

Huntington's Disease
Society of America

FAMILY
is everything

2015

YEAR IN REVIEW





“Every HDSA mission program grew in 2015.

We now have 45 percent more HDSA Centers of Excellence, a total of 19 Human Biology research awardees, and support from more than half of the US House of Representatives for the HD Parity Act! This is unprecedented impact for HD families which is complemented by the HDSA Annual Convention and our networks of more than 30 local education events, 50 HDSA supported social workers, 170 HDSA support groups and our national helpline. Team Hope is now 18,000 volunteers strong and Huntington’s disease is featured in the news on a daily basis.

These extraordinary efforts have not gone unnoticed. In 2015, **Charity Navigator, America’s largest charity evaluator, awarded HDSA four stars — its highest rating.** “HDSA outperforms most other charities in America,” said **Michael Thatcher**, Charity Navigator’s CEO.

Our work is far from done, but every day more families are able to depend on the help and hope that’s made possible by your support. At HDSA, **Family is Everything.** Thanks for being part of our family commitment to a world free of Huntington’s disease.”

— Louise Vetter,
HDSA Chief Executive Officer





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HDSA Centers of Excellence Program Expands to 29 Facilities

What is Huntington's Disease?

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. 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 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.

In the battle against Huntington's disease, no one fights alone. At HDSA, **Family is everything.**

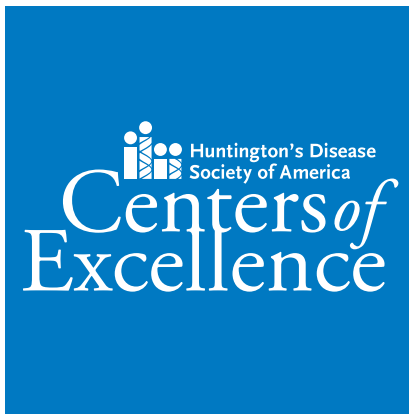
HDSA was founded in 1968 by Marjorie Guthrie, the wife of legendary folk singer Woody Guthrie. Woody died from HD complications in 1967 when he was only 55 years old, but the Guthrie family legacy lives on at HDSA to this day.



HDSA announced this year that twenty-nine outstanding Huntington's disease care facilities were awarded the designation of HDSA Centers of Excellence for 2015. Competition for the grants was intense with forty-two applications received from top-notch medical institutions around the country.

The 2015 HDSA Centers of Excellence represent a 45% increase from the twenty Centers awarded in 2014. The roster of Centers share an exemplary commitment to bringing more comprehensive care to more HD affected families across the United States, including a new 'boots on the ground' presence in at least ten states where the Center of Excellence program did not previously have reach. These include Delaware, Nebraska, North Carolina, North Dakota, Oregon, Pennsylvania, South Dakota, Tennessee, Vermont and West Virginia. In total, nearly \$800,000 will be funded to HDSA Centers of Excellence this year.

"HDSA is excited to recognize twenty-nine exceptional clinics in 2015 and directly support their comprehensive approach to helping families manage the challenges of Huntington's disease," said Louise Vetter, HDSA's Chief Executive Officer. "These awards are made possible by the incredible generosity of the HDSA community, who are united in their commitment to bring help and hope to more families, in every corner of the United States."



The HDSA Centers of Excellence provide an elite team approach to Huntington's disease care and research. At these world-class facilities, patients benefit from expert neurologists, psychiatrists, therapists, counselors and other professionals who have deep experience working with families affected by HD and who work collaboratively to help families plan the best HD care program throughout the course of the disease.

This year's program marks a turning point in HDSA's effort to increase access to experienced, multi-disciplinary care for HD families. The grant program expanded to support both regional collaborations and smaller, developing clinics, in addition to the classic, one-site centers. At all levels of the program, a commitment to clinical research is expected, as is the expectation of family support through ancillary services and social workers.

This review was led by the HDSA Center Program & Education Advisory Committee (CPEAC) and culminated with the launch of a new Center grant program in July 2014 (publicly available at HDSA.org) with requests for proposals open to all clinics in the United States who share HDSA's commitment to high-quality, comprehensive care and access to clinical research. ■

The 2015 HDSA Center of Excellence grantees is listed below alphabetically:

- Boston University Medical Center
- Cleveland Clinic
- Colorado Neurological Institute
- Columbia Health Sciences/
New York State Psychiatric Institute
- Duke University (NC)
- Hennepin County Medical Center (MN)
- Indiana University
- Johns Hopkins University (MD)
- Massachusetts General Hospital
- Ohio State University
- Rush University Medical Center (IL)
- Stanford University
- University of Alabama, Birmingham
- University of California,
Davis Medical Center
- University of California, Los Angeles
- University of California, San Diego
- University of California, San Francisco
- University of Florida
- University of Iowa
- University of Nebraska Medical Center
- University of Pittsburgh Medical Center
- University of Rochester (NY)
- University of South Florida
- University of Vermont,
Frederick Binter Center for
Parkinson's Disease and
Movement Disorders
- University of Virginia
- University of Washington (WA)
- Vanderbilt University Medical Center (TN)
- Virginia Commonwealth University
- Washington University School of
Medicine (MO)



2015 Highlights

HDSA's Online Presence Reaches New Heights

This year, HDSA launched a new and improved HDSA.org and the *HDSA Today* e-newsletter. The new site is 100% mobile friendly and features "Locate Resources" with Google Maps, DonorDrive fundraising platform and the world's most comprehensive Huntington's disease video library on the HDSA YouTube channel.

