

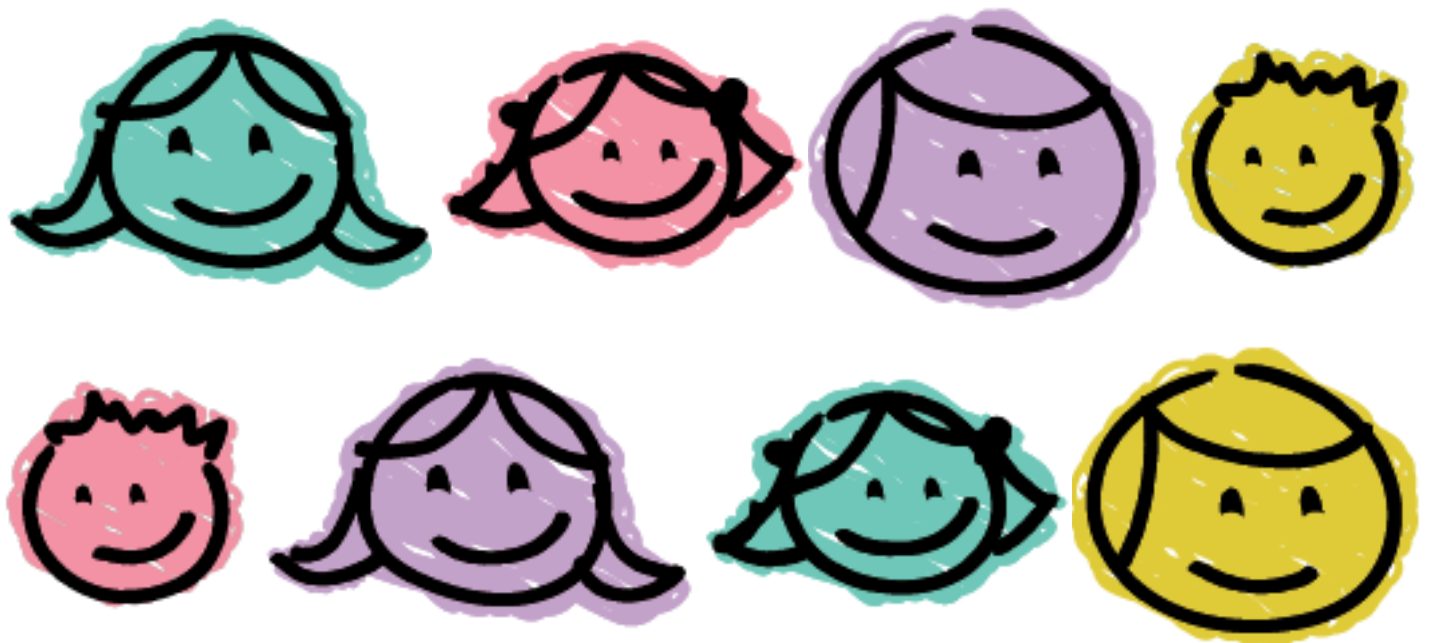


Huntington's Disease  
Society of America

[2014 Year in Review]



**Family is** *everything*





# Huntington's Disease Society of America

505 Eighth Avenue, Suite 902, New York, NY 10018  
(800)345-HDSA | [www.hdsa.org](http://www.hdsa.org)

## 2014 Year in Review



*"Because of your generosity, HDSA is advocating, educating and researching to bring the awareness, understanding and answers that improve the lives of everyone affected by Huntington's disease. We had an amazing year in 2014 reaching more people with our mission work than ever before. We look forward to all of the help and hope that this new year will bring as we work together to support every family touched by HD. Thank you for being a part of the HDSA family!"*  
– Louise Vetter, HDSA Chief Executive Officer

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# Family is everything

Huntington's disease is the quintessential family disease. With more than 30,000 symptomatic Americans, children of a parent with HD have a 50/50 chance of inheriting this fatal brain disorder. There are more than 200,000 people at risk across the United States and there is currently no cure, which is why we need your help today!

At the Huntington's Disease Society of America, **Family is everything.**

HDSA is the premier not-for-profit organization dedicated to improving the lives of everyone affected by Huntington's disease. 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 Huntington's disease and their families.

