

Fall Newsletter



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*Help for Today.
Hope for Tomorrow.*

Fall Education Event & National Youth Alliance Event

SUNDAY, September 24, 2017

Time: Registration begins at 11:30am
Event runs from 12:00pm – 4:00pm

Location: Schroeder Auditorium / Sanford Medical Center
Grange & 18th / Sioux Falls, SD



Guest Speaker:

LOUISE VETTER

CEO & PRESIDENT OF HUNTINGTON'S
DISEASE SOCIETY OF AMERICA

Join us for an afternoon of great information and camaraderie!
Information about clinical trials, National Youth Alliance,
where to find resources, and advocacy!

Panel Discussion with USD Medical Students

MONDAY, September 25, 2017

Featured Speaker: Louise Vetter / Panel from HDSA – SD Chapter

Location: University of South Dakota Medical School
Vermillion, SD

#HDTips & Caregiver's Corner

THREE WAYS TO SUPPORT SOMEONE WITH HD!

Article taken from Caring Voice Coalition website:

www.caringvoice.org

Here are three ways to support someone with HD. To help you take part in the mission to bring awareness to Huntington's disease (HD) – here are some ways to support HD awareness and those who have HD.

1. Keep growing your friendship.

Let any people in your life impacted by HD know a diagnosis doesn't change your love for them by continuing to show up in the ways you always do – or even more!

Need some ideas?

- Make plans for the future. Go to the movies. Cook a meal. Call regularly to check in.
- Let them know you're always available to talk.
- Send them articles or videos that make you think of them.
- Ask them for advice.
- Join in during awareness efforts like races, fundraisers or social media campaigns.
- Spread the word, the mission and the HD story with your network of people.
- Stay hopeful and ask them how you can help!

2. Educate yourself.

One difficult thing about any chronic illness but especially HD is facing misperceptions about some of the disease's visible symptoms. By understanding as much as you can about the disease, you can avoid being accidentally hurtful.

Continued on page 3

We're not done yet...



Medicare Benefits

Medicare's two year waiting period is particularly devastating for people with HD. Once a person with HD is finally deemed eligible for SSD benefits, they are forced to wait two years to receive Medicare benefits. During the two-year wait, HD's destructive impact cognitively and physically robs the person of their ability to live independently.

The Huntington's Disease Parity

Act (H.R. 842/S. 968) will improve access to Social Security Disability benefits and Medicare coverage for individuals with Huntington's Disease (HD). The legislation will...

Waive the Medicare two year waiting period, thereby ensuring individuals receive critical health benefits and care in the early stages of the disease.

We can make a difference and "tell our story!"

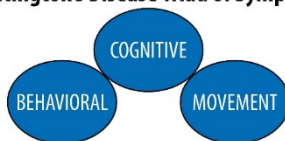
This is what we need to do...tell your Representative and Senators to work to Pass the Parity Act! To send a letter to your representatives and senators our story!

#HDTips COPING STRATEGY FOR APATHY

Do not interpret a lack of initiation or activity as "laziness." Educate family members and friends about the inability to "begin" or "initiate" behaviors and ask others to encourage participation in activities. Gently guide behaviors but respect "no."

 Huntington's Disease Society of America
Volunteer. Educate. Advocate. Donate.
HDSA.org (800)345-HDSA

#LetsTalkAboutHD Huntington's Disease Triad of Symptoms



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HDSA.org (800)345-HDSA

Continued from page 2

#HDTips & Caregiver's Corner

Learning more about HD goes a long way in showing your friend how much you care.

Here are some places to start:

- Huntington's Disease Society of America (HDSA) is the largest nonprofit providing resources, support and advocacy for HD. It's website is rich with resources explaining details of HD.
www.hdsa.org
- HD Buzz collects news articles written in plain English about advances in HD related medical developments.
- For the patient perspective, follow the HDSA #LetsTalkAboutHD campaign on social media. You will find many stories, photos and videos of people describing the impact HD has had on their lives.
- If books and movies are more your style, try these:
 - The Woman Who Walked into the Sea
 - Inside the O'Brien's
 - The Lion's Mouth Opens
 - Her Mother's Daughter

3. Spread the word.

Share the burden your friend and the HD community may feel to raise awareness and funds for HD. www.hdsa.org offers lots of opportunities to spread awareness, especially related to research, fundraising and advocacy.

Here are some ideas to spread awareness.

