease Society of America (HDSA) was founded in 1967 by Marjorie Guthrie, the wife of legendary folk singer Woody Guthrie. Woody died from HD complications when he was only 55 years old, but the Guthrie family legacy lives on at HDSA to this day.
- In the battle against Huntington's disease no one fights alone. At HDSA, family is everything!



SAMPLE VIDEO SCRIPTS

***If you need help with your videos, feel free to use the following scripts.
Use your phone or desktop to record quick videos supporting the campaign.***

•Hi I am _____ and Let's Talk About HD. Every child of a parent with Huntington's disease has a 50/50 chance of inheriting this fatal brain disorder with no cure. Please go to HDSA.org to learn more about Huntington's disease and join the fight.

•Hi I am _____ and Let's Talk About HD. Huntington's disease is devastating families across the United States and there is no cure. Please go to HDSA.org to learn more about HD and join the fight.

•Hi I am _____ and Let's Talk About HD. Huntington's disease manifests as a triad of motor, cognitive, and psychiatric symptoms, which progressively get worse over time. Please go to HDSA.org to learn more about Huntington's disease and join the fight.

•Hi I am _____ and Let's Talk About HD. Huntington's disease is described as having ALS, Parkinson's and Alzheimer's diseases –simultaneously. Please go to HDSA.org to learn more about Huntington's disease and join the fight.

•Hi I am _____ and Let's Talk About HD. (INSERT PERSONAL STORY HERE)
Please go to HDSA.org to learn more about Huntington's disease and join the fight.

•Hi I am _____ and Let's Talk About HD. Huntington's disease is a family disease and at HDSA family is everything. In the battle against Huntington's disease no one fights alone. Please go to HDSA.org to learn more about Huntington's disease and join the fight.



SAMPLE SOCIAL MEDIA POSTS

***Include infographics, photos and videos with your posts/tweets.
Tag celebrities, sports teams & major companies. Ask to share & retweet.***

- May is #HuntingtonsDisease Awareness Month...Join the #HDSAFamily and #LetsTalkAboutHD Visit www.hdsa.org for more information about HD and join the fight.
- This May #LetsTalkAboutHD to support the #HDSAFamily and build awareness about #HuntingtonsDisease. Visit www.hdsa.org for more information about HD and join the fight.
- May is #HuntingtonsDisease Awareness Month so #LetsTalkAboutHD and educate the world about #HuntingtonsDisease Visit www.hdsa.org for more information about HD and join the fight. #HDSAFamily
- #LetsTalkAboutHD Children of a parent with #HuntingtonsDisease have a 50/50 chance of inheriting the fatal gene that causes HD and there is no cure...yet. Learn more about HD and how to help at www.hdsa.org. #HDSAFamily
- Join the #HDSAFamily during #HuntingtonsDisease Awareness Month & #LetsTalkAboutHD. Visit HDSA.org for more info.



WHO TO ASK TO PARTICIPATE

- Friends & Family
- Community Organizations
- Politicians
- Pro & Minor League Players & Teams
- College Coaches & Teams
- Celebrities & Musicians
- TV & Radio Personalities
- Schools

SAMPLE REQUEST LETTER/EMAIL

Dear **XXXXX**,

I would like to invite you to join the Huntington's Disease Society of America in turning up the global volume on Huntington's disease awareness this May by participating in the #LetsTalkAboutHD social media initiative.

Simply record a short video using one of the scripts below and share it to social media in May using #LetsTalkAboutHD –it is that easy!

Here are some sample scripts:

- Hi I am _____ and Let's Talk About HD. Every child of a parent with Huntington's disease has a 50/50 chance of inheriting this fatal brain disorder with no cure. Please go to HDSA.org to learn more about Huntington's disease and join the fight.
- Hi I am _____ and Let's Talk About HD. Huntington's disease is devastating families across the United States and there is no cure. Please go to HDSA.org to learn more about HD and join the fight.
- Hi I am _____ and Let's Talk About HD. Huntington's disease is described as having ALS, Parkinson's and Alzheimer's diseases –simultaneously. Please go to HDSA.org to learn more about Huntington's disease and join the fight.

To learn more about HD visit HDSA.org and if you have any questions please feel free to contact me at **XXXXX**. Thank you!

#LetsTalkAboutHD

HD

Huntington's Disease Society of America

SHARE #LETSTALKABOUTHD PHOTOS

Make signs, frames and boards. Use #LetsTalkAboutHD when posting the images to social media





SOCIAL MEDIA PROFILE PHOTO FRAME

Support #LetsTalkAboutHD by adding a Twibbon profile filter. The Twibbon frame will automatically customize your Facebook & Twitter profile photos.

Go to: twibbon.com/support/letstalkabouthd

----- Support this campaign by adding to your profile picture -----



May is HD Awareness month. Please support the Huntington's Disease Society of America.



FOR MORE INFORMATION

www.HDSA.org/LetsTalkAboutHD

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