**When dealing with Huntington's disease, no one fights alone...**



**VOLUNTEER. EDUCATE. ADVOCATE. DONATE.**

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## Freeze HD Event Raises More Than \$100,000

On February 22<sup>nd</sup>, Jason Ritter, Tyler Ritter, Bryce Dallas Howard and Simon Helberg came together to support their friend Marianna Palka and her film *The Lion's Mouth Opens* at the star-studded Freeze HD event in Los Angeles. The spectacular sold out event had a silent auction with amazing prizes such as a lunch with Bryce Dallas Howard and her famed director dad Ron Howard, tickets to see *The Big Bang Theory* and much more. The event raised more than \$100,000 for HDSA.

*Pictured: Marianna Palka (top left), Bryce Dallas Howard (top right), Simon Helberg & Jason Ritter (bottom left)*



## The Lion's Mouth Opens

The *Lion's Mouth Opens* is a short documentary by director Lucy Walker featuring filmmaker Marianna Palka. Marianna's father suffers from HD and she documented her journey through the testing process. Marianna's close friends, Jason Ritter & Bryce Dallas Howard, are also in this powerful film.

*The Lion's Mouth Opens* was considered for Academy Award nomination and will air on HBO during National HD Awareness Month in May 2015.



## San Diego Celebration of Hope Raises \$112,000

The HDSA San Diego Chapter honored former SD Charger Rolf Benirschke on October 17<sup>th</sup> at the 2014 Celebration of Hope and netted \$112,000! The gala was attended by professional athletes, civic leaders, celebrities and featured a very entertaining coaches' roundtable from the top three sports organizations in San Diego: Buddy Black (SD Padres) ; Steve Fisher, (SD State University men's basketball); and Mike McCoy (SD Chargers). Mark Grant, sports personality on Fox Sports San Diego, was the event's emcee. Special thanks to event founder and Board Member Bill Johnston.



*Pictured Above: HDSA San Diego Board*

*Pictured Left: (l to r) Mark Grant, Mike McCoy, Buddy Black and Steve Fisher*

## NYC Family's 600-Mile Bike Ride to Toronto Raises \$20,000

The Methot family from New York City wanted to go the extra mile to raise funds and awareness for Huntington's disease; **make that an extra 600-miles!** The Family of four jumped on their bicycles and made their way from Manhattan to Toronto, Canada braving high volume traffic, flat tires and inclement weather. After safely arriving in Toronto, **Crank for the Cure** raised \$20,000 for HD.

"My Memere (grandma) has Huntington's disease and we want to help her," said 12-year old, Luca. "We wanted to do something big to show her how proud we are. It's not easy for her, but I know how to ride a bike and we tried to do something big to help her."

Luca, his younger brother Kalev (9) and parents, Karina and Christien, hit the road July 4<sup>th</sup> weekend on an incredible family journey. Each day started at 5am to do their best to avoid busier traffic and the smoldering summer heat, but there were extreme challenges along the way.

"One of the great challenges were the hills," said Karina. "Some hills were



accomplished under 18-wheeler duress where we were allotted 8 inches of shoulder and it is hard to climb and keep your wheel straight with pannier weight at your back tire. There were tears of frustration and bellows of fear. Intrepid kids. They are now tempered steel."

## Jason Evans Treks More Than 2,600 Miles Raising Awareness & Funds for HD

Jason Evans from Roseburg, Oregon completed an inspiring solo hike through the Pacific Crest Trail (PCT) to draw attention to and raise funds for HD. The incredible 2,650-mile trek took place in honor of National Huntington's Disease Awareness Month.

Unfortunately, Jason's family has been affected by HD. He elected to get tested for HD after his grandfather and mother were diagnosed with the disease. Jason and his wife, Nikki, have two children who they know have a 50/50 chance of carrying the mutated gene.

"I hike in the hope that possible risks to future generations may be mitigated someday," said Jason.



## Marathon Team Raises More Than \$80,000



On November 2<sup>nd</sup>, nineteen dedicated runners from eleven different states overcame challenging weather and 26.2 grueling miles at the 2014 TCS New York City Marathon. Those extraordinary individuals also raised more than \$80,000 for HD.

"We are so proud of our 2014 Marathon team," said Louise Vetter. "Training for a marathon is difficult enough, but this inspiring group went the extra mile to help raise funds and awareness for Huntington's disease and for that we are truly thankful."