- Take part in the #LetsTalkAboutHD
- Share and follow The Guthrie Sessions at HDSA.
- Ask your friend how you can help inform others.
- If people ask questions about the illness, ask your friend if you can step in so he/she doesn't have to explain.
- **Be a volunteer for the South Dakota Chapter! Join the Board of Directors!**

Calendar of EVENTS

Sept 9

Support Group Meeting;
10am to Noon;
Callie Library

Sept 24

Fall Education Event
Sanford Health
Schroeder Auditorium
Louise Vetter, CEO of
HDSA, Featured
Speaker

Sept 25

Panel discussion at USD
Medical School;
Vermillion, SD

October 14

Support Group Meeting;
10am to Noon;
Callie Library

November 11

Support Group Meeting;
10am to Noon; check
website for location

December 9

Support Group Meeting;
10am to Noon; check
website for location

Website:

siouxvalley.hdsa.org/



- Interested in being on our Board of Directors?
- Want to join a Committee?
- Want to get more Involved?
- Want to make a Difference?
- Contact one of our board members ASAP!



HDSA Launches First-of-its-Kind Free Telehealth Counseling for HD Families

Announcing free online therapy sessions for people affected by HD provided by **HDSA** and **American Well®**, a leading telehealth company. HDSA-trained licensed social workers and psychologists will be available to HD families in all 50 states.

To utilize HDSA's free telehealth portal, visit www.hdsa.amwell.com or download the free Amwell® app and use the codes **HDSA** or **HD** to access the Huntington's disease practice.

[CLICK HERE TO LEARN MORE](#)



Huntington's Disease
Society of America



FUNDING FOR THIS PROGRAM IS
PROVIDED BY A GENEROUS GRANT
FROM TEVA PHARMACEUTICALS.

Stay Connected

Website: siouxvalley.hdsa.org/

Watch your email for updates
regarding:

Support Group
Education Events
Amayllis Event
and much, much more!

Find us on FB!

Introducing HDNAVIGATOR! HDSA has an App!

The HDNavigator is a FREE mobile app created by the Huntington's disease Society of America. It is a FREE download by searching "HDNavigator" or "HDSA" in #itunes or #GooglePlay

The app was created to be a collection of useful tools and resources for all members of the HD Community. The app is available by the generous funding of Lundbeck Pharmaceuticals.



My Profile and Notes



Communication Board



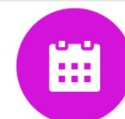
My Life Reminders



Locate Resources



Peer Connectors



Events, Apps & Links

#LetsTalkAboutHD



Symptoms usually appear between the ages of 30-50, and worsen over a 10-25 year period. Over time, HD affects the person's ability to reason, walk & speak.

There is no cure - Yet.



Huntington's Disease
Society of America
Volunteer. Educate. Advocate. Donate.
HDSA.org (800) 345-HDSA

Donations

Donations are being accepted until December 31, 2017 for **Team Hope Walk 2017** via the donor drive site: www.hdsa.org/thwsouthdakota or by sending to: PO Box 2675; Sioux Falls, SD 57101-2675. Reference Team Hope Walk.





South Dakota Chapter receives National Recognition!

The South Dakota Chapter was awarded the 2016 **Chapter of the Year** at the 32nd Annual National Convention in Schaumburg, IL. This is the most prestigious award that a chapter/affiliate can receive. There are 54 chapters and affiliates in the United States. The Chapter/Affiliate that works for the mission of HDSA through family service, education programs, advocacy, fundraising, communication and board development. One chapter and one affiliate is awarded this award at the annual National Convention.

In addition, the South Dakota Chapter was awarded the **2016 Outstanding Board Development Award**.

Dani Bergey, of South Dakota, recipient of the Donald A. King Fellowship

A South Dakota high school graduate, Dani Bergey, was awarded the 2016 HDSA Donald A. King Summer Research Fellowship. Dani grew up in Spearfish, SD and attended Spearfish High School until graduating in 2011. Throughout high school, she played four years of varsity soccer and was involved in many school activities including the debate team, student council, and math and art clubs. In college, Dani started up the first women's club soccer team at Montana State University and continued her interests in the arts in extracurricular activities. She graduated in 2015 with B.S. in Cell Biology & Neuroscience along with completing a minor in mathematics.

After college, Dani began working as a research associate at the Institute for Systems Biology in Seattle, WA. She worked in the labs of Dr. Nathan Price and Dr. Lee Hood where researched neurodegenerative disorders including HD. With the funding from the Donald A. King fellowship, Dani was able to pursue valuable training in programming and statistical modeling within the context of HD. Under the mentorship of Dr. Price and Dr. Seth Ament, she used RNA-sequencing data from a mouse model of HD to characterize gene expression changes across brain regions and cell types throughout disease progression.

