

We Are HDSA!



Huntington's Disease
Society of America

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NYA Members Eat Congress for Lunch: HDSA'S LOBBYIST RECAPS

By Jason A. Gromley, Esq., Vice President, Strategic Health Care

There are many excellent parts about representing HDSA in Washington, D.C. – but by far the most rewarding is seeing the transformation of devoted volunteers into super-advocates for the Huntington's Disease Parity Act of 2013 (H.R. 1015/S. 723). Members of the HDSA National Youth Alliance did it – and so can you!

On July 15, 2014, I got to watch a handful of National Youth Alliance members storm Capitol Hill, share their personal stories, obtain two Congressional co-sponsors before they even got to town, and three more before the end of the day. I haven't seen anything like that before!

Morgan McLane (PA), Amanda Butterworth (NC), Lauren Holder (NC), Jesse Lis (OH), Ashby Paca (VA), and Jolene Luther (WI/IA) traveled to D.C. to make a real difference in not only the lives of their families, but also the HD community. Through each of the 41 meetings, our advocates shared their personal stories, the damage that the delays in Social Security Disability and two-year waiting period for Medicare are causing, and the struggles of the HD community. "Before we got to DC I thought that we were going to be brushed off in every office and not feel listened to. It was amazing to sit down and tell my families/friends stories of dealing with Huntington's disease and actually feel as though some of the people on the other side cared," said Amanda Butterworth of North Carolina.

The Huntington's Disease Parity Act of 2013 is a commonsense solution to a very real problem for the Huntington's disease community. Every day individuals with HD are denied access to the Social Security system because of the use of medically inaccurate and outdated criteria. Currently, Social Security only looks at whether an individual with HD is experiencing chorea. They ignore the non-physical manifestations of the disease entirely. Additionally, after finally accessing disability

insurance, an individual with HD is then forced to wait two more years for access to Medicare – at a time in the disease progression where we can make the most impact on the emotional and mental manifestations. We need to change that! We need the HD Parity Act passed by Congress!

The Parity Act does two simple things. (1) It forces Social Security to update the criteria for Huntington's disease to be medically accurate. (2) It waives the two year waiting period for Medicare once disability is established. These two solutions for the Huntington's disease community will provide much needed support, not only to the HD individual, but also to the entire family. Being an advocate is as easy as telling your story and asking for help from your elected representatives. But we need you to do it TODAY!

We only have until the end of the year to get the HD Parity Act passed, and we have the momentum to do it – the only thing missing is you. August is the perfect time to reach out to your Members of Congress because they are back home in their local districts. Contact their offices and ask to meet with them while they are in town, attend a town hall event, or look for scheduled events where you can tell your personal story and ask for their help.

HDSA has an easy, step by step process set up to guide you through becoming an effective change maker for HD families by talking with you elected officials. To learn how to be an advocate for HD, please visit www.hdsa.org/advocacy, and watch my webinar, "Eating Congress for Lunch" at www.hdsa.org/ll. I'll leave you with the words of Morgan McLane: "If you feel so strongly about something, and if there's something you can do. Do it."

Stand up for HD today – and tell your Members of Congress to do the same!

Upcoming HDSA Educational Events

- August 9:** Tampa, FL
September 13: Portland, OR
October 18: Denver, CO

Upcoming Webinars

November 12:
Nutrition & HD

Register at [hdsa.org/ccorner](https://www.hdsa.org/ccorner)

HDSA E-mail List

Want to get more information about HDSA events and activities? Visit the HDSA website at www.hdsa.org to sign up!

Recommendations and Observations to Ponder

By Jessica Marsolek, LSW, HDSA Minnesota Chapter Social Worker

When your loved one needs 24-hour care, it can be a very difficult and emotional time for you and your loved ones. It is important to find the best home and long-term option, as moving a person with Huntington's disease and changing their routine can be very difficult for them.

There are not always a lot of options when it comes to nursing homes, as many areas have limited willingness to work with people with Huntington's disease. Careful thought into what is best for the patient and what will make them the happiest is the most important consideration when you are faced with options. Here are some things to consider when you reach this juncture:

Are the management and staff open to learning more about Huntington's?

If they are not very open, chances are they may not be very understanding or willing to work with the person if behaviors or issues arise for the person with Huntington's.