HDSA's presence online and in social media positions the organization as the world's online leader in Huntington's disease education, research and awareness. ■



"HDSA outperforms most other charities in America," said Michael Thatcher, CEO of Charity Navigator, America's largest independent charity evaluator. In 2015, HDSA received four stars — Charity Navigator's highest rating.

HDSA was also recognized as the **premier nonprofit organization dedicated to Huntington's disease** by these charity evaluators :

- National Health Council
- Great Nonprofits
- Charity Watch
- Guidestar
- Better Business Bureau



HDSA HD TrialFinder

The Huntington's Disease Society of America HD TrialFinder is a free, easy-to-use clinical trial matching service that connects individuals with Huntington's disease, caregivers, healthy volunteers and physicians with current studies. The continuously updated database includes both interventional, observational and biomarker studies being conducted at clinical trial sites across North America.

The trial listings in the HDSA HD TrialFinder come from publicly available sources, such as clinicaltrials.gov from the National Institutes of Health. In addition, direct outreach is being made to researchers and trial sites across the country to include their HD related clinical research studies in the HD TrialFinder database. All HDSA supported clinical research will be required to be placed in the HD TrialFinder database. ■



Life in HD

After folk music legend Woody Guthrie died from complications with Huntington's disease (HD) in 1967 at the age of 55, his wife Marjorie founded HDSA the following year. On May 27th, HDSA paid tribute to the Guthrie family legacy by going back to its roots with inspiring family stories and great music at the **2015 Life in HD** event at the Baruch Performing Arts Center in New York City.



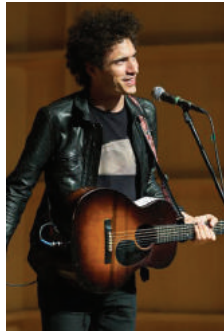
Woody Guthrie's granddaughter Anna Canoni

New York Times bestselling author **Lisa Genova** of *Inside the O'Briens* and Emmy Award winning anchor **Allie LaForce** shared the stage in an inspiring and educational conversation about HD and the impact it has on a family, before Woody Guthrie's granddaughter **Anna Canoni** discussed the Guthrie family's HD story and went on to introduce singer/songwriter **Marc Scibilia**.

Lisa's new book *Inside the O'Briens* portrays a Boston police officer battling the devastating symptoms of HD. *Inside the O'Briens* follows Lisa's last book, *Still Alice*, which was made into a major motion picture where actress **Julianne Moore** won several awards including an Oscar for her portrayal of a woman with Alzheimer's disease.

Allie LaForce was Miss Teen USA in 2005 and is currently one of the nation's top sports reporters. She is married to Los Angeles Angels' pitcher **Joe Smith**. Joe's mother, **Lee**, is courageously battling HD.

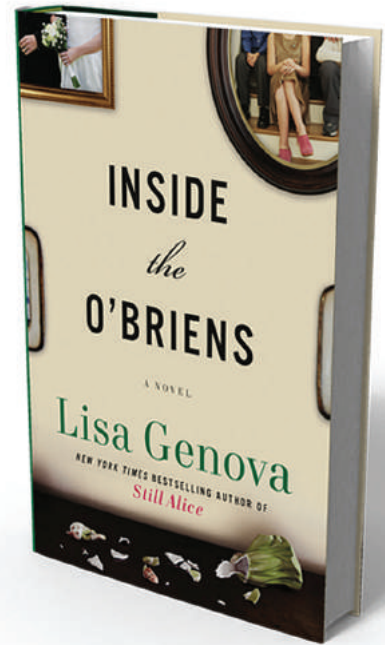
A highlight of Marc Scibilia's acoustic set was his rendition of the Woody Guthrie classic "This Land is Your Land" which gained Marc notoriety in the Jeep commercial during the 2015 Super Bowl. Marc also dedicated his song "Bright Day Coming" to HDSA's National Youth Alliance. ■



Marc Scibilia performs at "Life in HD".



From left: Louise Vetter, Allie LaForce, Lisa Genova, Marc Scibilia, Jennifer Leyton, and Anna Canoni at HDSA's Life in HD event at the Baruch Performing Arts Center in New York City.



Inside the O'Brien's

On April 7th, New York Times bestselling author and neuroscientist **Lisa Genova**



released her fourth novel, *Inside the O'Briens* which is about a family dealing with Huntington's disease. Lisa's previous book, *Still Alice*, was made into a major motion picture starring **Julianne Moore, Alec Baldwin, Kristin Stewart** and **Kate Bosworth**. Julianne Moore won an Oscar, Golden Globe, SAG and BAFTA Award for best actress in her role as a woman with early onset Alzheimer's disease.