Laura Thompson from Texas was the team's highest fundraiser bringing in an impressive \$10,765, while Jeff Dusek from Massachusetts was the fastest runner with a finishing time of 3:29:20. The rest of the team included: Monica Busovsky- Garcia (IN), Lindsey Christian (MN), Lynn Diaz (NJ), Jeff Dusek (MA), Delia Miller (NY), Stephanie Kidney (NY), MC Kislick (NC), Philip Kislick (NY), Jessica Melaro (PA), Gwen Owens (CA), Kathryn Ryan (MA), Elizabeth Schultz (IN), Christine Seperis (NJ), Trecia Simmonds (CA), Douglas Swartzendruber (MD), Camille Tulenchik (MN), Mandy Virola (NJ) and Michelle Witham (CO).



## 29<sup>th</sup> Annual Convention in Louisville

The Huntington's Disease Society of America hosted the 29<sup>th</sup> Annual Convention at the Galt House in Louisville, KY on July 20<sup>th</sup>-22<sup>nd</sup>. The Convention was the second largest in the event's history with more than 850 guests in attendance.

The Convention provided the world's largest singular opportunity to personally learn from and build relationships with a wide cross-section of the HD community. The spectacular event offered insightful research seminars from top clinicians and scientists from around the world who provided optimistic research advancements.



Festivities began on Thursday afternoon with the Team Hope kick-off walk around the Galt House with hundreds in attendance setting the tone for an incredible Convention.

Among the many remarkable supporters recognized at Convention, Destiny Hand of Seaford, Delaware was honored with the HDSA Youth Leadership Award for her extraordinary efforts

to raise awareness for HD. Hand, a high-school senior, is the volunteer coordinator of the Laurel, DE Team Hope Walk that raised over \$10,000 on May 17<sup>th</sup> at Trap Pond State Park. She also serves as a representative advocating for children of HD families in both the National Youth Association and HDYO.

Lauren Holder from North Carolina won the prestigious HDSA Person of the Year Award.



## 16<sup>th</sup> Annual Ride for the Cure

For the past 15 years, Marie Nemec, 70, and Charlotte Reicks, 78, of Grand Junction, CO have been biking to the HDSA National Convention to raise funds and awareness for Huntington's disease.

Their first ride took place in 1999, when they traveled coast to coast some 3,000 miles. The distance has gradually decreased, but this year's ride covered 800 miles in 13 days, starting in Sault Ste. Marie, Michigan following the Dixie Highway to Louisville.

This year they were joined by Gary Heiman, Devon Walker, Amy Mack, Kathy Lindner and Alina del Rio.

Together and with other Huntington's disease supporter, over the years they have pedaled over 20,000 miles and have raised more than \$530,000 to support HDSA's mission to improve the lives of people affected by Huntington's disease and their families.





## Strike Out HD hosted by New York Giant Geoff Schwartz Raises \$20,000

New York Giants' offensive guard Geoff Schwartz has seen a lot of big hits throughout his career, but admits that nothing hits a family harder than Huntington's disease. The NFL star has teamed up with HDSA as a national spokesman to help raise awareness in the fight against HD. Geoff volunteered his time to be featured in several public service announcements for HDSA which have already gained an incredible amount of attention on HDSA's social media accounts and website.

On Monday, October 20<sup>th</sup> at Frames Bowling Lounge in New York City, Geoff hosted the Strike Out HD event and helped raise nearly \$20,000.

"Geoff's family is directly affected by Huntington's disease which is why he wasted no time in getting involved to raise awareness of HD,"

said Louise Vetter. "Because it is passed down from your parents, HD is the quintessential family disease, affecting generations of loved ones. With Geoff's help, we will be able to reach out to more folks across the country to join HDSA's team and support more families with HD."

## Pie in the Face Challenge

Over the summer, the HD Community came together to build awareness for Huntington's disease with folks from coast to coast participating in the "Pie in the Face Challenge." HD families, friends and supporters, captured videos of themselves taking a pie in the face, as well as make generous financial contributions to HDSA. The HDSA national office staff in NYC and board members participated as well.

"Once the campaign started around August we noticed a significant spike in our online donations," said Louise Vetter. "It was great to see the community work together in a fun, yet effective initiative to build awareness and funds for HD support & research."





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## 2014 Team Hope Highlights

### #1 Central IL Team Hope Walk

When: June 21<sup>st</sup>, 2014

How much raised: \$100,445

How many participated: 400

**Highlight:** The Central IL Team Hope Walk volunteers initially cancelled their walk after their community in Central Illinois was devastated by tornadoes in the fall of 2013. However they rebounded from that natural disaster and coordinated their first ever Team Hope Walk last June. This event catapulted to new heights of HDSA success becoming the highest grossing Team Hope Walk in 2014 raising over \$100K.