Outside of science, Dani is a soccer enthusiast and an artist. This past year, she illustrated a mini textbook for a health sciences program called BioScience Montana, with topics spanning neuroscience, metabolomics, and infectious diseases. She has recently moved to Chicago, IL where she will begin an M.S. degree in Biomedical Visualization this fall - a program that will play well off her artistic and scientific interests. She wishes to work in the field of HD after completing her degree, in order to help communicate the science to patients and other HD and neurodegenerative disease researchers.

About the Award

The annual HDSA Donald A. King Summer Research Fellowship for the year of 2016 was comprised of a small summer grant gifted to three young researchers in the field of HD. The purpose of the program is both to attract young scientists to HD research and to contribute to the growing HD literature in order to understand pathology.

<http://hdsa.org/hd-research/the-donald-a-king-summer-research-fellowship/>

Dani's Summer Project

The type of cells that undergo the most dramatic degeneration in HD are neurons that reside in the striatum. Her results support the notion that along with neurons, glial cells hold an important role during disease progression. In particular, she found a specific group of cells that undergo significant gene expression changes in the same time frame as striatal neurons. This trend is not limited to the striatum, but also occurs dramatically in the cortex. Her summer research contributes to understanding the unique responses of various cell types and tissues to the mutant Huntingtin protein.

What Is Huntington's Disease?

Huntington's disease is a fatal genetic disorder that causes the progressive breakdown of nerve cells in the brain.

HD deteriorates a person's physical and mental abilities usually during their prime working years and has no cure.

Every child of a parent with HD has a 50/50 chance of carrying the faulty gene that causes Huntington's disease.

Today, there are 30,000 symptomatic Americans and more than 200,000 at-risk of inheriting the disease.

In approximately 10% of cases, Juvenile Huntington's disease (JHD) affects children or adolescents. JHD typically progresses more rapidly than adult onset HD.

The symptoms of HD are described as having ALS, Parkinson's & Alzheimer's diseases - simultaneously.



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*Help for Today,
Hope for Tomorrow.*

Board Member Feature:

Cindy Trager



Family: Husband of 26 years: Kevin

Occupation: Dispatcher at K & J Trucking, Inc.

How long have you served on the HDSA South Dakota Chapter Board? 12 years

HDSA South Dakota Chapter Board positions held or Committees served: Secretary, Nomination Committee, Team Hope Walk Chairman, and Fundraising.

Why did you choose to be part of the Board? To make people aware of Huntington's Disease and how it effects the person and their family members. I lost my grandmother, an uncle and aunt and my father to HD. My brother and cousins are currently struggling with the disease so I am passionate about raising monies to find treatments and ultimately a cure.

Hobbies: I officiate High School and College Volleyball and if not on the court I love to be camping!!

Save the Date!

Join us for the **33rd Annual HDSA Convention** in the city of stars — Los Angeles, California — at the Los Angeles Airport Marriott.

June 7-9, 2018 / Los Angeles, CA

Stay tuned for more details at HDSA.org

HDSA LA
33RD ANNUAL CONVENTION
LOS ANGELES, CA
JUNE 7-9, 2018

**Never Give Up Hope
&**

**FIGHT
HARD**



**Huntington's Disease
Society of America**
Volunteer. Educate. Advocate. Donate.
HDSA.org (800)345-HDSA



3rd Annual Tee Off Fore HD Golf Event

What an amazing event! Seventeen teams of four attended the golf fundraiser at Spring Creek Golf Course in Harrisburg, SD on Saturday, August 26, 2017.

We raised \$14,145 for our HDSA Mission!





ABOUT HDSA

The Huntington's disease Society of America is the premier nonprofit 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 and hope for tomorrow for people with Huntington's disease and their families.

In a battle against Huntington's disease no one fights alone. At HDSA, family is everything!

HDSA's network of 54 chapters and affiliates, 41 HDSA Centers of Excellence, social workers and support groups provides a seamless connection for help, education and outreach to HD families and health care professionals across the United States.

MISSION

To Improve the lives of everyone affected by Huntington's disease and their families.

VISION

A world free of Huntington's disease

HDSA History

The organization was founded on September 18, 1967 by Margorie Guthrie, the wife and legendary folk singer Woody Guthrie. Woody died from HD complication on October 3, 1967 when he only 55 years old, but the Guthrie family legacy lives on at HDSA to this day.

