

# Spring Newsletter



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## Spring Seminar 2015

Come join us for an afternoon of great information and camaraderie! Dr. Michael Kruer and team from our Sanford HD Clinic will be our featured speakers for our spring seminar event. Information about clinical trials, nutrition, where to find resources and advocacy!

Featured Speaker  
**Dr. Michael Kruer**  
 Neurologist  
 Sanford HD Clinic



**Saturday**  
**April 11, 2015**  
**12:30 to 4 PM**  
**Prairie West Library**  
**7630 W 26<sup>th</sup> Street**

## Sanford HD Clinic

Dear All,  
 The Sanford Huntington Disease Clinic has been hard at work since the last update, adding two new staff members to the clinic team, social worker Nate Anderson and family therapist Diane Johnson-Mitchell. Nate's presence in the clinic provides much-needed support to families and individuals navigating the often confusing landscape that encompasses insurance, disability, and social supports. Diane brings to the clinic a wealth of experience in counseling individuals and families

facing difficult or challenging circumstances. We are thrilled to have them join us.

In addition, just last month we learned that our application to the HDSA was accepted! The Sanford Huntington Disease Clinic is now an official satellite site of the Hennepin County HDSA Level I Center of Excellence directed by Dr. Martha Nance. Dr. Nance has been instrumental in helping us achieve this status. Our collaboration with Hennepin County will support specialized

training sessions for the Sioux Falls team to help deliver leading edge HD care throughout one's journey with HD. This status will also help boost the clinic as we seek to expand our services even further, adding more providers for comprehensive management and ultimately bringing clinical trials to the region.

We thank everyone for your support.

Warm wishes,  
 Michael Kruer, MD  
 Lior Borovik, CGC



**April Support Group Meeting**

**Saturday, April 11**  
**11am to noon**

Prairie West Library  
 (same location as seminar)

**Calendar of EVENTS****APRIL 11th**

Support Group Meeting  
Prairie West Library  
11am to Noon

Spring Seminar  
Prairie West Library Noon  
to 4pm

**MAY 2nd**

Team Hope Walk  
Sertoma Park  
9:30am Registration starts

**MAY 9th**

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

**JUNE 13th**

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

**JUNE 25th -27th**

National Convention in  
Dallas, TX

**JULY 11th**

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

**AUGUST 8th**

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

**SEPTEMBER 12th**

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

**SEPTEMBER 27th**

Fall Education Event at  
Sanford Health Auditorium

**OCTOBER 10th****NOVEMBER 14th****DECEMBER 12th**

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

**Team Hope Walk \* 5K \* 10K****Saturday, May 2, 2015****Sertoma Park**49<sup>th</sup> Street & Oxbow (Sioux Falls)

9:30 am Registration  
11:00 am Walk/Run Begins

Register at: [www.hdsa.org/thwsiouxvalley](http://www.hdsa.org/thwsiouxvalley)**For Information Contact:**

Debbie Stadley Augustad  
Call: 612-816-0145  
Email: [debstadley@gmail.com](mailto:debstadley@gmail.com)  
Visit: [www.hdsa.org/sv](http://www.hdsa.org/sv)

**Open to the  
Public...****Invite Friends!****Live Auction at NOON**

- *South Dakota Beef Package*
- *Restaurant Packages*
- *Canary Package*
- *Sioux Falls Zoo Package*
- *Grand Casino Package*
- *Barn wood Wine Rack with Wine*
- *Two Custom Bean Bag Toss Game*
- *Rock from Hard Rock Engraving*
- *& many more fabulous items!*

**SCHWAN'S FUNDRAISING  
EVENT THROUGH  
DECEMBER 31ST 2015**

Schwan's will donate 5% of  
your purchases to our Sioux  
Valley HDSA Chapter.

**Order on-line:**

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**

**Website \* FaceBook \* Social Media**

Visit our chapter HD website at: <http://www.hdsa.org/svch/index.html>.