### #2 Los Angeles, CA Team Hope Walk

When: September 27<sup>th</sup>, 2014

How much raised: \$70,052

How many participated: 200

**Highlight:** Thanks to the prodigious efforts by the Los Angeles Chapter, their Team Hope committee and their committed volunteers were able to nearly double their \$40K budget in 2014 by grossing over \$70K through the support of over 200 participants.

### #3 Naperville, IL Team Hope Walk

When: May 18<sup>th</sup>, 2014

How much raised: \$66,812

How many participated: 618

**Highlight:** The Naperville, IL Team Hope Walk has long been the Illinois Chapter's signature walk. Many thanks to the tireless efforts and dedication from the Hodgson family, many Chapter volunteers and countless friends in the community, this walk has blossomed from one of HDSA's first walks to one of the largest fundraising and participant led Team Hope Walks in the country.

### #4 New York City Team Hope Walk

When: October 2<sup>nd</sup>, 2014

How much raised: \$62,259

How many participated: 75

**Highlight:** The New York City Chapter Team Hope Walk has soared to new heights in recent years by more than doubling their revenue. Their success can be tied to recruiting new team members and raising additional monies through social media.

### #5 San Francisco, CA Team Hope Walk

When: October 25<sup>th</sup>, 2014

How much raised: \$56,514

How many participated: 250

**Highlight:** San Francisco is our fifth highest grossing Team Hope Walk across the country, and brings together communities of friends from all over the Bay Area to walk for Hope. With a walk route that takes participants beneath the Golden Gate Bridge it is also one of the most beautiful Team Hope Walks to participate in!





### #6 New Jersey Team Hope Walk

When: September 28<sup>th</sup>, 2014

How much raised: \$52,899

How many participated: 175

**Highlight:** Coordinated and hosted by The New Jersey Chapter, the New Jersey Team Hope Walk has turned it into one amazing walk! Held in Edison, New Jersey, this walk has grown by leaps and bounds, quickly becoming one of the largest grossing Team Hope Walks in the country.

### #7 Dallas, TX Team Hope Walk

When: October 19<sup>th</sup>, 2014

How much raised: \$47,770

How many participated: 350

**Highlight:** The Greater North Texas Affiliate's Team Hope Walk has shown tremendous growth since its inception two years ago. They have raised \$80K combined to date for both walks and are already well into the planning stages for 2015 and recruiting new participants, teams and sponsors.

### #8 St. Louis, MO Team Hope Walk

When: April 26<sup>th</sup>, 2014

How much raised: \$42,957

How many participated: 420

**Highlight:** The St. Louis Chapter for many years has coordinated great Team Hope Walks! Their walk raised \$42,957 in 2014 thanks to the many volunteers, teams, sponsors, participants that come back year after year to help organize, support and attend this great community event!

### #9 Liberty, MO Team Hope Walk

When: October 11<sup>th</sup>, 2014

How much raised: \$42,795

How many participated: 300

**Highlight:** The Liberty, MO Team Hope Walk had the largest jump in year over year gross revenue for a Team Hope Walk! Their numbers went from \$12K in 2013 to over \$45K in 2014! Their success was due in most part to a stellar volunteer coordinator and very hard-working committee!



### #10 San Diego, CA Team Hope Walk

When: April 14<sup>th</sup>, 2014

How much raised: \$42,680

How many participated: 250

**Highlight:** The San Diego Chapter Team Hope Walk has only been held for the past 2 years, grossing \$40K in 2013 and over \$42K in 2014. Attended by over 250 participants at a beautiful park in San Diego this event is successful because the Chapter has volunteers that rally together with motivation and enthusiasm to get everyone in their community involved and to educate their community about HD and HDSA. Way to go San Diego!