Besides the physical building itself, what is the vibe the staff gives you?

Are the staff smiling, or appear to be enjoying their work and the people that they work with?

Does the staff treat the patients with kindness and respect?

What types of activities do they have that may be tailored to a person with HD, or one who may be younger than their usual population? Would they be open to adapting their activities to be HD friendly?

Ask a couple of the residents what they think about living at the facility.

You will probably get candid opinions and they will probably be your best advice as to what it is like to live there.

Have they ever had a resident with Huntington's disease? At times a facility may have had a very limited or negative experience with one or very few HD residents and they can be afraid of working with another. This is unfair as everyone with HD is very different, but it may be the only HD reality these facilities know.

What types of services come into the facility? Going out to appointments can be very nerve wracking for people with HD, so the more onsite services the better (i.e. Dental, Optometry, Podiatry, Psychology, Psychiatry, Neurology, etc ...)

What types of interventions do they take when someone falls, have behavioral symptoms, or when someone is attempting to leave?

Do they have music or pet therapists on staff for their residents?

At times the transition is more difficult for the loved ones than for the person with Huntington's disease. Long term care facilities can sometimes provide the person with Huntington's disease more socialization, friendship, structure and routine than they had when living in the community.

Understanding Behavior

Now available! *Understanding Behavior (Second Edition)* by Jane Paulsen, PhD and Arik Johnson, PsyD.

Thanks to a generous educational grant, HDSA is able to offer this updated guide to HD families and their medical professionals at no cost.

Since the first edition of *Understanding Behavior* was published in 2000, much has been added to our understanding about HD including behavioral changes that take place along the continuum of the disease.

Written specifically for medical professionals, this second edition contains strategies that can be shared with caregivers as well as case studies that illustrate many of the most challenging behaviors associated with HD.

To obtain a copy of *Understanding Behavior* for your physician, psychiatrist, therapist or family counselor, contact Anita Mark-Paul at amarkpaul@hdsa.org

for Reading a Scientific News Story

By Ed Wild, MRCP, PhD, Editor-in-Chief, *HD Buzz*. Original article appeared on Sept 5, 2011 on HDBuzz.net.

How science reaches the public

Science becomes 'official' when an article about a piece of research is published in a peer-reviewed scientific journal. But a lot of science reaches the public through press releases.

Increasing competition over scarce funding means that getting results published in a scientific journal may not be enough for scientists to keep their work going.

The agencies that fund science take their lead from the public, so one way for researchers to secure funding is to get the public excited about their research. When a piece of work has so far only focused on a small area, one way to excite people is to get them to imagine the whole glacier, rather than just the snowflake.

Universities and research companies have press offices whose job is to encourage scientists to produce press releases in which they often speculate about what applications their work may have down the line.

Of course, part of what science does is to come up with real-world uses for new discoveries. But it's a double edged sword, because many things that might happen, never do.

Another layer of speculation can get added when press releases are turned by bloggers and journalists into news stories. Writing about big breakthroughs in common diseases gets more clicks and sells more papers than writing about small progress and obscure conditions.

What's the harm?

The result can be that press releases and news articles sometimes end up promising things that the scientific research could never deliver - or which are much further away than an article suggests.

This isn't the fault of the individual scientists, or of the press office, or the bloggers or journalists, or of the people reading the stories. Nobody sets out to mislead - but sometimes that can be the outcome, and it's bad news because it can lead to disappointment and loss of hope.

Ten Golden Rules

The good news is that disappointment can be avoided if readers know what to look for.

So, HDBuzz has come up with Ten Golden Rules for reading a press release or scientific news article. They're here to help you to draw hope from scientific news where it's warranted - and avoid being let down where it's not.

- **Be skeptical of anyone promising a "cure" for HD** now or in the near future.
- If something sounds **too good to be true**, it probably is. "The good news is that disappointment can be avoided if readers know what to look out for."
- Has the research been **published in a peer-reviewed scientific journal?** If not, the press release may not be much more than speculation.