It is updated at least monthly with upcoming events and notes of interest. Different information is found by clicking on a topic tab along the left side of the page. If there's a topic you'd like included, let us know. Our current and 2014 newsletters can be viewed on our website!

**The HDSA Sioux Valley Chapter South Dakota Facebook page** currently has 317 followers/likes – with lots of news ones just recently added (most likely due to the upcoming Team Hope Walk/Run). The page is updated frequently and contains lots of good HD info. Check it out soon! In the meantime, please do these two things TODAY:

1. "LIKE" our HDSA Sioux Valley Chapter South Dakota Facebook page!
2. Invite your ENTIRE "friend" base to also LIKE our Facebook page - even if they live across the US and they maybe are not your "BEST" friend – do it anyway!

## Greetings from Nate Anderson, Social Worker

Greetings! I am writing to introduce myself to the HDSA membership and their supporters. My name is Nathan "Nate" Anderson, a social worker with the Huntington's Disease Clinic at Sanford Health in Sioux Falls. I am proud to be working as a part of this team. This role in neurology is just one of many at "The Castle" where I serve outpatients in every specialty area. Broadly, I help patients and their families to connect with resources to meet needs. This can include emotional support, dealing with systems and bureaucracies, advocacy and self-advocacy efforts, strategizing and

prioritizing, coping with difficulties, caring for the caregiver, and referral to other sources of assistance.

My background includes a BA degree in social work and an MA in education from Augustana College, 21 years of employment at Children's Care Hospital & School (now LifeScape), 7 years at South Dakota Parent Connection (the statewide parent training & information center regarding children & youth with special needs of all kinds ages 0-26), and now 2 years at Sanford. Along the way, my wife and I shared our home for 33 years with dozens of foster children with a variety of special needs.

So much for the professional side of things... you also deserve to know a bit of my personal self. My family includes my wife, 4 adult children, 4 grandchildren, and elderly parents with rapidly advancing medical issues and physical limitations. My biggest interest outside of home and family and work is making music with guitar, harmonica, and voice.

It has been a pleasure to get to know several HD families, both in the clinic setting and at meetings of the Sioux Valley HDSA chapter, and it will be great to connect with more and more as time goes on.

## Faces of HD

As part of our annual May Awareness Month campaign we are featuring a new "Face of Huntington's" every day. The profiles will be posted on the HDSA website, on the HDSA Facebook Page, our chapter website, our chapter Facebook page and distributed via email daily.

In May we work to increase awareness of HD and HDSA to a wider audience, and explain why people outside the HD community should be interested and supportive of the work being done in HD research and care. There is nothing more compelling than hearing about an individual's or a family's struggle to face the challenges of HD on a daily basis. So please ask your friends and colleagues to visit this page daily or send them a copy of the email you receive. It will go a long way in convincing them that they should learn more, and hopefully become a volunteer or supporter with HDSA.

Our thanks to everyone who has volunteered to tell their story in this forum. And thank you for helping to bring Help for Today and Hope for Tomorrow to everyone affected by Huntington's disease.

If you would like to submit a story please send your story and a picture to [debstadley@gmail.com](mailto:debstadley@gmail.com).

## 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 Team Hope Walk, educational events or other fundraising events, please email:*

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

### May is HD Awareness Month


May is HD Awareness Month and a great time to educate people outside the HD community about Huntington's disease and how they can join us in our efforts to provide "Help for Today and Hope for Tomorrow" to everyone affected by HD.

## SAVE THE DATE


**MONDAY, MAY 4<sup>TH</sup> - 11am to 11pm!!**

Another "YUMMY" way to raise "dough" for our chapter! Dine at PizzaRev on May 4<sup>th</sup>. Present this coupon and/or mention our chapter! PizzaRev will donate 20% of the proceeds to our chapter! Enjoy!