## ADVOCACY

**Due to the incredible work of our advocates, HDSA has been able to successfully advance legislation and policy to improve the lives of HD families, including passage of GINA, the Genetic Information Nondiscrimination Act, and having Adult onset HD and Juvenile Onset HD be added to the Social Security Administration's Compassionate Allowances List.**

**These successes would not have been possible without the continued involvement of dedicated individuals in the HD community.**

### 2014 NYA Advocacy Days

*Jason Gromley, Esq., Vice President Strategic Health Care, HDSA Advocacy Advisor*

#### NYA Advocacy Pitch

When I sat down with Morgan McLane (Pennsylvania) at the 2014 HDSA National Convention in Louisville, KY; I didn't expect our conversation about advocacy to turn into three separate NYA Fly-Ins to advocate for the Huntington's Disease Parity Act of 2013 (H.R. 1015/S. 723). But this year, with the organizational efforts of Morgan and fellow NYA Board Member Amanda Butterworth (North Carolina), the NYA brought 19 advocates to Congress throughout July, August, and September. Together, they had over 140 meetings and garnered 25 new co-sponsors (so far). Every NYA member, from 11-year old Kelly Samulski (Michigan) to several "honorary NYA advocates" who joined the efforts, took time out of their busy lives to advocate on behalf of not only their friends, families, and themselves – but on behalf of the entire HD community.

The bipartisan HD Parity Act (H.R.1015/S.723), would reform the broken Social Security Disability and Medicare systems for individuals with HD. The bill will (1) prevent Social Security from using the outdated medical criteria that they are currently using to determine disability; and (2) allow individuals with HD to immediately qualify for Medicare once they are disabled (instead of waiting for 2 years). Our legislation, which would change the lives of individuals with HD and their families, is much closer to becoming a reality because of the efforts of the entire HD community – especially the concerted efforts of the NYA. By having the courage to bring their personal stories directly to policy makers, these advocates proudly stood up as HD champions for our entire community.



By sharing their unique and powerful HD stories with Congress this year, the NYA has not only educated and recruited new legislative champions for individuals with HD – but they have inspired other individuals in the HD community (of all ages) to join in our advocacy efforts!

One of the most important things that came out of the "Summer of the NYA" is the engagement of so many first-time HD advocates in the NYA. From July to September this year, the NYA has sent 13 first-time advocates to Washington, D.C. It takes a lot of courage to take those first steps, and every one of these advocates did an incredible job, but I'd like to highlight a few individuals in particular.

#### Jolene Luther (Iowa)

Jolene, a research assistant at the University of Iowa's PREDICT-HD Study, used the experience of helping to care for her grandfather as he progressed through late-stage HD as a motivation to pursue a cure for the disease. Jolene "won the genetic lottery" when her mom tested negative for the HD gene, but – until we find a cure – she is deeply committed to helping ease HD's burden for everyone in the community. This commitment brought Jolene to Washington twice this year, where she used her personal experiences and research background to convince office after office to co-sponsor the HD Parity Act.

#### Kelly Samulski (Michigan)

It's hard to say which is more impressive about Kelly's commitment to advocacy – the fact that she's 11-years old, or that she blew every office away with her knowledge and commitment to helping the HD community. Not only did Kelly come to Washington, D.C. twice this summer to advocate for the HD Parity Act – flying alone for the first time in September – but she prepared her entire speech by herself. Kelly's strong voice, and her personal experience, helped explain the importance of passing the bill to help individuals in the HD community live more dignified and fulfilling lives.

## MaryAnn Emerick (New York)

MaryAnn is an example of a new advocate going from 0-1,000 in no time. MaryAnn volunteered to meet with Congressman Crowley's (D-NY) office, but didn't expect to actually get a meeting with the Congressman himself. Within a few days of her meeting request she was sitting across the table from Mr. Crowley in his New York office and receiving his commitment to co-sponsor the HD Parity Act. A few weeks after meeting Congressman Crowley in New York, MaryAnn was in Washington, D.C. sharing her compelling story with even more offices – getting co-sponsor after co-sponsor. Just a few weeks after that, she was sitting down with FoxNews.com to share her family's HD story and details about the Parity Act.



While Jolene, Kelly, and MaryAnn are amazing advocates, they aren't alone. From the NYA members and allies that joined them in Washington, D.C. to the advocates that are raising awareness for the HD community in cities and towns across the country – together we are making a difference. The NYA's hard work has already paid enormous dividends this year – and something tells me that we haven't seen anything yet.

## General Advocacy Pitch

Huntington's disease advocacy takes many forms – from community awareness campaigns, fundraisers, and one-on-one conversations – everyone can be an HD advocate. All of these efforts are immensely important to bring HD out of the shadows, and make sure that every member of our community knows that they are not alone. But HD Advocacy also means reaching out to your elected officials and advocating for policies that would help our community – like the Huntington's Disease Parity Act of 2013 (H.R. 1015/S. 723).

