



**Huntington's Disease
Society of America**

Creating The Right Strategic Communications Approach for HDSA

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HD Community Getting to the Desired State

Where Are We Now

HD Patients & Families:

HD families often get information exclusively through their local neurologist and don't tap into vast resource network at HDSA

Healthcare Industry:

Top pharma (Pfizer, Novartis, Merck, Sanofi) now have a rare disease portfolio but there is very little discussion / research addressed specifically about HD.

General Public:

For the most part, people that do not know a Huntington's family (most people), do not understand what HD is or why they should care.



Where Do We Want to Be

HD Patients & Families:

HD patients and families understand (either via physician, hospital or online SEO/ media campaigns) that the first place they should go to for critical resources and information about the disease is the HDSA.

Healthcare Industry:

Pharmaceutical and biotech companies are well aware of HD, they are vested in HD research and know that the HD patients are aligned with HDSA as its leading patient and family voice,

General Public:

The public knows that HD is a terrible neurodegenerative disorder that can be cured with the right resources and research; they know that HD research can be the key to other cures – PD, MS, ALS – and we all benefit when HD is cured/



Somewhere between the Current and Desired State is the key to the HDSA Communications program. How do we get from where we are now, to where we want to be?

What Makes HDSA and Huntington's Disease So Compelling To Us & Others

- The Disease Itself – Mix of ALZ, PARK and ALS
- Family /Genetic Aspect of HD is compelling – Dominant Gene
- The Heritage of HDSA – Guthrie Story
- Rare Diseases Are Finally Getting Attention – Big Pharma now has rare disease divisions for profit AND halo effect
- HD is starting to be part of a national dialogue thanks to recent Novel by acclaimed author, HBO documentary, etc.
- The Science Story – Clinical Progress in HD Can inform other neurodegenerative research

What Makes HDSA and Huntington's Disease Irrelevant To Others

- Most People have never heard of HD; Low Awareness among general population.
- Even People that know what HD is, are significantly more likely to care about diseases that could affect them or their family
- Young people have absolutely no idea who Woody Guthrie Is
- HD doesn't have a Michael J Fox to carry the message to the public, upper crust society and congress
- HDSA wants to spend precious dollars on resources for families and research vs. marketing

**Given Pros and Cons –
What Do You Think We Should Do?**

What is Public Relations?

Public relations is not an ad or commercial, it is understanding your target audience and building a connection and credibility with them.

**Good storytellers win
when it comes to brand growth.**

Everything we do in life,
every bit of news,
every bit of memory
is a story that we shape to our own needs.

So, here is what we did...

In the battle against Huntington's disease no one fights alone.

At HDSEA, **Family is** *everything.*

- HD is an inherited disease that devastates families
- The importance of family support
- Many family members become primary caregivers
- The impact HD has on those at-risk
- The impact HD has on family planning

Volunteer. Educate. Advocate. Donate.

Action words to get people involved

The New www.HDSA.org

Locate Resources using Google Maps

Locate Resources

Show Only:

- HDSA Chapters
- HDSA Centers of Excellence
- HDSA Support Groups
- HDSA Social Workers

Please Note: The following providers and services listings are maintained for information purposes only. Inclusion in the list does not constitute an endorsement or recommendation by the Huntington's Disease Society of America, Inc.

- Physicians
- Adult Day Care Facilities
- Legal Resources
- In-Home Care resources
- Geriatric Care Managers
- Physical Therapists
- Long-Term Care / Nursing Homes
- Speech Therapists
- Genetic Testing Centers

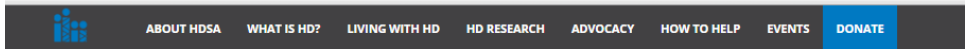
Your Location: Distance: 1000 miles

Enter your street address, city, state, OR Zip Code

SEARCH RESULTS



Clear definition of HD with use of graphics & video



*Help for Today.
Hope for Tomorrow.*

Search

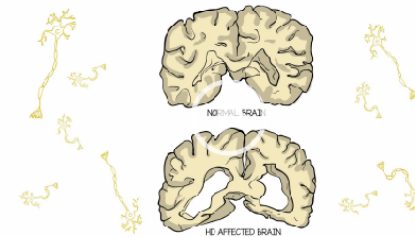


WHAT IS HD?

What Is Huntington's Disease?

STAGES OF HD THE SCOPE OF HD WHO IS AT-RISK? GENETIC TESTING & FAMILY PLANNING PRENATAL TESTING JHD OVERVIEW
AN END TO HD? WHERE TO FIND HELP PUBLICATIONS

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 during their prime working years and has no cure. HD is known as the quintessential family disease because every child of a parent with HD has a 50/50 chance of carrying the faulty gene. 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 - simultaneously.

Symptoms usually appear between the ages of 30 to 50, and worsen over a 10 to 25 year period. Ultimately, the weakened individual succumbs to pneumonia, heart failure or other complications. Everyone has the gene that causes HD, but only those that inherit the expansion of the gene will develop HD and perhaps pass it on to each of their children. Every person who inherits the expanded HD gene will eventually develop the disease. Over time, HD affects the individual's ability to reason, walk and speak.

HDSA's YouTube Channel Is The World's Most Comprehensive Huntington's Disease Video Library

- **Promotion**
- **Education**
- **Research**
- **Advocacy**
- **Caregiving**
- **And Much More!**



Simply copy the video link that is best appropriate and share to recruit new volunteers and/or supporters!

Social Media Engagement



Join the
conversation on our
social media
channels



Use of Hashtags

- #HDSAFamily
- #HuntingtonsDisease
- #HDTips
- #HDSAGuthrieSessions
- #HDWorkoutTips
- #HDFacts
- #HDSABaltimore

HD Workout Tips with Shana Verstegen



Provide educational videos to encourage proactive lifestyle
Encourage people with HD that they can still be active



- Tell the story on how HD SA was founded
- Pay tribute to the Guthrie Family Legacy
- Cultivate relationships with artists
- Introduce HD & HD SA to a new audience



- Social media initiative during HD Awareness Month to turn up the volume on HD conversations
- Engage celebrity support to introduce Huntington's disease & HDSA's mission to a wider audience

The Power of

WHAT IF?

to Engage People
Outside the HD Community

- What if this was your life?
- What if a cure for HD can treat ALS, Parkinson's & Alzheimer's?
- What if YOU can make a difference?

**What Would You Add
To This 2016 Program?**

Questions? Comments? Ideas?

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