Inside the O'Briens, published by Simon & Schuster, has received excellent reviews and has brought a great deal of awareness to the devastating impact that Huntington's disease has on an individual and their family. The book also includes a call to action which has generated more than \$30,000 which will directly support HDSA's Human Biology Project. ■

2015 Highlights



Thanks To Our Corporate Leadership Partner

Special thanks to **Teva CNS** — our Corporate Leadership Partner. Teva CNS provides a total approach to disease management, offering sustainable, indispensable medicines and patient support services that improve outcomes in conditions affecting the **central nervous system**. Teva is a leader in neuroscience, pain management, and neuropsychiatry. ■

Thanks To Our Dallas Convention Sponsors

- **Auspex Pharmaceuticals**
- **Lundbeck, Inc.**
- **Teva Pharmaceuticals**
- **MetLife**
- **Pfizer, Inc.**
- **Raptor Pharmaceuticals**
- **CHDI Foundation**
- **BioMarin Pharmaceutical Inc.**
- **Broda Seating**
- **ISIS Pharmaceuticals**
- **Omeros Corporation**
- **Vaccinex**



Dallas Convention

HDSA hosted its 30th Annual Convention at the Hyatt Regency at Reunion in Dallas, Texas on June 25th -27th.

More than 800 guests attended the world's largest Huntington's disease family gathering which included world-class workshops and keynote speakers, a Team Hope walk, Texas Hold'em Tournament and Celebration of Hope Gala. In attendance were people with HD, family members and caregivers, volunteers, as well as renowned clinicians and scientists in the HD field. This year marked the fourth largest HDSA Convention in its history.

"HDSA's 30th Annual Convention was an exceptional event, bringing together the best of education, advocacy and research to create three days of family-focused learning for the Huntington's disease community," said **Louise Vetter**. "For many families affected by HD, Convention is the one time each year when they don't feel isolated by this rare disease, and they are empowered by the resources and inspiration they gain from Convention to fight HD in their daily lives."

Filmmaker **Marianna Palka** received the 2015 HDSA Person of the Year award and thanked everyone via video message from Scotland. Marianna starred in the powerful HBO documentary *The Lion's Mouth Opens* which was directed by acclaimed filmmaker Lucy Walker. The short film follows Marianna's brave journey through the HD testing process with her close friends by her side.

Singer/songwriter **Marc Scibilia** also sent a special video message and performance of his hit song "How Bad We Need Each Other" which was played during the Opening Ceremony. ■



Top Row: Attendees enjoying the wonderful camaraderie of the Convention.

Above: The solemn Blue Light Ceremony commemorating those impacted by HD.

At Right: Angela Mabry and Seth Rotberg received the HDSA Youth Award for their work with HDSA's National Youth Alliance.





NYC Marathon Team Raises More than \$125,000

HDSA's New York City Marathon team raised more than \$125,000 to support HDSA's mission to improve the lives of everyone affected by HD. At the world's largest marathon, HDSA finished in the top 18 among all charity partners.



"We had a goal of \$70,000 and our team absolutely crushed that mark," said Louise Vetter CEO of HDSA. "For a rare disease organization to finish in the top 18 of all the charity partners at the NYC Marathon is a true testament to the commitment the community has to helping families affected by Huntington's disease and providing hope to one day end this horrible disease."

This year's team was made up of 24 members from twelve US states. The team's most successful fundraisers were **Clark Wrigley** (Parsippany, NJ) who raised \$30,115 and **Christy Ericson** (Menlo Park, CA) who raised \$17,747. **Jonathan Quackenbush** (Boston, MA) was the team's first finisher with an impressive time of 3:42:09. The rest of the team consisted of **Doug Buskin** (Denver, CO), **Elizabeth Christian** (Suffolk, VA), **Stacie Constas** (Dover, NH), **Sheila Damiani** (Mesa, AZ), **Ashley Driscoll** (Richmond, VA), **Jennifer Henel** (Alexandria, VA), **Noah Houghland** (New York, NY), **Marisa Hughes** (Boston, MA), **Melissa Jeng** (Seattle, WA), **Mindy Kincade** (Haslet, TX), **Maggie Kiselick** (New York, NY), **Rebecca Martinez** (Campbell, CA), **Kathleen McCarthy** (So. Boston, MA), **Katie Mullin** (Brant Rock, MA), **Kelly Mullin** (Pembroke, MA), **Heather Rennie** (Brighton, MA), **Kendrick Ribeiro** (Menlo Park, CA), **Laura Schmit** (Salem, CT), **Josh Silverstein** (Brooklyn, NY), **Devin Sullivan** (New City, NY) and **Deborah Zimmerman** (Pfafftown, PA). ■

HDSA on NASH FM in New York City

HDSA CEO **Louise Vetter** stopped by the NASH FM studio in New York City as a guest on **Kelly Ford's NASH Matters** radio show. The half hour segment focused on Huntington's disease research as well as HDSA services and upcoming events. ■



NASH's Kelly Ford (left) with Louise Vetter.

anchors Raise \$10,000 on CNN Quiz Show



On Labor Day, CNN anchors **Alisyn Camerota** (left) and **Chris Cuomo** took the stage for "The CNN Quiz Show: TV Edition" hosted by **Anderson**

Cooper. Despite a valiant third place finish, Alisyn and Chris brought in \$10,000 and an incredible amount of awareness

for the charity of their choice, the Huntington's Disease Society of America. Alisyn revealed on the show that her cousin's family is affected by Huntington's disease and HDSA is an organization very close to her heart. Alisyn also recorded a very informative PSA from the CNN New Day studio about Huntington's disease which can be viewed on the HDSA YouTube Channel. ■



2015 Highlights

Huntington's Disease ID Bracelets

To help prevent law enforcement interactions from escalating and to inform medical professionals about Huntington's disease, HDSA presented a new item to the HD community, Huntington's disease ID bracelets. The bracelets are \$12 and includes shipping and handling.

