

# Fall Newsletter



## INSIDE THIS ISSUE:

Tee off Fore HD	2
Calendar of Events	3
Don't Stay Away	3
Chapter Website	4
Amaryllis Sale Begins	4
Inside the O'Briens	5
Advocacy Update	5
Caregiver Burnout	6
Communication Tips	7
NFC Update	8
Resources	8

## Fall Education Event 2015

SUNDAY, SEPTEMBER 27<sup>TH</sup>, 2015 / NOON TO 4 PM  
Schroeder Auditorium / Sanford USD Medical Center

## Featured Speaker Dr. Jane Paulsen

University of Iowa

**USD Education Event  
Panel Discussion  
Monday, September 28<sup>th</sup> 10 am to Noon  
Sanford School of Medicine /  
University of South Dakota**

Dr. Jane Paulsen will be the featured speaker.  
In addition, caregivers, siblings, and people with HD will be speaking as a panel to the medical students at USD.

This event is funded by the Huntington's Disease Society of America (HDSA) through an unrestricted educational grant from Lundbeck.



## Save the Date

Winter Fundraising  
Event at  
"The Market"

**Saturday, Dec 5th  
Noon to 4pm**

Downtown Sioux Falls  
196 E. 6<sup>th</sup> Street

We are working on a **FUN**  
event with a **live auction!**  
Stay Tuned!

Presented By



To register contact:

[debstadley@gmail.com](mailto:debstadley@gmail.com)



## Tee Off Fore Huntington's Disease

1<sup>st</sup> annual charity golf tournament •• four person scramble

**Saturday, September 19th**

**Northern Links Golf Course, Sioux Falls, SD**

**Registration:** 8 am •• **Shotgun Tee-off:** 9 am •• **Cost:** \$180 total per team  
This includes entry into event, 9-holes of golf, riding cart and lunch

Proceeds from the event go towards the Sioux Valley Chapter of Huntington's Disease Society of America in the fight to improve the lives of people affected by HD and their families.

Huntington's Disease is a fatal genetic disorder that causes the progressive breakdown of nerve cells in the brain. It's been described as a combination of ALS, Parkinson's and Alzheimer's.

### AWARDS

- \* Winning Team
- \* Longest Drive
- \* Closest to the Pin

### DRAWING

- \* Make sure to buy your tickets for a chance to win an autographed jersey of Clay Matthews from the Green Bay Packers!!
- \* Only 200 tickets available!

### Jersey Tickets:

1 for \$25 or 3 for \$50

Contract Brad Lingen:  
[brad.lingen@gmail.com](mailto:brad.lingen@gmail.com)



In case of cancellation of event due to weather all sponsorships and team registrations will be considered a donation to SVHDSA.

## Calendar of EVENTS

### **SEPT. 12**

Support Group Meeting  
check [www.hdsa.org/sv](http://www.hdsa.org/sv)  
for location; 11am to 1pm

### **SEPT. 19**

Tee Off Fore HD – Golf  
Northern Links, Renner,  
SD  
8am Registration  
9am Tee Off

### **SEPT. 27**

Fall Education Event  
Sanford Health  
Auditorium  
Amaryllis sales start!

### **SEPT. 28**

USD Panel Discussion  
Vermillion, SD

### **OCT. 10**

Support Group Meeting  
check [www.hdsa.org/sv](http://www.hdsa.org/sv)  
for location; 11am to 1pm

### **OCT. 31**

Amaryllis Sales End  
Submit orders to Margaret  
Geertsema

### **NOV. 14**

Support Group Meeting  
check [www.hdsa.org/sv](http://www.hdsa.org/sv)  
for location; 11am to 1pm

### **DEC. 5**

Fall Fundraising Event  
The Market  
Downtown, Sioux Falls

### **DEC. 12**

Support Group Meeting  
check [www.hdsa.org/sv](http://www.hdsa.org/sv)  
for location; 11am to 1pm

## Don't Stay Away

By Jessica Marsolek / Minnesota Chapter Social Worker

When someone you care about has HD, sometimes it can be hard to know how to support them and their caregiver. I often hear that those within our HD community feel isolated in their community.

