

Spring Newsletter



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Super-Sized Support Group Meeting & National Youth Alliance Event

SATURDAY, APRIL 6, 2019

Time: 10:30am – 2:00pm

Location: Dow Rummel, Gathering Room
1321 W. Dow Rummel, Sioux Falls, SD

Join us for an event of great information and camaraderie!

Lunch will be served!

RSVP via email to Rebecca Donaldson
rdonaldson@hdsa.org

Featuring:

Diane Johnson Mitchell & Jaclyn Schaap – Sanford HD Clinic
Rebecca Donaldson – HDSA South Dakota Chapter Social Worker

NYA Event

Kaylee Dollerschell & Samantha McAllister – Augustana University

Watch your email for additional information!





Huntington's Disease Society of America South Dakota Chapter

TEAM HOPE WALK / 5K & 10K SERTOMA PARK

49th Street & Oxbow, Sioux Falls, SD

Saturday, May 4th, 2019

- Registration – 8am
- 10K Start – 8:45am
- Walk / 5K Start – 9am
- Live Auction – 10:15am

Register by clicking here: <https://hdsa.org/thwsouthdakota>

BUILD YOUR FUNDRAISING TEAM – CREATE A FUN EVENT WITH YOUR FAMILY & FRIENDS!

TEAM AWARDS:

(These categories will include online & regular donations)

1. Team with the most participants registered
2. Top Team that raises the most money
3. Best Dressed / Costumed Team

New this Year... Raise \$1000 by Wed. May 1st and you will become a member of the "*Team Hope Inspiration Club!*" Your name will be announced at our walk, your name will be in the HDSA Team Hope E-Blast and HDSA will send you a special gift.

For Information:

Darwyn Sprik: 605-413-5808

Doreen Heikes: 605-201-7898

Debbie Stadley Augustad: 612-816-0145

Email: debstadley@gmail.com

Website: www.siouxvalley.hdsa.org



Caregiver and Social Work Corner

By Rebecca Donaldson, Chapter Social Worker

Caregiving can be a challenge. It is important to recognize how taking care of your self is essential as well! There are many resources out there ranging from HDSA to other organizations in your area. Depending on your location, caregivers may qualify for [Respite Care](#) to provide caregivers with temporary relief from caregiving. Active Generations in Sioux Falls offers a caregiving program to aid caregivers in dealing with stress. Although not HD specific, it can provide information and support for all caregivers. Please visit <http://caregiverssd.org/support-for-caregivers/stress-busting/> if you are interested!

For support, HDSA offers several different online support groups including caregivers, parent caregiver, at risk/not tested, and newly added 25-45 tested +/-no symptoms. These groups allow individuals to connect with others in specialized groups as well as connect with individuals across the nation. Please visit www.supportgroupcentral.com/hdsa.

Our SD Chapter continues to have monthly support groups in Sioux Falls the first Saturday of the month at Dow Rummel. If you are interested in attending these meetings live remotely, please contact me!

GREAT PLAINS RARE DISEASE SUMMIT

The Annual Great Plains Rare Disease Summit is on Saturday, May 10-11, 2019 at The Sanford Center in Sioux Falls, SD. Huntington's Disease will be the featured rare disease. Seth Rotberg will tell his HD story about his mom having HD and also being gene positive himself.

Our HDSA South Dakota Chapter will be present at the event with a table in the exhibit area. Friday, May 10th is targeted towards physicians, researchers and genetic counselors. The Saturday, May 11th session is focused on rare disease patients, their families and caregivers.

SAVE THE DATE
The Annual Great Plains Rare Disease Summit

May 10 - 11, 2019
Sanford Center, Sioux Falls, S.D.

Friday, May 10
Targeted towards physicians, researchers, scientists and genetic counselors

Saturday, May 11
Topics important to rare disease patients, their families, and caregivers.

CoRDS | SANFORD RESEARCH

Learn more at www.sanfordresearch.org/cords/events

Calendar of EVENTS

April 3

HDSA National Youth Alliance Convention Scholarships Due

April 6

Super-Sized Support Group Meeting /Spring Education Day
10:30am-2:00pm
Dow Rummel Gathering Rm

April 11

34th Annual HDSA Convention Scholarships Due

May 1

Team Hope Inspiration Club – Raise \$1000 by May 1. See page 2.

May 4

Team Hope Walk
8am Registration
8:45am 10K Run
9am Walk/5KRun
10:15 Live Auction
Sertoma Park

May 10-11

Great Plains Rare Disease Summit @ Sanford Center, Sioux Falls, SD

June 8

Support Group Meeting;
11am – 1pm
Dow Rummel

June 27-29

National Convention
Boston, MA

July 13

Support Group Meeting;
11am – 1pm
Dow Rummel

34rd Annual HDSA National Convention

June 27-29 * Boston, MA

Three days of education, family, fun and camaraderie!