HDSA partnered with a vendor to provide families with a valuable ID bracelet that is comfortable and affordable. To keep costs low for families, HDSA does not profit off the sales of the bracelets. ■



FDA Hearing

More than 250 family members affected by Huntington's disease from across the United States joined HDSA at the U.S. Food and Drug Administration's (FDA) Public Meeting on Huntington's Disease Patient-Focused Drug Development. The hearing, which was advocated for by HDSA, was a one-of-a-kind opportunity for families to directly educate officials about the devastating impact of HD. Teva Pharmaceuticals provided a grant to help provide travel support for many families attending the hearing.

At the highly-anticipated meeting, the FDA heard from HD patients and family members about their experience with the symptoms of HD, as well as the treatment needs and priorities of families.

"We are grateful that the FDA included Huntington's disease in one of only 20 public meetings to inform the regulatory landscape of drug development," said Louise Vetter. "We are confident that by hearing directly from affected families, the FDA will appreciate the urgency of bringing new therapeutic options to market for Huntington's disease, as well as gain better insight into what types of treatments matter most to patients and their families."



To ensure that the FDA hears from the greater HD community and not only those who are participated in-person and via webcast, in preparation for the hearing HDSA developed two surveys asking HD patients and caregivers about their perspectives on the HD symptoms that matter most to them and the types of treatments they desire. HDSA received more than 3,600 responses from these online surveys and shared the top-line results from these important surveys with the FDA prior to the public meeting. ■



PHOTO BY GENE VERITAS

FDA regulators at the Public Meeting on HD Patient-Focused Drug Development.

The Lion's Mouth Opens Premieres on HBO

During HD Awareness Month critically-acclaimed filmmaker **Lucy Walker's** *The Lion's Mouth Opens* premiered on HBO and generated a great deal of awareness for HD. The powerful short film follows **Marianna Palka** as she courageously goes through the HD testing process with close friends by her side. ■



Left: Marianna Palka (left) and Louise Vetter at special screening of *The Lion's Mouth Opens*.
Center: Scene from HBO's *The Lion's Mouth Opens*.
Right: Poster for HBO's *The Lion's Mouth Opens*.

NY Giant Great Howard Cross Visits HD Families



The New Jersey Chapter helped facilitate a visit from former New York Giants tight end, **Howard Cross**, to JFK Hartwyck at Cedar Brook. The HD facility was also part of a special news coverage to bring awareness to HD and the JFK and was featured on NJTV. ■



Nastia Liukin Supports HDSA

Olympic Gold Medalist **Nastia Liukin** volunteered her time to promote the Huntington's Disease Society of America Team Hope Walk program in a video PSA shared widely on social media. ■

HDSA Regional Highlights

NORTHWEST REGION

Team Hope Walk

Seattle, WA
\$24,016

Team Hope Walk

Spokane, WA
\$13,609

Team Hope Walk

Boise, ID
\$16,400

Team Hope Walk

Portland, Oregon
\$7,600



Team Hope Walk / Seattle, WA

PACIFIC SOUTHWEST REGION

San Diego Celebration of Hope Gala

On October 10th, the HDSA San Diego Celebration of Hope welcomed 400 guests to The Irving House and raised more than \$300,000 to fight HD. The event honored the President of B.H. Gold Insurance **Mr. Bill Habberger** and L.A. Angels pitcher **Joe Smith** who delivered an emotional speech on how HD has impacted his family. The night also featured ESPN's **Lisa Salters, Jon Gruden** and **Mike Tirico**.



Los Angeles Angels pitcher Joe Smith and his mother Lee at the San Diego Celebration of Hope Gala in October.

Team Hope Walk

San Francisco, CA
\$76,402

Rock n' Roll Marathon

San Diego, CA
\$72,000

Orange County Chapter Team Hope Walk

Irvine, CA
\$27,000

SOUTH CENTRAL REGION

Team Hope Walk

Denver, CO
\$26,000

Team Hope Walk

Dallas, TX
\$22,600

Team Hope Walk

Austin, TX
\$22,000

Team Hope Walk

San Antonio, TX
\$22,000



Denver Bronco Cheerleaders lend their support to the Denver Team Hope Walk in September.