The Richfield, MN support group gave some tips to help with support someone you care about who has HD and their caregiver:

1. Don't Stay Away! Just because you don't know what's going or what to say, just be there.
2. HD is isolating, help to stay engaged with the family who has HD.
3. It shows your character, if you can be my friend through sickness and in health.
4. Help Out when able. It would be really nice if someone would sit with the loved one affected by HD, so that their caregiver can run errands.

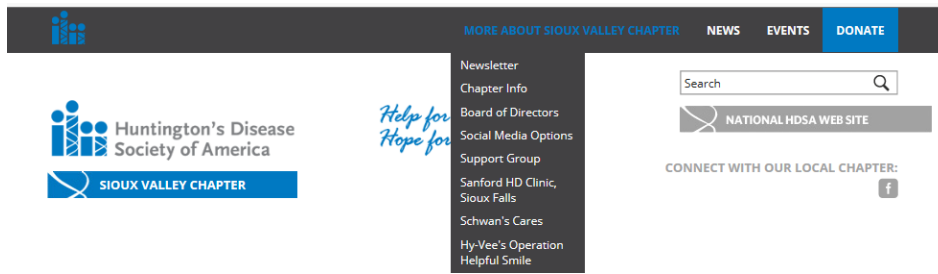
Many families are choosing to create a Caring Bridge website to help keep friends and family members informed about their loved one who is living with an illness. [www.Caringbridge.org](http://www.Caringbridge.org) now has an option to create a "Share the care" calendar to allow for caregivers (or someone willing to help) to list what they could use assistance with: running errands, meals, sitting with loved one or visits. Once the calendar is established, friends and family can log into the caring bridge site of their loved one and sign up to support whenever and however often they are able. This is a great way to ask for support, without having to literally ASK for support.

The new ***HD Medical Alert Bracelets*** are available! The bracelets are brand new in August! They will help our loved ones in times when we are not able to be their advocates with law enforcement and/or medical professionals. They are available on [www.hdsa.org](http://www.hdsa.org)



## Chapter Website

Have you checked out our chapter's new HD website yet? If not, go to: [siouxvalley.hdsa.org](http://siouxvalley.hdsa.org). It's updated at least monthly with upcoming news, events and items of interest. Click on different pull-down menus to find more topics and information. If there's a new topic you'd like included, let us know.



In the Spring 2015 newsletter, we reported our next “to-do” was to add links on this website where you could read past editions of the chapter's newsletter. Actually, when you navigate to our website using Mozilla Firefox (or something other than Windows Internet Explorer), three newsletters are linked up and are viewable under the topic of “Newsletter.” For some reason, however, only the Spring 2015 newsletter is found when using Internet Explorer. If needed, use an alternative Internet search engine to view our website. In the meantime, we'll continue to search for an answer. Stay tuned!

In addition to our chapter's website, sign up on HDSA's National email mailing list at <http://hdsa.org>. In the lower portion of their home screen, there's a big blue area where you can sign up for various HD topics of interest.

Encourage friends, volunteers, family, donors, and such to sign-up as well.



## Amaryllis Sales Begin

The Amaryllis Sale begins on Sunday, September 27<sup>th</sup>! The complete kit includes an amaryllis bulb, pot, and growing medium. Each amaryllis cost \$10. The amaryllis bulbs can be ordered by color (Red Lion, Apple Blossom, Minerva or Athene) or assorted by case. A case is 16 bulbs.

- Red Lion is all red
- Apple Blossom is pink and white
- Minerva is red and white
- Athene is white



These are great gifts for Christmas, housewarming, employees, teachers, co-workers, clients, get well, birthday and much more.

Please contact Margaret Geertsema with your amaryllis order. Deadline is Saturday, October 31<sup>st</sup>.

