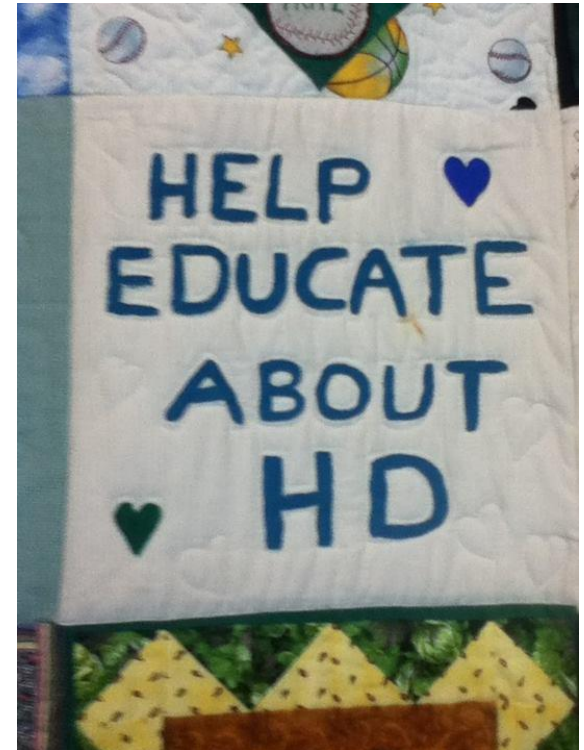


Field - Based Education & Advocacy: HDSEA's Lay & Professional Resources

Presentation Overview

HDSA is here to help you educate about HD!

- ☐ Educational Resources
- ☐ Field Based Event/Speaker Resources
- ☐ Grant Seeking Resources & HDSA Educational Grant
- ☐ Resources for Healthcare Professionals
- ☐ Resources to Educate Law Enforcement
- ☐ Resources to Educate Lawmakers



Educational Resources

NEW TO HD

RESEARCH

LIVING WITH HD

ABOUT HDSA

HOW TO HELP

RESEARCH

[HDSA RESEARCH](#)[GRANT APPLICATIONS](#)[RESEARCH NEWS &
REPORTS](#)[RESEARCH WEBINAR
SERIES](#)[CLINICAL TRIALS](#)[HDBUZZ RESEARCH
NEWS](#)[HD GENE
SYMPOSIUM: 20
YEARS](#)[THERAPIES IN
PIPELINE](#)[RESEARCH
CONFERENCES](#)

Research



HDSA: A Leader in Global HD Research

Since 1999, the HDSA has committed more than \$18 million to fund research with the goal of finding effective treatments to slow Huntington's disease. Our past research efforts have also helped increase the number of scientists working on HD and have shed light on many of the complex biological mechanisms involved in HD.

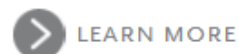
In 1997, HDSA launched an innovative, new approach to tackle HD. We brought together a group of some of the most well-known and prolific HD researchers from around the world to work together in teams to tackle large biological topics hypothesized to be involved in HD pathogenesis. This team of researchers was called the *Coalition for the Cure*. The Coalition Teams published important findings regarding the function of the huntingtin protein, potential new targets and pathways to treat HD and helped generate new animal models of HD to aid in HD drug discovery efforts.

While funding for the Coalition for the Cure ended in 2009, the HDSA remains committed to continuing our long tradition of supporting HD research. With the

Human HD Biology
Fellowship Program
HUNTINGTON'S
DISEASE SOCIETY OF
AMERICA ANNOUNCES
FIRST-EVER HD HUMAN
BIOLOGY PROJECT
AWARDS

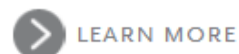
[READ MORE](#)

HDSA Research

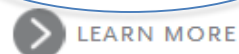


Research News & Reports

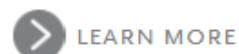
Read about the latest Huntington's disease research and research being done in related diseases



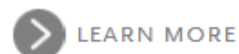
Clinical Trials



HD Gene Symposium: 20 Years

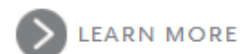


Research Conferences

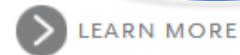


Research Pipeline

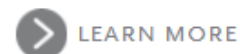
Grant Applications



Research Webinar Series

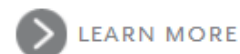


HDBuzz Research News

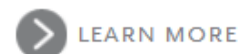


HD Gene Symposium: 20 Therapies in Pipeline Years

Drugs, supplements, and therapeutic approaches which are actively moving through the research pipeline are graphically represented.