**LETS RAISE SOME DOUGH!**



20% OF PURCHASES WILL SUPPORT

**Sioux Valley HDSA Fundraiser!**

**MONDAY, MAY 4 | 11:00 AM - 10:00 PM**

3901 W 49TH STREET SIOUX FALLS, SD  
(South Louise Ave in the Pier 1 Parking Lot)

Present this flyer or simply mention us at the register

## 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.*

*Quoting Jennifer Simpson, LMSW – Manager of Advocacy and Education, in HDSA's We Are HDSA! - Issue 1, Feb/Mar 2015:*

"We have had a monumental month for Advocacy at HDSA! On February 10, Representative Adam Kinzinger (R-IL) introduced the Huntington's Disease Parity Act of 2015 in the House of Representatives (H.R. 842). The bill was introduced with an astounding 103 bi-partisan original co-sponsors, representing 33 states as well as the District of Columbia. Over half of those original co-sponsors signed on to

the bill after hearing from our HD Advocates tell their stories. During the last Congress, it took almost two years to get as many sponsors as the H.R. 842 has gained in just one month.

The introduction of the Parity Act has created an enormous amount of momentum, and our next obstacle to tackle is the Senate. In order to really send the message to Congress that this is a common-sense bill for all Americans, we are looking for a Republican Senator to stand alongside our long-time champion Senator Gillibrand (D-NY) and introduce the Parity Act in the Senate. We have been meeting with

Senators Cassidy (R-LA) and Boozman (R-AR), but they need to hear from their constituents why they need to be the one to take action and stand up for HD families in the Senate....

If you are interested in getting involved in Advocacy, whether it's talking to a Senator or Representative, starting a local grassroots campaign, or even just writing a letter, call or email me at (212) 242-1968 x226 or [jsimpson@hdsa.org](mailto:jsimpson@hdsa.org) to find out how you can get involved."

## Advocacy Update

**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)

**HDSA Upper Midwest**  
**Regional Director**  
Shari Mathewson  
612-232-5238  
[smathewson@hdsa.org](mailto:smathewson@hdsa.org)

**Sanford Huntington's  
Disease Clinic**

- Dr. Krueger  
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

Being a brand-new volunteer on HDSA's National Field Committee, I'm still learning the ropes. There are eight of us NFC volunteers assigned to assist the current leaders of HDSA's 53 chapters and affiliates. As I understand my role, I will be a volunteer-to-volunteer resource person on this two-way street to discuss or suggest how to find committee and board volunteers, fundraising ideas and to just generally be a support and sounding-board for them. I have been assigned to the five chapters and two affiliates in the Pacific Southwest Region and will be visiting with those folks located in San Diego, Los Angeles, Orange County, Northern California, Arizona, Las Vegas and Utah. All contacts are made via email or telephone and we hope to meet as a region while at the upcoming HDSA convention in Dallas. From those leaders I've visited with, it's interesting to hear that the majority first volunteered to help with a local Team Hope Walk – which led to serving on the local board.

**Meal Tips** from Eileen Krueger, Chapter Social Worker

A member of our group has come up with a plan that helps their son's family with meal planning. The plan is that they get enough food containers for a month. They look for recipes that are high calorie meals that he enjoys to eat – different hot dishes, lasagnas, etc. They will cook and/or prepare the food together as a family. Place them in containers and then stack them in the freezer.....So when his family is not at home he does not have to prepare the meal --- all he needs to do is reheat in the microwave! Your family and or friends could do the same. Just get the reusable containers and have some fun cooking. If anyone else has useful tips to help let us know.

**30TH ANNUAL HDSA NATIONAL  
CONVENTION**

June 25-27th  
Hyatt Regency at Reunion in Dallas, TX

Registration, convention details and hotel  
information available at:  
[www.hdsa.org/convention](http://www.hdsa.org/convention)

**NATIONAL SCHOLARSHIPS** available through HDSA.

Lundbeck is sponsoring a scholarship for first time attendees. **April 10th is the deadline** for this scholarship. Go to [www.hdsa.org/convention](http://www.hdsa.org/convention) for details.

National Youth Alliance is also sponsoring scholarships. **April 3rd is the due date!** Go to [www.hdsa.org/convention](http://www.hdsa.org/convention) for details.