## Volunteers Needed

We are always looking for volunteers to help carry out our educational and fundraising events. Volunteers can be anyone in our lives that want to give back to their community. They don't need to have HD in their families --- but, they are interested in helping us execute our HDSA mission.

Volunteering provides an opportunity to meet new people and to pursue interests in your daily life. Volunteering can also provide career experience - it can offer you the chance to try out a new career without making a long-term commitment. It is also a great way to gain experience in a new field. If you are interested in volunteering at our events, please email:

Debbie at [debstadley@gmail.com](mailto:debstadley@gmail.com)

**AmazonSmile**

Shop at AmazonSmile and Amazon will make a donation to the Huntington's Disease Society of America (HDSA).

Up to 0.5% of your purchase will benefit HDSA.

[www.smile.amazon.com](http://www.smile.amazon.com)

GET STARTED TODAY!

**Inside the O'Briens.....by Lisa Genova**

Through the story of the O'Brien family, you will gain compassion and awareness for what it feels like to live with Huntington's. You can join Lisa Genova in putting that compassionate awareness into action.

By making a donation to Huntington's research, YOU can be part of the progress that will lead to a cure. Go to [www.lisagenova.com/donate-to-hdsa/](http://www.lisagenova.com/donate-to-hdsa/) to make a donation to Huntington's research.



**Advocacy Update**



On July 27th and 28th, members of HDSA's National Youth Alliance are flying to Washington, D.C. to storm Capitol Hill. They will spend two full days meeting with Members of Congress, asking for their support for the Huntington's Disease Parity Act (H.R. 842/S. 968). Even if you can't be there with them in Washington D.C., the NYA wants your voice to be heard! Just click below to fill out a form, and the NYA will hand deliver your message to your Members of Congress!

**HDSA MISSION**

The mission of HDSA is to improve 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.

**Definition:** HDSA advocacy works to advance legislation and policy to improve the lives of HD families by raising awareness about HD in the U.S. Congress, by promoting legislation, policy and regulations that would help individuals in the HD community, by educating Federal agencies about HD, and by partnering and collaborating with national organizations

that have common goals.

**Check out** <http://cqrcengage.com/hdsa/actioncenter> to see how you can help. This link takes you to facts you'll find helpful when contacting your representatives in Congress.

By the time this newsletter reaches you, we'll know how successful these

members of HDSA's National Youth Alliance were in their visits with Members of Congress on July 27 and 28, 2015. The NYA is comprised of young people between the ages of 9 and 29.

Keep a close eye on this outstanding group of dedicated young folks as they move mountains in their advocacy efforts in Washington, D.C. and beyond!

## Care for the Caregiver

by Mayo Clinic Staff

[www.mayoclinic.org](http://www.mayoclinic.org)

As the population ages, more caregiving is being provided by people who aren't health care professionals. These informal caregivers provide 80 percent of long-term care in the United States. A caregiver is anyone who provides help to another person in need, such as an ill spouse or partner, a disabled child, or an aging relative. However, family members who are actively caring for an older adult often don't self-identify as a "caregiver."

Recognizing this role can help caregivers receive the support they need.

### Caregiving is rewarding but stressful.

Caregiving can have many rewards. For most caregivers, being there when a loved one needs you is a core value and something you wish to provide. But a shift in roles and emotions is almost certain. It is natural to feel angry, frustrated, exhausted, alone or sad. Caregiver stress — the emotional and physical stress of caregiving — is common. People who experience caregiver stress can be vulnerable to changes in their own health.

### You aren't alone.

If you're like many caregivers, you have a hard time asking for help. Unfortunately, this attitude can lead to feeling isolated, frustrated and even depressed. Rather than struggling on your own, take advantage of local resources for caregivers. To get started, contact your local Area Agency on Aging (AAA) to learn about services in your community. You can find your local AAA online or in the government section of your telephone directory.

