

HUNTINGTON'S DISEASE AWARENESS MONTH

MAY 2017

CAMPAIGN TOOLKIT



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's time the world talks about Huntington's disease!

Campaign Goals

- Build HD awareness by encouraging 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 and messages 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 30,000 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*.
- The Huntington's Disease Society of America (HDSA) was founded in 1968 by Marjorie Guthrie, the wife of legendary folk singer Woody Guthrie. Woody died from HD complications in 1967 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 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 & TWEETS

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

Facebook

May is #HuntingtonsDisease Awareness Month...Join the #HDSAFamily and #LetsTalkAboutHD Visit www.hdsa.org for more information about HD and join the fight. Please Share.

This May #LetsTalkAboutHD to support the #HDSAFamily and build awareness about #HuntingtonsDisease. Visit www.hdsa.org for more information about HD and get join the fight. Please Share.

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. Please Share.

#LetsTalkAboutHD Did you know that children of a parent with #HuntingtonsDisease have a 50/50 chance of inheriting the fatal gene that causes HD and there is no cure? Learn more about HD and how to help at www.hdsa.org. Please Share.

Twitter

Join the #HDSAFamily during #HuntingtonsDisease Awareness Month & #LetsTalkAboutHD Visit HDSA.org for more info

Hey @JTimberlake May is #HuntingtonsDisease Awareness Month so #LetsTalkAboutHD #HDSAFamily Visit HDSA.org for more info



LOGO

Use the #LetsTalkAboutHD logo in your social media posts, videos & photos





For Immediate Release

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#LetsTalkAboutHD Campaign Turns Up the Global Volume on Huntington's Disease During HD Awareness Month in May

New York, NY (May 2017) – The Huntington's Disease Society of America (HDSA) has announced that it will once again conduct the incredibly successful **#LetsTalkAboutHD** social media campaign during Huntington's Disease Awareness Month in May. HDSA, the world's largest non-profit organization dedicated to Huntington's disease, has already secured several endorsement videos from celebrities and other supporters which will roll out daily in May.

The initiative encourages anyone affected by Huntington's disease to share their experiences on social media through videos, photos or personal stories using #LetsTalkAboutHD. You can follow and contribute to the conversation on Twitter (@HDSA) and Facebook (facebook.com/HDSofA). For more information on the campaign please visit www.HDSA.org/LetsTalkAboutHD.

"Let's Talk About HD educates the world about the devastating impact of Huntington's disease," said Louise Vetter, CEO of HDSA. "HD impacts every individual and family differently and it's time the world knows our story."

Huntington's disease 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 during their prime working years and has no cure. Every child of a parent with HD has a 50/50 chance of inheriting the faulty gene that causes HD.

Today, there are approximately 30,000 symptomatic Americans and more than 200,000 at-risk of inheriting the disease. Many describe the symptoms of HD as having, ALS, Parkinson's and Alzheimer's diseases – **simultaneously.**

The Huntington's Disease Society of America is the premier nonprofit organization dedicated to improving the lives of everyone affected by HD. From community services and education to advocacy and research, HDSA is the world's leader in providing help for today, hope for tomorrow for people with HD and their families.

To learn more about Huntington's disease and the work of the Huntington's Disease Society of America, visit www.hdsa.org or call (800) 345-HDSA.



TWIBBON

Support #LetsTalkAboutHD by adding a Twibbon profile filter. The Twibbon will automatically customize your Facebook & Twitter profile photos. Go to: http://twibbon.com/Support/hd-awareness-month

Support this campaign by adding to your profile picture (?)







Don't worry, you'll get a chance to preview your Twibbon before it is added.



WHO TO ASK TO PARTICPATE

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



CHECKLIST

- ✓ Add the Twibbon to your profile pic
- ✓ Upload #LetsTalkAboutHD profile banner art
- ✓ Post #LetsTalkAboutHD to your social media using videos, photos & stories
- ✓ Get your friends & family involved with #LetsTalkAboutHD
- ✓ Retweet & share other **#LetsTalkAboutHD** posts
- ✓ Tweet at your favorite celebrities asking for retweets (RT)
- ✓ Contact local public figures to participate in #LetsTalkAboutHD
- ✓ Use #LetsTalkAboutHD to promote local HDSA events



FOR MORE INFORMATION

www.HDSA.org/LetsTalkAboutHD

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In the battle against Huntington's disease, no one fights alone. At HDSA, family is everything. Learn more at HDSA.org/LetsTalkAboutHD