For me, the best part about the HDSA advocacy program is the empowerment of our community. Whenever a new advocate – regardless of where they are from, what their career is, or their background – takes the first step and engages with their elected officials about HD, our entire community benefits. Over the last four years I have had the benefit of seeing hundreds of individuals take those first steps, and can't say how proud I am to have

many of those once first-time advocates as leaders in our community today.

Given the significant impact of sharing your personal HD story with your elected representatives, it is surprisingly easy to get involved.

**Step One:** Make your interest known! Email [HDSA@shcare.net](mailto:HDSA@shcare.net) to share your interest in getting involved, where you live, and how easy it is for travel.

**Step Two:** You will be contacted with instructions on who to contact for a meeting, how to prepare for a meeting, and what to talk about. We will walk you through the process step-by-step.

**Step Three:** Meet with your Representative/Senator for about 30 minutes to share your HD story and how the HD Parity Act would make a difference in your life.

Not only do the individual stories of advocates make an enormous difference – but you can dedicate as much time, energy, and resources to the cause as you are able – and see enormous results from even the simplest efforts. I'd like to share a few stories of advocacy, and how these members of our community have helped individuals with Huntington's disease by educating their Members of Congress.

## Teresa Casale (Washington, D.C.)

As Congress returned to Washington in early 2014, Teresa turned the sudden death of her cousin from HD into a call for action – becoming a regular in the Halls of Congress. Dedicating almost every Friday to HD advocacy, Teresa attended almost 70 Congressional meetings – convincing 17 Members of Congress to co-sponsor the HD Parity Act. Teresa also dedicated her time to training other advocates – helping HDSA's advocacy team produce a webinar and joining our advocacy training seminar at the 2014 Convention in Louisville, KY.

## Gary Belcher (Oklahoma)

Gary took his personal experience with Huntington's disease directly to his Congressman, Tom Cole (R-OK), in a meeting at the Congressman's district office in November. Gary, a first time HD advocate, used his passion (and preparation) to educate Mr. Cole about HD, the struggles that our community faces every day, and the need to pass the HD Parity Act. Because of Gary's meeting, Congressman Cole has not only co-sponsored the bill, but has offered his staff's assistance in navigating the disability and Medicare processes.

*continued on page 14*

George Yohrling, PhD, HDSA Director of Medical & Scientific Affairs

This year marked another busy year for the Huntington's Disease Society of America and the global HD community. In 2014, we saw the commencement of several exciting new trials for HD from major pharmaceutical companies and the completion of the First-HD and ARC-HD trials. However, we also heard of the unfortunate termination of the two largest trials ever conducted for HD, 2CARE and CREST-E. Without a doubt, the most exciting news of the year came when it was announced that Isis Pharmaceuticals will officially begin its first clinical trial for a huntingtin lowering drug in 2015. While this is just the beginning for this drug, it marks a moment long in the making by scientists and even longer in waiting by HD patients and families. For the first time ever, a drug, specifically designed for Huntington's disease, will finally get its chance in the clinic.

Scientists, clinicians and HD families from around the world came together at many large meetings in 2014 to hear about the latest in HD research. Large crowds of people attended the CHDI Foundation Therapeutics Conference in Palm Springs, the European HD Network meeting in Barcelona, the Huntington Study Group meeting in Minnesota and the Society for Neuroscience in Washington, DC. Last, but certainly not least, in June, the HDSA held our 29th Annual Convention in Louisville, Kentucky. Approximately 900 people came to hear the latest in research, education, care and advocacy for HD and have a little fun too!

This year, HDSA significantly expanded our flagship research initiative, the HD Human Biology Project. In the 2014 Research Investor's Report you will see summaries of the eight new research projects HDSA has begun to support. In addition, exciting data are now beginning to emerge from the labs of the 2013 Human Biology Project winners.

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 HDSA Centers of Excellence with the goal of studying HD in humans. We believe this approach is critical for the acceleration of treatments for HD as everyone agrees that the most important observations to guide researchers in the hunt for therapies for HD will be those made in people actually affected by HD.

In February of 2014, the HDSA Board of Trustees made a



strong statement to the community by formally endorsing the Enroll-HD study that is organized by the CHDI Foundation. Never before has HDSA endorsed a clinical study, but the organization felt strongly that the scope and potential impact of Enroll-HD required its full support.

Enroll-HD, is a global, multi-faceted research platform that will help guide drug development, clinical trials and HD patient care for years to come. HDSA is encouraging all HD impacted families to consider getting involved.