## Caregiver Burnout from Eileen Krueger, Social Worker

One of the sessions for the social workers at the past National Convention was on **Caregiver Burnout**. It is always good to be reminded and to get new information on this topic. We talked about the stress that is involved in caring for a family member and also extended caregivers.

When you ask the question about who are caregivers you get different answer from different perspectives. So let's think about caregivers who usually come to mind? Those caregivers that come to mind are the immediate family members caring for the person in the home. But what if we think about other people that are involved. The person with HD has siblings, so we think about them as part of this group. What about the children in the home? Then there are the extended family. Also the professionals involved like the doctor and specialists, the police officers that encounter the HD person, and other people in the community that encounter this person and family. Now that you are thinking differently about this you will think of a lot more people that are involved.

Well as a social worker, I think of how do we deal with and improve or find help for the families and the community dealing with the family and the person with HD?

Here's an idea --- Let others help you. For example, what happens when people ask what they can do to help? Most of us say, "**We are doing OK**". But are we really?

The thought that was presented was this: MAKE A LIST. Make a list you say. A list of what? The answer is what you need. This list can include, but is not limited to: Food brought to the house, take the person with HD on and outing if they will go, or come sit with the person so you can get out. Then there are things like mowing the lawn, putting in a ramp or other household changes that may help the family.

The most important thing I think to remember is how you feel when you help others or can do something for someone else. You feel pretty good. So let them feel good to help you. This can make a huge difference in your life and the life of the person you are caring for.

Another topic at the National Convention was the **LAW ENFORCEMENT TOOL KIT!**

The tool kit is actually two different pieces.

- The one piece is for the caregiver
- The second piece is for our local law enforcement agencies

The caregiver tool kit is meant to help families avoid some of the things that were happening to some of our HD people around the U.S. There is also an element of what to do when or if a person with HD does get incarcerated, or stopped by law enforcement.

The law enforcement tool kit was designed for the community to present to the local law enforcement centers as an education piece for the local police.

By taking this to your local station we are hoping to serve more than one purpose. The local police get to know that we have HD families out in the community and the police are being educated on how to handle an encounter with the HD person. They also get involved with the families usually as a secondary contact. One of the goals for HDSA is to educate, and that includes our communities. Please contact me if you would like the tool kits.

### **SCHWAN'S FUNDRAISING EVENT THROUGH DECEMBER 31<sup>ST</sup> 2015**

Now through December 31, 2015, Schwan's will continue to donate 5% of your purchases to our Sioux Valley HDSA Chapter. Here's how to place your order:

#### **Order Online:**

1. Go to [www.Schwans-Cares.com](http://www.Schwans-Cares.com)
2. Enter Campaign ID: **17851**
3. Click "Buy Now" button to purchase an eGift Card or "Shop Now" to place a product order.

**Order by Phone:** Call 1-855-870-7208 and provide Campaign ID: **17851**

### **CONGRATS TO THE SIOUX VALLEY HDSA CHAPTER!**

### **NATIONAL WINNER OF "THE BEST NEW FUNDRAISING EVENT" OF 2014!**

**The Event = Wine & Canvas \* Painting for a  
Cure \* held in Sioux Falls (December 2014)**



## **What can I do to help someone with Huntington's disease communicate?**

Although alternative methods of communication are available, people with HD generally prefer to attempt verbal communication for as long as possible, even if their speech becomes hard to understand. Family members and other communication partners can help by **encouraging the speaker to:**

- speak more slowly;
- say one word at a time;
- repeat the word or sentence when necessary;
- rephrase the sentence;
- exaggerate the sounds;
- speak louder (taking a deep breath before speaking);
- describe what he or she is trying to say if he or she can't think of the word or indicate the first letter of the word;
- use gestures;
- keep sentences short;
- use alternative techniques, such as word boards, alphabet boards, picture boards, or electronic devices.