Thanks To Our National Team Hope Walk Sponsors

- Auspex Pharmaceuticals
- Lundbeck, Inc.
- Teva Pharmaceuticals
- Carefoam



Huntington Society of America



GREAT LAKES REGION

Northeast Ohio Chapter An Evening in Paris — Celebration of Hope Gala

Cleveland, OH
\$100,000

Wisconsin Chapter Re-Prom

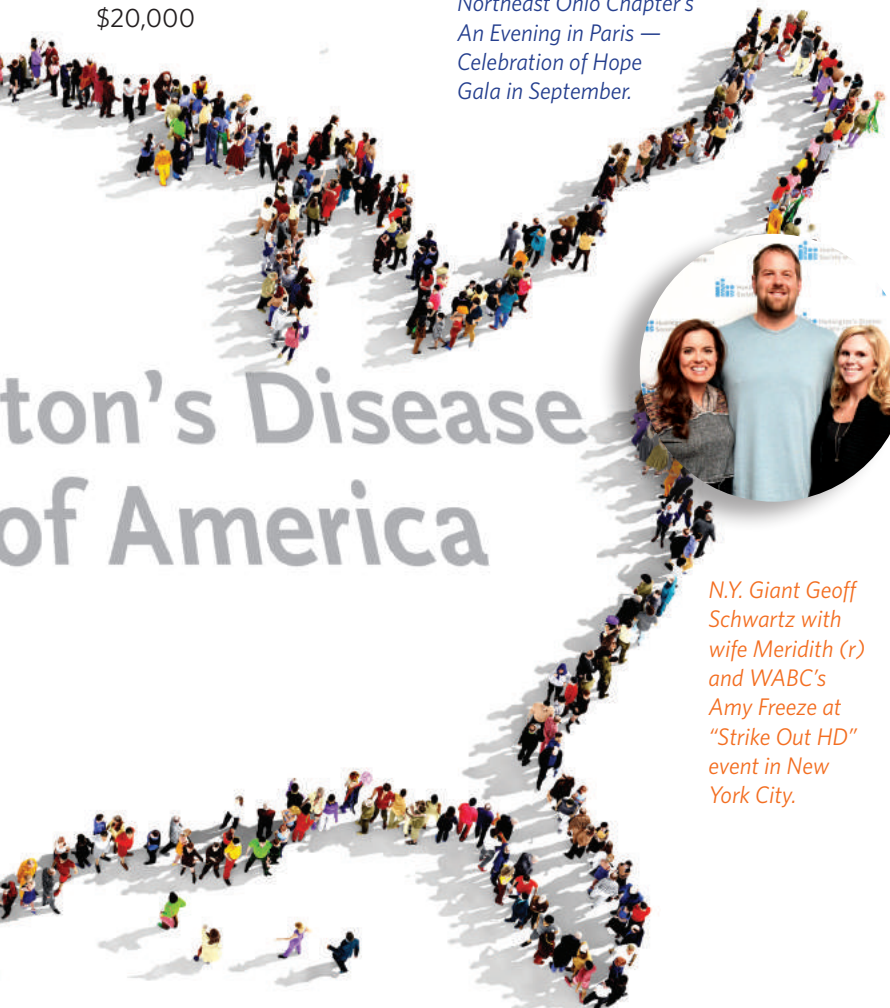
Madison, WI
\$70,000

Great Lakes Region Annual Golf Tournament

St. Louis, MO
\$20,000



Oooh la la! Revelers enjoy Northeast Ohio Chapter's An Evening in Paris — Celebration of Hope Gala in September.



N.Y. Giant Geoff Schwartz with wife Meridith (r) and WABC's Amy Freeze at "Strike Out HD" event in New York City.

ton's Disease
of America

SOUTHEAST REGION

24th Annual HD Triathlon

Miami, FL
\$70,000

Athlete participating in the HD Annual HD Triathlon in Miami, FL.

Team Hope Walk

Atlanta, GA
\$31,408

Team Hope Walk

Orlando, FL
\$20,000

Fall Golf Classic

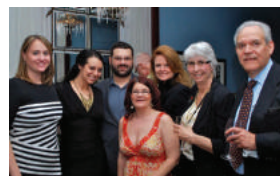
Garner, NC
\$18,045



NEW ENGLAND / ALBANY REGION

New England/ Albany Region Corks & Forks Event

Albany NY
\$47,425



HDSA supporters gather at New England/Albany Region's Corks & Forks Event.

Team Hope Walk

Tewksbury, MA
\$46,884

Team Hope Walk

Boston, MA
\$45,626

Celebration of Hope Gala

Cambridge, MA
\$27,671

NEW YORK / NEW JERSEY REGION

Strike Out HD New York City

New York Giant **Geoff Schwartz** hosted the 4th Annual Strike Out HD Bowling event at Frames Bowling Lounge in New York City in October. The sold-out event welcomed more than 150 guests and raised nearly \$50,000. The event was co-chaired by **Jennifer** and **Mark Leyton**. Also making an appearance was WABC-TV meteorologist **Amy Freeze**.

Team Hope Walk

Long Island, NY
\$52,381

Team Hope Walk

Edison, NJ
\$51,300

Team Hope Walk

New York, NY
\$46,000

MID-ATLANTIC REGION

Mid-Atlantic Region Blue-Tie Celebration of Hope Gala

Chevy Chase, MD
\$54,095



Friends and families enjoying the Mid-Atlantic Region's Blue Tie Celebration of Hope Gala in Maryland.