As 2014 comes to a close, we hope that you will see in the latest edition of our Research Investor's Report that 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. The Research Investor's Report is available for download at [www.hdsa.org](http://www.hdsa.org).

### HDSA Launches First "HD News" App

At the 29th Annual HDSA Convention, HDSA launched its new Huntington's disease news app that is available for all mobile devices. Titled "HD News" and available through iTunes and Google Play, the free app provides up-to-date news and event information from HDSA.org, research summaries from HDBuzz.net, as well as the latest news related to HD drug discovery and development from Science Daily and Medical News Today. The best way to find the app is by simply searching for "HDSA".

"HD News is one stop shopping for everyone who follows Huntington's disease science and related news," said Louise Vetter. "We're excited to be able to provide the first customized news app for the HD community as we continue to look for new ways of bringing valuable information and support for families affected by Huntington's disease."

The app was custom designed for HDSA by Apptomics and made possible by an education grant from Auspex Pharmaceuticals.



## HD Support

**HDSA currently has 40 Social Workers & 170 support groups across the United States working to provide valuable support to the HD community. HDSA social workers assist families with navigating HD by providing information, referrals and by helping to start and maintain support groups.**

### Support group, why me?

*Amanda Miller, LMSW, HDSA Center of Excellence at the University of Iowa*

Have you ever attended an HD support group meeting?

The reality is that most people impacted by diseases like Huntington disease, whether they are caregivers, at risk, presymptomatic or living with HD, have never been to a support group meeting. The reasons vary from individual to individual and family to family. Among the many reasons, the most common misconceptions about the value of support groups fall into a few categories. Let's examine each misconception.



### 1. I don't really need it yet, but when I do, I'll look into it.

Perhaps you just found out HD is in your family, but you're not "sick" and don't know anyone who is. Perhaps you are just beginning the caregiving journey and you do not yet feel that your stress is to the level of needing peer support. Whatever your stage in the lifelong journey with HD it is never too soon to discover others like yourself. Support groups provide a platform for individuals and families to connect with others who can guide, share, cry, laugh, celebrate and grieve with each other. To those of you thinking "I'm just not there yet," I challenge you to restructure your view of what a support group can offer. The group isn't simply a mechanism for responding to problems. It offers the chance to build relationships with those who can help you before you find yourself knee-deep in crisis. In financial terms, think of it as your savings account of support: you build it now so you have it later.

### 2. I'm not really comfortable talking about my feelings with strangers.

Many people fear being vulnerable in a room full of strangers. The group members will likely be strangers initially. Fear not! There are no requirements to share your secrets and fears. I counsel potential support group members to come to the meeting with the main goal of simply listening. Hear the experiences of others, let yourself be open to the idea of meeting others impacted by HD, but know that there are no rules of engagement beyond showing respect to those around you. Only be present in the room and be mindful of those around you and their circumstances. With time, the room is no longer full of strangers, but rather a collection of individuals with whom you've had the opportunity to develop meaningful, mutually supportive relationships. If you feel comfortable, share your reasons for attending. Perhaps you have a specific question about a symptom or maybe you don't know why you're there. The best part of an HD support group is that you don't have to know the answers. You don't even have to know the questions. Just know that your level of participation is completely up to you. Your entry into the group will be respected and supported as you figure out your comfort level.

### 3. I talk to my family and friends about the issues, so don't really need more support.

A theme present in so many HD families is the beautiful existence of informal support from family and friends. Those that have that support are fortunate. Support groups are not designed to replace that. Rather, support groups augment the love and comfort you find in your personal life. They provide the opportunity for people experiencing similar life struggles to share with each other their successes and failures while not having to worry about possibly burdening their friends and family. In a support group, members can ask about experiences they may not feel comfortable sharing with members of the family (are you comfortable having a conversation with your family about your partner's changing intimacy).

Don't overlook the value that you as a member may provide to the group. You have the opportunity to have a tremendous impact on others who are living in circumstances not unlike your own. Many group members value their role in the group as it relates to what they can do for others, and in that service they find peace. This disease isn't easy and you don't have to do this alone. Hear about the experiences of others. Seeking support isn't a sign of weakness; it's one of the best indicators of a person's strength. HD is a long and challenging opponent; give yourself the opportunity to have as many resources as possible in your fight. Find a support group near you. Check out the HDSA website [www.hdsa.org/sg](http://www.hdsa.org/sg) for a support group in your state. Interested in starting a group? Fill out the form on the support group page.