The following are some suggestions for the listener:

- eliminate distractions (TV's, radio, large groups of people);
- keep questions/statements simple;
- ask one question at a time;
- use yes/no question format as much as possible;
- pay attention to gestures and facial expressions/changes;
- if you do not understand what is being said, don't pretend that you do; ask for clarification or repeat what you think was said in the form of a question, such as, "Did you say...?"
- try to keep to familiar topics;
- encourage the speaker to use his/her specific compensatory strategies;
- allow enough time for the person to convey his/her message;
- most important, be patient with the speaker.



**AMERICAN  
SPEECH-LANGUAGE-  
HEARING  
ASSOCIATION**

**Sioux Valley Chapter  
HDSA**

PO Box 2675  
Sioux Falls, SD  
57101-2675



**Resources**

**Social Worker  
Sioux Valley Chapter**

Eileen Krueger  
612-910-6651  
[ekrueger@hdsa.org](mailto:ekrueger@hdsa.org)

**Board President  
Sioux Valley Chapter**

Debbie Augustad  
612-816-0145  
[debstadley@gmail.com](mailto:debstadley@gmail.com)

**Sanford Huntington's  
Disease Clinic**

- Dr. Matos  
Neurologist
- Lior Borovik  
Genetics Counselor
- Nathan Anderson  
Social Worker
- Diane Johnson  
Mitchell – Family  
Therapist  
Sanford Health -  
Sioux Falls, SD  
605-312-1000

**NFC Update** from Margaret Geertsema, Chapter Vice President

At the National Convention held in Dallas in late June, newly updated and consolidated agreements for Chapters and Affiliates were rolled out for first inspection and discussion at the Leadership Day training session. Basically, this is a “how-to” guide that lists what the chapter or affiliate can expect from HDSA, and what HDSA can expect from the chapter or affiliate. Sioux Valley’s Board of Directors will be reviewing this agreement over the next year as it becomes effective January 1, 2017. Changes can be scary – but our chapter is already doing most (if not all) of the things listed in the agreement. By delaying the implementation date to 2017, HDSA’s and the NFC’s intent is to provide adequate time for chapters or affiliates to become compliant.

As background for the new agreements, six volunteers from across the USA (of which I was one) served on HDSA’s Field Task Force (“FTF”) throughout 2014. We twice met in person and also held monthly telephone conference calls while we reviewed every document found in HDSA’s vast library – no matter which roll-out version those were. We also reviewed sample agreements adopted by several other similar non-profit organizations to look for ways HDSA’s documentation could become more concise and up-to-date. After reviewing all of this, the FTF merged all of HDSA’s common/still viable content into the new Chapter and Affiliate Agreements, deleted outdated materials/references and rewrote applicable new language into this one new agreement (well, technically two – one for chapters and one for affiliates). HDSA’s Board of Trustees met in 2013 and 2014 and adopted the recommendations made by the FTF, and the FTF was dissolved at the end of 2014.

Effective January 1, 2015, I was invited to serve a two-year term as a volunteer-to-volunteer for HDSA’s National Field Committee (“NFC”). There are currently eight NFC volunteers assigned to assist the current 54 chapters and affiliates. This role is intended to be a two-way street to brainstorm on how to find committee and board volunteers, new or successful fundraising ideas and to just generally be a support and sounding board. I am assigned to the five chapters and two affiliates in the Pacific Southwest Region (San Diego, Los Angeles, Orange County, Northern California, Arizona, Las Vegas and Utah). In addition, due to health issues another NFC volunteer is experiencing, I am also the temporary NFC volunteer for the Minnesota and Northern Plains (Grand Forks, ND) chapters and the Northern Prairie Affiliate in Fargo, ND. All contacts are made via email, Facebook or telephone. While at convention in Dallas, I was able to meet and visit with representatives from each of my assigned chapters or affiliates. It’s great to have a face to match to a name.

HDSA is always searching for new volunteers to serve on the NFC. If you have served in a leadership capacity in a chapter or affiliate and are interested in serving on the NFC, please contact me and I will pass along your interest to HDSA and to the NFC.