Lehigh Valley

Team Hope Walk

Bethlehem, PA
\$16,036

Team Hope Walk

Baltimore, MD
\$12,083

Christine Ellen

Memorial Golf Classic

Dumfries, VA
\$10,895

2015 Highlights

Huntington's Disease Society of America Adds Call Center Component to HD TrialFinder

The Huntington's Disease Society of America is pleased to announce that it has added a phone-based service to its repertoire of resources for the Huntington's disease community. This new feature was made possible in

part by a grant provided by the **Gies Foundation**. **HD TrialFinder** is the only comprehensive, constantly updated database of institutional review board-approved HD trials taking place across North America.

licly available sources, such as clinicaltrials.gov from the National Institutes of Health, and are supplemented by HDSA's direct outreach to researchers and trial sites across the country to include their HD related clinical research studies in the HD TrialFinder database. Additionally, all HDSA-supported clinical research is now required to be placed in the HD TrialFinder database.

time. Navigators answer questions about the trial process and connect individuals with trial sites based on their unique profile. Patients and caregivers will be encouraged to share their trial matches with their healthcare professionals to help decide whether a clinical trial is appropriate. Navigators will not recommend or endorse particular trials. Their role is to help individuals navigate HD clinical research opportunities by providing educational support.



part by a grant provided by the **Gies Foundation**. **HD TrialFinder** is the only comprehensive, constantly updated database of institutional review board-approved HD trials taking place across North America.

HD TrialFinder is now a web and phone-based clinical trial matching service that connects individuals with Huntington's disease, caregivers, healthy volunteers and physicians with current studies. The trial listings in the HDSA HD TrialFinder come from pub-

licly available sources, such as clinicaltrials.gov from the National Institutes of Health, and are supplemented by HDSA's direct outreach to researchers and trial sites across the country to include their HD related clinical research studies in the HD TrialFinder database. Additionally, all HDSA-supported clinical research is now required to be placed in the HD TrialFinder database.

"HDSA is proud to launch this family-centered call center with **EmergingMed**," said **Louise Vetter**, Chief Executive Officer at HDSA. "We hope that the addition of the Clinical Trials Navigator resource will help make the process of getting involved in clinical trials less overwhelming for HD families."

In addition to the full suite of online resources, individuals can now call HDSA-trained Clinical Trial Navigators from 9:00 a.m. -5:00 p.m. eastern

time. Navigators answer questions about the trial process and connect individuals with trial sites based on their unique profile. Patients and caregivers will be encouraged to share their trial matches with their healthcare professionals to help decide whether a clinical trial is appropriate. Navigators will not recommend or endorse particular trials. Their role is to help individuals navigate HD clinical research opportunities by providing educational support.

"HD TrialFinder is an important tool to help empower the HD community to start a conversation with their physician about the clinical trial options available to them," said **George Yohrling, PhD.**, Senior Director, Mission and Scientific Affairs at HDSA, "We know that access to the novel research and treatments currently in development can provide hope to families that may feel there is none." ■

HDSA's HD TrialFinder can be accessed at www.HDTrialfinder.org or by calling our toll-free line: (866) 890-6612. The technology and platform for the HDSA HD TrialFinder are provided by EmergingMed.



HD Workout Tips with Shana Verstegen

World champion fitness pro **Shana Verstegen** has volunteered her time and expertise to provide valuable tips to help HD families live a healthier lifestyle. Shana's videos can be found on the HDSA YouTube Channel and new tips are posted each week! ■

Raising Awareness of Huntington's Disease

In December former TV news reporter **Charles Sabine** and Pfizer's Chief Medical Officer **Dr. Freda Lewis-Hall** raised much-needed Huntington's disease awareness on CBS's *The Doctors*. At the conclusion of the segment, Mr. Sabine personally endorsed the incredible efforts of HDSA! ■



HDSA Announces New Career Development Fellowship

The Huntington's Disease Society of America is now accepting letters of interest for a new research fellowship program specifically designed to develop new scientific leaders in the quest to better treat and one-day cure Huntington's disease. **The Berman/Topper Family Huntington's Disease Career Development Fellowship** is a three-year grant for young scientists to work collaboratively with their mentors and other committed HD health professionals to help develop the fellow into an independent HD leader.

HDSA partnered with the **Berman** and **Topper** families to launch this new program in response to the desperate need for career development mechanisms for young HD researchers and the stagnant budget at the National Institutes of Health, which had been a traditional grant funder of new scientists.

"HDSA is grateful for the partnership of the Berman and Topper Families

who share our goal to ensure that the pipeline of passionate and bright HD scientists and clinicians remains full," said **Louise Vetter**, Chief Executive Officer at HDSA. "This Career Development Fellowship program is a unique commitment to developing the next generation of passionate and innovative HD scientists."

"We are excited to work with HDSA to provide an opportunity to attract new minds to the battle against HD. We hope that each person involved in this program will in some way contribute to greater knowledge of the disease and ultimately to causing a cure," said **Michael Berman**, speaking on behalf of the Berman and Topper families.