Help for today. Hope for tomorrow.

FAMILY IS EVERYTHING!



On May 11, HDSA premiered the new documentary *Her Mother's Daughter* in New York City. The 32nd Annual National Convention attendees viewed it. This film was created by Rae Maxwell and produced by HDSA. It introduces the world to Kathi O'Donnell and shows the divesting impact that Huntington's disease (HD) and juvenile Huntington's disease (JHD) has had on the O'Donnell family. This is a powerful documentary of family, love and hope – across generations and against all odds. The South Dakota Chapter will be receiving a copy of the documentary soon. Tell us if you would like to see it!

Team Hope Walk / Run 2017

Team Hope Walk/Run 2017 was a great success! Thank you to our families, friends, sponsors and participants for their continued support! This was our HIGHEST VOLUME & BEST EVENT yet – revenue was \$40,445! Congratulations!



The 2018 Team Hope Walk will be our 10th Annual!!!

Would you like to be part of the planning committee? **YES!**

We would love your help to make the 2018 Team Hope Walk the best yet!

Contact a Board Member today to volunteer!

Board Member Feature:***Darwyn Sprik***

Family: Andrea (wife), Jenna (11), Jacob (7)

Occupation: Financial Advisor/Owner of Sprik Financial Group

How long have you served on the HDSA South Dakota Chapter Board? 3 years

HDSA South Dakota Chapter Board positions held or Committees served: Fundraising Committee to help organize events and promote/draw in sponsors for the events

Why did you choose to be part of the Board? I chose to be a part of the board to learn more about what Huntington's Disease was and see firsthand the impact of what this disease has on the family members and care takers. I have enjoyed being on the board and getting to know each board member and seeing the board tackle the various challenges that are always present with a board. There are many decisions that need to be made, but it seems as that the 3-legged goal has always remained:

1. Raise awareness to the public of what Huntington's is
2. Providing support to the families that are dealing with this disease
3. Raise funds for research so that someday a cure may be found

It has been a great learning experience and these are some truly great people to work with!

Hobbies: I enjoy spending time with my family – whether taking a vacation or two a year or chasing our kids around to a baseball, basketball or football game! I also really enjoy getting out on a golf course and enjoying time with friends – while trying score well! =)

HDSA's National Youth Alliance (NYA)

The NYA motivates youth to get involved in their local HDSA Chapters, Affiliates, and Support Groups in efforts through education, fundraising, advocacy and awareness for Huntington's disease.

The NYA is a collection of children, teens and young adults from across the country. We are made up of young women and men ages 9-29 that are impacted by Huntington's. The NYA is dedicated to our vision of being the last generation with Huntington's disease and as an essential part of the future of HDSA; we pride ourselves on our ability to persevere throughout the years. Since 2004, NYA has grown from a small group of kids to over 500 members!

It is our mission to not only support young people within the HD community, but also inspire the youth of HDSA to get involved in the battle against HD and be proactive in this fight.

The NYA is dedicated to making ours the last generation with Huntington's disease."

When is it Time for Nursing Home Placement?

Kari Plumtree, MSW
South Dakota Chapter Social Worker

Being a Social Worker for the Huntington's Disease Society of America, often I get asked "When is it time for nursing home placement?" Each case of course is different, but the answer is never clear. Here are a few things I recommend.

- Have a conversation with your loved ones, find out what they want.
- Look into the area you desire.
- Visit each facility and take a tour.
- Check into a long-term care policy, and what it will cover.
- Seek advice on financial planning (if desired) from a financial advisor or other trusted individuals.
- Narrow it down to a few facilities and if necessary get on a waiting list.

Making this decision is extremely hard and doing a few things before will help everyone with this transition. I am here to answer questions and assist in anyway, please give me a call at 605-261-5068.

South Dakota Chapter HDSA

PO Box 2675
Sioux Falls, SD
57101-2675
Phone # contacts below.



Resources

Social Worker
South Dakota Chapter
Kari Plumbtree
605-261-5068
kplumbtree@hdsa.org

Board President
South Dakota Chapter
Debbie Augustad
612-816-0145
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

South Dakota Chapter Board of Directors

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Gail Nash / 605-359-1545 / gail.nash63@gmail.com
Honorary Board Member – Kevin Sandbulte



AmazonSmile

Shop 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



HDSA MISSION

The mission of HDSA is to improve the lives of everyone affected by Huntington's disease.