Scientific Advisory Board



Stem Cells

LIVING WITH HD

HD CARE

ADVOCACY

COMMUNITY
SERVICES

PUBLICATIONS

ANNUAL
CONVENTION

HDSA FORUM

Living With HD




HD Care

Find information on the progression and stages of the disease as well as local resources for the entire family: From HDSA Centers of Excellence, to Social Workers, Caregiver resources, Publications, and other valuable information.


 LEARN MORE

Advocacy

Learn more on how to participate in Huntington's Disease Society of America's advocacy movement and raise your voice for legislation and policy to improve the lives of HD families.


 LEARN MORE

Community Services


 LEARN MORE

Publications


Marker Magazine
Toward a Cure
We Are HDSA
Article Connect
Law Enforcement Kit

 LEARN MORE

Annual Convention

 LEARN MORE

HDSA Forum

 LEARN MORE

Myths about HD:

HDSA is researching myths and misinformation about HD. If you have recently heard any myths or misinformation about HD, please fill out the survey at www.hdsa.org/myths. The information gathered will be used for future initiatives.

[READ MORE](#)

To contact the HDSA Social Worker closest to you, please call 800-345-HDSA (4372)

[READ MORE](#)

LIVING WITH HD

HD CARE

[Stages Of HD](#)[Living At Risk](#)[Juvenile HD](#)[Caregivers](#)[HDSA Chapters](#)[Caregiver's Corner
\(Webinars\)](#)[Lunch & Learn
\(Webinars\)](#)[Nutrition](#)[Ask the Social Worker](#)[Treatment Guidelines
for Huntington's
disease](#)[GINA](#)[Living With HD](#) | [HD Care](#)

In this family care section you will find resources that will enable you to improve the quality of life for your loved one and your family. If you have questions, or need further information, please contact Seth J. Meyer at 212-242-1968 ext. 240 or via e-mail at smeyer@hdsa.org.

[Stages of HD](#)[Living at Risk](#)[Genetic Testing Centers](#)[Juvenile HD](#)[Caregiver Information](#)[Nutrition](#)[Equipment Board](#)[Caregiver's Corner \(Webinars\)](#)[Ask the Social Worker](#)[GINA](#)[Disability](#)[Treatment Guidelines for Huntington's Disease](#)[Long Term Care](#)

COMMUNITY
SERVICES

PUBLICATIONS

Past Editions of The
Marker

Past Editions of Toward
a Cure

We Are HDSA
Newsletter

HDSA Article Connect

Law Enforcement Kit

Understanding
Behavior

ANNUAL CONVENTION

HDSA FORUM

topics

[Advocacy](#)

[Behavioral Disorder](#)

[Caregiving](#)

[Clinical Trials/Research](#)

[Cognitive Disorder](#)

[Disability/Benefits](#)

[Genetic Testing /Counseling](#)

[General](#)

[Health Care](#)

[Juvenile-Onset HD](#)

[Long Term Care](#)

[Personal Stories](#)

[Physical Therapy/Occupational Therapy/Speech Therapy/Nutrition:](#)

[Planning](#)



Huntington's Disease
Society of America

LIVING WITH HD

HD CARE

ADVOCACY

COMMUNITY
SERVICES

PUBLICATIONS

ANNUAL
CONVENTION

Convention
Registration

Hotel
Accommodations

Transportation

Convention
Scholarship
Opportunities

HDSA Convention
Sponsors

Past Presentations

PAST CONVENTION PRESENTATIONS:

[2013 CONVENTION PRESENTATIONS](#)

[2012 CONVENTION PRESENTATIONS](#)

[2011 CONVENTION PRESENTATIONS](#)

[2010 CONVENTION PRESENTATIONS](#)

[2009 CONVENTION PRESENTATIONS](#)

[2008 CONVENTION PRESENTATIONS](#)

HDSA Webinars

HDSA has 40+ webinars archived on the HDSA website & available to field leaders

- **Research Webinar Series:** Current research topics from HD experts
- **Caregiver's Corner:** Geared specifically towards caregivers. Available at
- **Lunch & Learn:** Broader range of topics
Available at
- **Topic-Specific Series** (Disability, Advance Planning)
- **Field Webinars:** Topics like fundraising & budgeting on the extranet for chapter leadership

HELP FOR TODAY, HOPE FOR TOMORROW

New to HD
Research
Living with HD

About HDSA
How to Help
Log In

Physicians
Extranet

CONNECT

888-HDSA-506 (Helpline)
212-242-1968
hdsainfo@hdsa.org
505 Eighth Avenue
Suite 902
New York, NY 10018