Scientists and clinicians who are no more than five years removed from obtaining their Ph.D. or completing their residency/fellowship and who are interested in a career in Huntington's disease research or care are invited to apply for the Berman/Topper Family Huntington's Disease Career Development Fellowship. Applicants cannot have their own laboratory and must identify an individual who will

serve as their mentor and supervisor throughout the duration of the three-year award. Each three-year award provides up to \$80,000/year of which \$75,000 is designated for salary and research support, plus an additional \$5,000 for travel/education related to the fellowship. ■

To submit an application to the Berman/Topper Family Huntington's Disease Career Development Fellowship or to download the detailed Request for Proposal, please visit www.hdsa.org. Completed applications must be received by HDSA no later than Monday, February 29, 2016, at 5:00 p.m. (EDT). For more information, contact Dr. George Yohrling, HDSA Senior Director, Mission and Scientific Affairs, at gyohrling@hdsa.org.



Research Report



2015: A Year of Unprecedented Hope

This was a landmark year for the Huntington's Disease Society of America and the global HD community. HDSA continued to expand their patient-focused research commitments and launched new resources, such as the HD TrialFinder to accelerate the clinical development of new HD drugs. This is essential as never before have we had so many companies pursuing HD therapies in the clinic.

Huntingtin Lowering Drug Trials Begin

Without a doubt, the scientific highlight of 2015 was that the first clinical trial for a huntingtin lowering drug began. Since the identification of the gene that causes HD in 1993, the research community has been working hard to devise ways to eliminate huntingtin at its roots. This summer, **Ionis Pharmaceuticals** (formerly Isis Pharmaceuticals) announced that a phase 1/2a study to test the safety of their antisense oligonucleotide (ASO) that lowers huntingtin had begun. While this is just the beginning for this drug, it marks a moment 22 years in the making. This is the first time a drug, specifically designed for Huntington's disease has been administered to HD patients.

HDSA Chairman Jang-Ho Cha, M.D. accepts donation from Mrs. Sandra Hurley.



HD TrialFinder

HDSA released a first-of-its-kind clinical trial matching resource for the HD community, called **HD TrialFinder**. It matches a patient's clinical information to the criteria for HD clinical trials that are currently recruiting around the country. This resource provides families with the most up-to-date information about trials and direct lines of contact to their local study sites.

Without a doubt, the scientific highlight of 2015 was that the first clinical trial for a huntingtin lowering drug began...

This is the first time a drug, specifically designed for Huntington's disease has been administered to HD patients.

Human Biology Project

HDSA's major research initiative, the **Human Biology Project**, entered its third year in 2015. The Human Biology Project was launched in 2013 as a critical piece of HDSA's mission to support impactful HD research that will help guide us closer to effective therapies. The research we support is all patient-centric and done in collaboration with HD clinics from around the globe with the goal of understanding HD in the only place it occurs, in humans.

This year, thanks to the generosity of **Mrs. Sandra Hurley** of Arlington, TX, this year's top scoring **Human Biology Project** proposal from **Amber Southwell** from the University of British Columbia was given the additional honor of being named winner of the **Dr. Janis Brown Memorial Award**. Sadly, Janis passed away in September 2014 after a long battle with HD. Mrs. Hurley — Janis' cousin and caregiver — wanted to honor her legacy with this award and presented HDSA with a check for \$174,000!

Genetic Modifiers

The term "Genetic Modifiers" also became mainstream in the HD community in 2015. Two separate studies were published that identified potential genetic factors in one's DNA that could impact or "modify" the clinical onset of HD. One such modifier was found in a region of DNA that controls the expression of the huntingtin gene. In another study, a consortium of researchers from around the world published a ground breaking study that identified two regions of DNA (on Chromosomes 8 and 15) that appear to alter the course of HD in people. Both studies provide clues that could assist in the development of new therapeutic approaches for HD.

HDSA and the research community have made tremendous progress towards meaningful clinical trials that will hopefully modify the course of HD and bring relief and hope to you — our HD families. ■



— **George Yohrling, Ph.D.**
HDSA Senior Director,
Mission & Scientific Affairs

Advocacy Report

2015 was a record-breaking year for HD related legislation and HD Advocacy. We have continued to push for advancement in policy and legislation to improve the lives of HD families, as well as engaged with federal agencies to educate them about the experiences of those affected by Huntington's disease. Without the bravery, passion and persistence of the HD community none of this would have been possible.



NYA members meet with U.S. Congressman Sam Johnson (R-TX) in his Washington, D.C. office to present him with a map of Texas signed by HDSA Convention attendees encouraging support of the HD Parity Act. Rep. Johnson is a member of the House Committee on Ways and Means where he serves as the Chairman of the Social Security Subcommittee and sits on the Health Subcommittee.

The Summer of the NYA

HDSA's National Youth Alliance kicked their advocacy efforts into high gear in 2015. More than 20 members of the NYA made their way to Washington, D.C. this summer to complete three advocacy fly-ins, and take part in more than 300 meetings with Senators and Representatives about the **HD Parity Act**. While advocates were storming the Hill, hundreds of HD community members around the country sent in messages of support for the HD Parity Act and made their voices heard alongside the NYA.