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Team Hope

By CJ Redfern, Manager, Team Hope Walks

Team Hope is the Huntington's Disease Society of America's (HDSA's) largest national grassroots fundraising event. Thousands of families, friends, co-workers, neighbors and communities walk together each year to support HDSA's fight to improve the lives of people affected by HD and their families. From registering, to forming a team, to sponsoring an event, to volunteering, you too can help make a difference in so many lives. Join Team Hope and help us provide help for today, hope for tomorrow! Learn more by visiting www.hdsa.org/teamhope, and please check out the list below for an upcoming Team Hope Walk nearest you!

Walk City & State	Walk Date	HDSA URL	Walk City & State	Walk Date	HDSA URL
Traverse City, MI	8/9/2014	www.hdsa.org/thwtraversecity	Salt Lake City, UT	9/13/2014	www.hdsa.org/thwsaltlake
Milwaukee, WI	8/9/2014	www.hdsa.org/thwmilwaukee	Denver, CO	9/13/2014	www.hdsa.org/thwdenver
Battle Creek, MI	8/16/2014	www.hdsa.org/thwbattlecreek	Chattanooga, TN	9/13/2014	www.hdsa.org/thwchattanooga
Fox Valley, WI	8/17/2014	www.hdsa.org/thwfoxvalley	Joplin, MO	9/20/2014	www.hdsa.org/thwjoplin
Madison, WI	8/23/2014	www.hdsa.org/thwmadison	Virginia Beach, VA	9/20/2014	www.hdsa.org/thwvabeach
Omaha, NE	8/24/2014	www.hdsa.org/thwomaha	Durham, NH	9/20/2014	www.hdsa.org/thwdurham
Indianapolis, IN	9/6/2014	www.hdsa.org/thwindy	San Antonio, TX	9/20/2014	www.hdsa.org/thwsanantonio
Boston, MA	9/6/2014	www.hdsa.org/thwboston	Atlanta, GA	9/20/2014	www.hdsa.org/thwatlanta
Long Island, NY	9/7/2014	www.hdsa.org/thwlongisland	Royal Oak, MI	9/21/2014	www.hdsa.org/thwroyaloak
Toledo, OH	9/13/2014	www.hdsa.org/thwtoledo	Madison, CT	9/21/2014	www.hdsa.org/thwct
Lansing, MI	9/13/2014	www.hdsa.org/thwlansing	Oklahoma City, OK	9/21/2014	www.hdsa.org/thwokc
Springfield, MO	9/13/2014	www.hdsa.org/thwspringfieldmo	Hamilton, OH	9/27/2014	www.hdsa.org/thwhamilton
Louisville, KY	9/13/2014	www.hdsa.org/thwlouisville	Washington, DC	9/27/2014	www.hdsa.org/thwdc
Erie, PA	9/13/2014	www.hdsa.org/thwerie	Burlington, VT	9/27/2014	www.hdsa.org/thwvermont
Lehigh Valley, PA	9/13/2014	www.hdsa.org/thwlehigh	Los Angeles, CA	9/27/2014	www.hdsa.org/thwlosangeles
Albany, NY	9/13/2014	www.hdsa.org/thwalbany	Little Rock, AR	9/27/2014	www.hdsa.org/thwlittlerock
Lowell, MA	9/13/2014	www.hdsa.org/thwlowell	Ankeny, IA	9/27/2014	www.hdsa.org/thwankeny
Seattle, WA	9/13/2014	www.hdsa.org/thwseattle	Edison, NJ	9/28/2014	www.hdsa.org/thwedisonnj
Buffalo, NY	9/13/2014	www.hdsa.org/thwbuffalo			

TEN GOLDEN RULES for Reading a Scientific News Story (Continued from Page 3)

- Ask yourself whether the press release is announcing the **results of a project** - or just the start of the project, a new partnership or funding approval. There's a big difference.
- The only way to show that something works in HD patients is to **test it in HD patients**.
- A positive result in an **animal model of HD** is a very good start - but can't be called a cure - and plenty of things that work in mice fail when tested in humans.
- Something that **hasn't been tested in an HD animal model** has a very long way to go to become a treatment.
- **Your mind is like a house** - it's good to keep it open, but if you leave it wide open, you never know who'll walk in.
- Not sure about something you've read? **Ask HDBuzz to write about it!**
- Finally, remember that **every day, science moves us towards effective treatments** for HD. Even negative results and treatment failures help us to focus on more fruitful ideas.

Thank you
Auspex



QR Code

Please scan here
to visit the
HDSA website