SUPPORT

Donate
Shop

SOCIALIZE



EXTRANET

Extranet Page Login

USERNAME:

PASSWORD:

LOGIN

[forgot your password?](#)

[Costco Grant Application](#) (PDF, 242.7K)

[remove]

Category: Grassroots Fundraising Programs

Uploaded Jul 29, 2011 by

Last viewed by: [Chapters HDSA](#)

[add comment]

[Grant and Employee Volunteer Opportunities for Chapters, Affiliates, and Regions](#) (PDF, 614.4K)

[remove]

Category: Communications

Uploaded Jul 1, 2013 by [Sam Peters](#)

Last viewed by: [Chapters HDSA](#)

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[Important Grant Info from 990](#) (Word, 815.0K)

[remove]

Category: Grassroots Fundraising Programs

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[Sarah Pattison](#)
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[add comment]

[Kohl's Cares Application](#) (PDF, 238.6K)

[remove]

Category: Grassroots Fundraising Programs

Uploaded Jul 29, 2011 by

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[add comment]

[Walmart Facility Giving Program](#) (PDF, 40.0K)

[remove]

Category: Grassroots Fundraising Programs

Uploaded Jul 29, 2011 by

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[add comment]

Field-Based Event/ Speaker Resources

HDSA Educational Event Manual

- HDSA has a manual that can walk you through the process, as well as a timeline for success.
- Both are available as a handout, as well as on the Extranet for Chapter & Affiliate leaders.
- You can also contact Jane Kogan at jkgogan@hdsa.org for a copy.



Budgeting for your Educational Event

- Recruit Committee Members
- Meet with your Chapter, Affiliate or Regional Staff and discuss your Educational Event.
- Create an Educational Event budget worksheet, with revenues and expenses, which can be submitted through your Region or your local Chapter for approval.
- Other ideas that should be considered are the following:
 - Event Dates
 - Venue ideas (local Hospital, Company or Community Rooms might equate to donated space)
 - Put together a list of potential attendees
 - Book speakers that are **geographically close**
 - **NO HONORARIA** of any kind
 - Marketing your event
 - A/V needs
 - Refreshments/Food
 - Printing & Postage

Budgeting for your Educational Event



Expenses

- As a non profit, we are we are all quite accustomed to keeping track of our expenses via:
 - Utilizing the three bid rule
 - Hosting a successful event on a shoestring budget
 - Soliciting free products and services through expressing to everyone in your community why they should support the mission of HDSA...It's certainly because we all believe in HDSA and the mission.
- One avenue to explore is through building a relationship with a local company in town....
 - Host your Educational Event in their company space such as a lobby or cafeteria or event room
 - Make copies of event programs and flyers on their equipment
 - Ask the company to donate food and from their food service's
 - Work with their communications team publicize this event
 - Recruit their company employees to volunteer to support this event which can lead to new Chapter and Affiliate volunteers



Budgeting for your Educational Event

- Silicon Valley Community Foundation provides free community meeting space for nonprofit organizations. SVCF encourages your organization to make use of our state-of-the-art facilities to host meetings, trainings, informal gatherings or retreats
- Need space for your board meetings, staff retreat or special program? The United Way Community Resource Center has free meeting space for nonprofit organizations. Rooms can accommodate groups ranging from 5 to 500. There is no charge for space during regular business hours. A modest security fee covers evening and/or weekend use. Space fills up quickly – schedule your next event today. The United Way Community Resource Center is located at 50 Waugh Drive, convenient to area freeways; parking is free.
- A few years ago, The San Diego Foundation took the step of purchasing a building in Point Loma's beautiful Liberty Station. The move was not just about obtaining a new, environmentally friendly asset for the organization, but was also made out of the desire to create a professional and welcoming space for both The Foundation team and others in the nonprofit and philanthropic sectors. We are pleased to provide the opportunity for organizations to reserve one of our many conference and meeting rooms for their needs. Reservations are on a first come, first serve basis.
- The Boston Foundation welcomes community organizations to use our available conference room space for meetings. Our conference rooms are a variety of sizes, from the South Boston Room with a seating capacity of 32-40 classroom style, and 70 theater style; the Dorchester Room with seating capacity of 20; the Roxbury Room with seating capacity of 24; and the Hyde Park Room which seats up to twelve. - See more at: <http://www.tbf.org/investing-in-non-profits/conference-space#sthash.gssH24PW.dpuf>