The youngest NYA member to storm the Hill this summer was **Connor Lis**. At just 11 years old, Connor made a lasting impression on the Ohio Congressional delegation. A first time advocate, he was joined and supported by his mother **Jesse Lis**, a long time HD Advocate and Board Member of the Northeast Ohio Chapter. Connor met with his Ohio Senators, and blew them away by walking them through his HD family tree, and talking to them about how he and his family have been affected by HD. Afterwards, **Senator Sherrod Brown (R-OH)** was so impressed he sent Connor a personalized letter to thank him for his advocacy. The Summer of the NYA not only pushed the **HD Parity Act (H.R. 842)** past an historic 220 co-sponsors in the House of Representatives, but it showed us that no matter how old you are, you can make a difference in the lives of folks affected by Huntington's disease. ■

Convention 2015

We had an incredible Convention in Dallas, Texas! Because of the hard work of HD Community members in Texas, we had representatives from the offices of **Sen. John Cornyn (R-TX)**, **Rep. Kay Grainger (R-TX12)**, **Rep. Eddie Bernice-Johnson (D-TX30)** and **Rep. Marc Veasey (D-TX33)** in attendance to listen to the

stories of three Texans affected by HD, **Kaitlin Klarer**, **Susan Reasor** and **Charles Kelley**.

During the meet and greet, folks in the audience had the opportunity to meet and talk to the Congressional offices about their HD stories and the impact the HD Parity Act would have on their lives. The impact of those stories has resonated with those Members of Congress, not just at that Meet and Greet, but for months afterwards. We cannot thank everyone in the Texas HD Community enough for all their hard work to bring so many members of the Texas Congressional delegation to Convention so they could hear so many HD stories! ■



Last Word in the First Person

After losing both her son and grandson to Huntington's disease, E.J. Garner of Olympia, WA was motivated to raise awareness of HD and raise funds for research. She did so in dramatic fashion. Ms. Garner undertook a challenging 650 mile pilgrimage through the north of Spain — the Camino de Santiago (Way of St. James). Many take up this route as a form of spirituality or retreat for their spiritual growth. Ms. Garner did it to honor her beloved son and grandson. Here is her story in her own words...

One Step at a Time

My Journey Along the Camino de Santiago

I can hardly believe it, but I actually did it! After walking for 47 days and 656 miles, I completed the Camino de Santiago Pilgrimage. After starting in St. Jean Pied de Port, France on Sept. 21, 2015, I arrived in Santiago, Spain on Oct. 7 then completed my pilgrimage in Finesterre, Spain on Oct. 14.

This pilgrimage was two years in the making. My friend Karla first planted the Camino seed in my mind in 2013 and who ultimately was my partner in this journey. I planned to do the walk in part to honor my grandson Matthew, who had passed away from Huntington's disease and to raise awareness and funding for HD research. The walk took on added meaning when HD took the life of my son Scott, earlier in the year.

Every year since 2006 I've participated in the HDSA-OC Team Hope Walk held at a beautiful park in Irvine, CA.



Well this year I wanted to do something extra special to honor and remember Scott and Matthew, who both passed away from Huntington's disease. So I decided to combine the HDSA-OC Team Hope Walk with my goal of walking the Camino. It allowed me to continue my mission to bring awareness to Huntington's disease while raising funds for research. With the help and generosity of friends and family they blew away my fundraising goal by donating nearly \$15,000!

I didn't walk this journey alone. I had all those supporters in my heart, providing added comfort and encouragement. And hanging on my backpack was a picture of Scott and Matthew, so you see I was in good company.

Part of my mission is to raise awareness of Huntington's disease and I was able to share my story many times with those who asked about the picture of my son and grandson on my backpack. Others asked, "Why are you walking the Camino?" That question provided me another opportunity to share my HD story.

Each time I was emotionally or physically challenged with the walk and start to think "I can't go any further," I would get signs of encouragement. There was one stretch along the five day walk across the meseta (desert) when all I could

see for miles and miles in front of me was the white gravel road disappearing into the horizon. My left heel was really hurting and I was hot (weather was 80°F+). Along the side of the road was scrub brush dried from the hot sun. It was probably the most challenging moment of the walk.



Matthew (left) & Scott Bradley

Suddenly two light blue butterflies fluttered around me. Then more blue butterflies. It was my message from Scott and Matt to keep going. They would fly alongside me until I reached the destination for the day. This seemed to happen every time I struggled to continue. Butterflies (blue, white, yellow, orange & black) would suddenly arrive to fly escort. On the last day of my journey, when I was walking about 10 meters toward the final Camino Way Marker at the lighthouse in Finesterre — a yellow and black butterfly joined me until I reached the lighthouse. I couldn't help but believe Scott and Matthew were there at the finish line. I couldn't have made it without them. ■



— E.J. Garner, October, 2015

To learn more about E.J.'s incredible journey visit <https://2015ejwalksthecamino.wordpress.com/>

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505 Eighth Avenue
Suite 902
New York, NY 10018

800-345-HDSA
212-242-1968 (National Office)

www.hdsa.org

The Blue Light Ceremony held each year at HDSA's Annual Convention commemorates those whose lives have been affected by Huntington's disease. This report is a look back at the work and progress undertaken to battle HD and provide support to those impacted.