## Guidelines for Finding a Nursing Home

Gwen Johnson, RN-BC, Nurse Manager, Good Samaritan Specialty Care Center and Jessica Marsolek, LSW, MN Chapter Social Worker

Huntington's disease comes with many challenges, requiring increasingly more care as the disease progresses. There may come a time that the family or caregiver is no longer able to provide the care at home even with the help of family, friends and other services.

It is never an easy discussion for any family when long-term care placement needs to be considered. It brings up many mixed emotions of guilt, grief, and loss on top of being already physically and emotionally exhausted.

So where do you begin? There are only a few long-term care facilities around the country that have specialized HD units. (The states that have these facilities include CA, IN, MN, MA, NJ, NY, VT).

If there are no long term care facilities in your area that specialize in HD, contact your local nursing homes, ask if they would be willing to accept someone with HD, and request a tour. Sometimes facilities when hearing the diagnosis of Huntington's disease say, "we are not able to meet their needs." This may be true, but it is often that they have only heard of the challenging issues that are associated with HD, such as aggressive behaviors or the risk of falling. You can help educate a long-term care facility about how Huntington's disease affects your loved one. HDSA can provide materials to help you educate the facility and can offer an in-service so staff better understand the disease.

Be honest with the facility about the challenges of caring for your loved one and also about the person's routine, their likes and dislikes. Hopefully you will meet a professional who is interested and compassionate. Admitting a person

with HD may be a challenge but as a family member, you are willing to assist to provide context for the care of this individual.

Be prepared to talk to the facility about your loved one's financial situation. Payment for care can include private pay, private insurance or state Medicaid.

You may also wish to consult with an elder care attorney if there are special financial issues. <http://www.naela.org/>

HDSA has social workers around the country that can assist you. Support groups can be helpful as others will understand the range of emotions you may experience when considering long term placement for your loved one. To find your local social worker or support group leader, please visit [www.hdsa.org](http://www.hdsa.org) or contact Anne Leserman at the HDSA national office at 800-345-HDSA (4372) or [aleserman@hdsa.org](mailto:aleserman@hdsa.org).

The following website is available to check on the performance of nursing homes. Don't let this information be your only guide. Do ask the questions listed below. [www.medicare.gov/nhcompare/](http://www.medicare.gov/nhcompare/).

Here are some things to consider when you visit a facility that you might not find looking at a website about a certain facility.

Is the facility willing to learn more about HD?

Do staff treat patients with kindness and respect?

Is the facility able to adapt activities that are more appropriate for the age of your loved one?

What types of ancillary services come to the facility (instead of patients going out to appointments like dentist, podiatry, psychiatry)?

What types of interventions do they take for a person who might have falls or is attempting to leave?

Remember to let what you see and feel help guide you as to where to place your loved one to ensure not only quality of care but also quality of life.

### Advocacy continued from page 11



### Betsy Crutcher (West Virginia)

When I first met Betsy, it was at the 2013 HDSA Washington, D.C. fly-in. In meetings with the West Virginia delegation, Betsy communicated the very real struggles that an HD family experiences when they don't have access to the necessary resources – like Social Security Disability and Medicare. Betsy's first hand account was moving, and effective – but she didn't stop her advocacy when she returned home. She continued to push for the HD Parity Act by writing to her Members of Congress, and helped us achieve our very first co-sponsor from West Virginia, Congressman David McKinley (R-WV).

It is because of advocates like Teresa, Gary, Betsy, and hundreds of others across the country that we have had our most successful advocacy year ever. Not only do we have the highest number of co-sponsors on the HD Parity Act that we have ever had – but more importantly – we have more advocates involved in our efforts than ever before.

## National Youth Alliance

The National Youth Alliance provides a support network for youth coping with Huntington's disease in their lives. This wonderful program is in place to educate, engage and inspire young people and their families when dealing with HD and Juvenile HD.

For more information about the NYA please visit [www.hdsa.org/nya](http://www.hdsa.org/nya).



## 2015 Convention Save the Date



Take part in the 2015 HDSA Annual Convention in Dallas, Texas on June 25-27. Convention is the world's largest singular opportunity to personally build relationships with members from the entire spectrum of the HD community.

Sponsorship, scholarship and exhibitor opportunities are available.

For more information about Convention and to register please visit [www.hdsa.org/convention](http://www.hdsa.org/convention).





# Huntington's Disease Society of America

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