Budgeting for your Educational Event

Revenue Sources

- ☐ HDSA Educational Grant provided by Lundbeck (2014 only)
- ☐ Sponsorships
 - All sponsorships received must be used for educational event
- ☐ In-Kind Donations
- ☐ Exhibitor Space
- ☐ Silent Auction
- ☐ Book Shop/Store
- ☐ Registration Fees
 - Nominal
- ☐ Process to subsidize based on need
- ☐ Raffle (*contingent on state law*)
- ☐ Local Grant Opportunities



Event Tips

Do

- ✓ Submit a proposed budget during budget season or work with your staff contact.
- ✓ Plan dates 6-8 months **in advance** to allow for speakers
- ✓ Have a few potential dates in mind
- ✓ Be sure to **schedule breaks**
- ✓ Schedule a **longer lunch** to allow for networking time
- ✓ Think about scheduling to make food/refreshments **budget-friendly**

Don't

- ✓ Don't start too early in the day
- ✓ **Don't Overspend!** Budget friendly events are more sustainable
- ✓ Don't schedule at the same time as other events. Try to avoid scheduling two events in the same month
- ✓ Don't schedule during long weekends/holidays
- ✓ Don't overschedule! People need breaks
- ✓ Don't forget your audience
- ✓ Don't forget to leave time for questions

HDSA Speaker Resources

- ❑ HDSA Presentations: Clinical Trials, Advocacy, Nutrition, Talking with Kids
- ❑ Clinical Trials Diplomats
- ❑ Research Ambassadors
- ❑ Speakers Bureau



Contact Jane Kogan at jkogan@hdsa.org to be connected to HDSA Resources

HDSA Educational Grant & Grant Seeking Resources

HDSA Educational Grant



Educational grant (made possible by Lundbeck) can be used to underwrite the cost of an educational event or a support group speaker. Contact Jane Kogan at jkogan@hdsa.org with questions or to apply.

Full Day Event

- ☐ Must contain HDSA Advocacy
- ☐ Must contain Clinical Trials/Clinical Trials Diplomat/Research Ambassador
- ☐ Must contain Nutrition OR Talking With Kids presentation
- ☐ No more than \$40 spent per attendee

NOTE: in some cases, clinical trials & advocacy presentations can be combined into one.

Half Day Event

- ☐ Must contain HDSA Advocacy & Clinical Trials consolidated presentation
- ☐ No more than \$40 spent per attendee

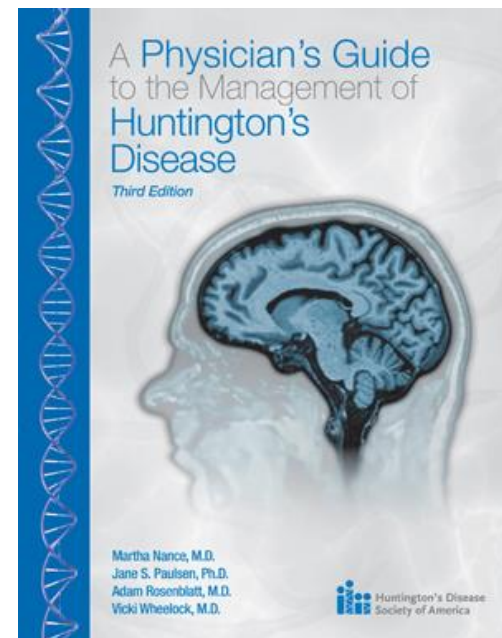
Support Group Speaker

- ☐ Must contain HDSA Advocacy & Clinical Trials materials
- ☐ Grant can either reimburse modest refreshments or speaker travel.

Resources for Healthcare Professionals

Resources for Healthcare Professionals

- HDSA Online CME
- CEUs for Social Workers
- Physicians Guide for the Management of HD
- Understanding Behavior in HD
- Dedicated sections of the website for Physicians and social workers



Resources to Educate Law Enforcement

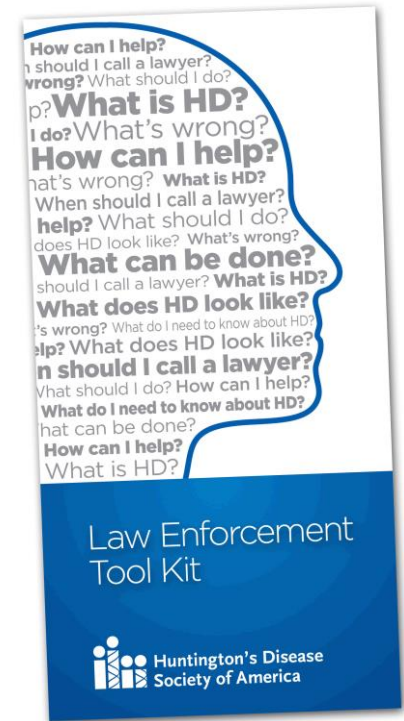
HDSA Resources for Law Enforcement

Who is our Audience

- Caregivers/HD Family Members
- Law Enforcement

Tool Kit Components

- HD Family Members
 - HDSA Caregiver Guide
 - HDSA Resources to Personalize (HD Profile & My Crisis Template)
- Law Enforcement
 - HDSA Law Enforcement Guide
 - HDSA Law Enforcement Presentation





I Have Huntington's Disease

Insert
passport
photo
here

NAME / BIRTHDATE _____

ADDRESS/PHONE _____

I am currently taking (PLEASE LIST MEDICATION & DOSAGE):

As prescribed by:

DOCTOR _____

PHONE _____

DOCTOR'S SIGNATURE _____

HISTORY OF SUICIDE ATTEMPTS: YES ____ NO ____

Profile Card

 Huntington's Disease Society of America

Huntington's disease is a genetic, neurodegenerative disorder.
Symptoms may include:

- Staggering gait
- Jerking or abrupt movements
- Slurred speech
- Slow response to questions
- Disorientation
- Irritability
- Combabiveness
- Impulsive behavior
- Sexually inappropriate behavior
- Explosive outbursts or temper


In Case of an Emergency, please contact:

NAME 1 / PHONE NUMBER 1 _____

NAME 2 / PHONE NUMBER 2 _____

Special Instructions
 [ie. Eating and/or Swallowing difficulties. Seizure prone (keep calm). Do not use restraints. Becomes violent. Hearing impaired. Eyeglasses, etc.]

Additional Comments:

 Huntington's Disease Society of America

Resources to Educate Lawmakers

Advocacy

- **Huntington's Disease Parity Act:** Improves access to Social Security Disability & Medicare benefits (handout).
 - Attend the Advocacy Workshop on **Friday 4:00 to 5:15 in Carol Ford**
 - Visit the Advocacy Table in the Exhibit Hall.
- **Attend a Reception with Congress** (*Special Convention Activity*)
 - Come to the Advocacy Meet & Greet on **Friday 5:30 to 6:30** to meet and personally thank Congressman John Yarmuth, as well as meet with a member of Senator Mitch McConnell's staff
- **Advocate from your home**
 - Sign up to be an E-Advocate at www.hdsa.org/join to get advocacy updates
 - Take action for HD at www.hdsa.org/takeaction

NEW TO HD

RESEARCH

LIVING WITH HD

ABOUT HD SA

HOW TO HELP



ADVOCACY

SSA Failing HD Families

Ask Congress to support the Huntington's disease Parity Act

TAKE ACTION

D
Local
Chapter

JOIN
A Support
Group

FIND
A Center of
Excellence

INVESTIGATE
Clinical
Trials

DONATE
Support Our
Programs

Resources to Educate Legislators

LIVING WITH HD

HD CARE

ADVOCACY

[What is Advocacy](#)

[Latest News](#)

[HDSA Advocates in Action: Voices of HD](#)

[Feedback Form](#)

[Facebook](#)

[More Links](#)

[HDSA Advocacy Video Contest \(2012\)](#)

[Medicare Improvement Standard: JIMMO](#)

[HDSA Comments on Proposed SSA](#)

Living With HD | Advocacy



Advocacy

HUNTINGTON'S DISEASE PARITY ACT (H.R. 1015/S. 723)

[Raise Your Voice for HD Parity!](#) Click on the link to take action

[Learn More](#) Click on the link to learn about the challenges that individuals with HD currently experience when applying for Disability, and waiting for their healthcare during the Medicare Waiting Period.

[H.R. 1015 Cosponsors](#) Click here to see who is cosponsoring H.R. 1015

[S. 723 Cosponsors](#) Click here to see who is cosponsoring S. 723

[HD Parity Act Toolkit](#) Click for documents you can download.

VOICES OF HD

[Voices of HD](#) Click to read stories about individuals who are speaking up for HD.

[H.R. 1015](#) House Bill Language: *Huntington's Disease Parity Act of 2013*

[S. 723](#) Senate Bill language: *Huntington's Disease Parity Act of 2013*

[Take Action](#) : Click on the link to go to HDSA's E-Action Center!

[READ MORE](#)

Social Media

[Join the HDSA Advocacy Group on Facebook](#)

[HDSA Advocacy Facebook Page](#)

[HDSA Advocacy Twitter](#)

[READ MORE](#)

Discussion