Registration is OPEN! <https://hdsa.org/about-hdsa/annual-convention/>

Registration, convention details and hotel information available at www.hdsa.org.

Scholarship Information

The scholarship program is made possible by the generous support of Lundbeck.



- **National Convention Scholarship**

This scholarship is open to first time Convention attendees who are not residents of Massachusetts. Must be 18 years or older as of 1.1.19. Open to residents of US only. Massachusetts Residents - please see separate application.

- **Application Deadline**

Applications must be **received** no later than midnight, Wednesday, April 10, 2019. The application and all required signatures are to be mailed to:

Huntington's Disease Society of America
505 Eighth Avenue, Suite 902
New York, NY 10018
Attention: Robert Coffey

Applications may also be submitted via fax to 212-239-3430 or a scanned pdf may be emailed to rcoffey@hdsa.org. Applications may also be submitted online at www.hdsa.org/scholarship

<https://fs22.formsite.com/hdsa/dgfkjd3q7n/index.html>

- **National Youth Alliance (NYA) Scholarship**

The scholarship is open to any current or alumni member of the NYA who did **NOT** receive a scholarship in 2018. You must be a registered member of HDSA's NYA to apply. Membership information is available at www.nya.hdsa.org.

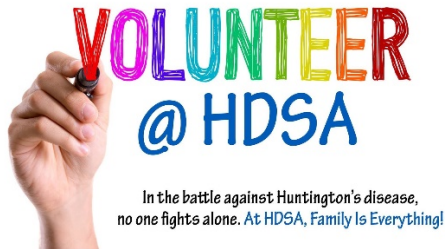
NYA alumni applications will receive full consideration from the Scholarship Committee. However, scholarships will only be awarded if funding is available after current NYA member scholarships have been awarded.

All Scholarship recipients are expected to attend NYA Day on Thursday, June 27, 2019 as well as all pertinent workshops and NYA activities during the course of the National Convention. You will also be required to volunteer either for silent auction preparation or at the NYA table during the Convention.

This fund was established to benefit all current members of the NYA and exists thanks to the support and generosity of families at the annual NYA Silent Auction and other events held at the annual HDSA National Convention, as well as fundraising efforts by NYA members throughout the year.

Applications must be received no later than midnight, Wednesday, April 3, 2019.

<https://fs22.formsite.com/hdsa/fwxdqsk4za/index.html>



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.

If you are interested in volunteering, please email either:

Brad Lingen
brad.lingen@gmail.com

Doreen Heickes
dmhoeck22@hotmail.com

HDSA MISSION

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

Healthcare Reform Can't Happen in the dark

Let Your Senator Know What HD Patients Need in Healthcare Reform

Tell your Senator that we need healthcare reform that works for families affected by Huntington's disease!



The *Huntington's Disease Parity Act* (H.R. 2589/S. 1197) will improve access to 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.
- Take Action Now!

Click below to take action and support the HD community!

[Your Senator Needs to Hear From You...](#)

<http://cqrcengage.com/hdsa/home?0>



THIS WEEK IN
HUNTINGTON'S
DISEASE
RESEARCH
WITH DR. LEORA FOX

Keeping you up-to-date on HDSA research activities, recently published work about Huntington's disease, historical moments in HD research and more.

Check out:

- <https://hdbuzz.net>
- <https://hdsa.org/blog/>

Stay up-to-date on the latest HD research! Dr. Leora Fox is the Manager of Mission and Research Programs at HDSA. Dr. Fox writes a weekly blog about HD research for everyone to understand. Also check out HDBuzz! HDBuzz is a website about HD research. In plain language. Written by scientists. For the global HD community.



NATIONAL YOUTH ALLIANCE (NYA)

There are four NYA Retreats planned for 2019! All of the retreats are free with the proper registration.

- Pittsburgh (April 19-21)
- Chicago (Early August, date TBD)
- New Orleans (Late September, date TBD)
- Sacramento (November 8-10)

What happens at an HDSA National Youth Alliance (NYA) Youth Retreat?

- Incredible opportunities to learn, bond and meet other young people who are affected by Huntington's disease.
- Educational sessions led by professionals on topics that are important to youth affected by HD.
- Fun activities and games!

Who can attend?

- Young people aged 12-29 whose lives are touched by Huntington's disease.

Do youth under 18 have to be accompanied by an adult?

- Yes! If you are under 18, you need to be accompanied by a parent, legal guardian or older sibling who is over the age of 22.

How much does the Youth Retreat cost?

- Nothing! It's free! There is no registration cost or attendance fee thanks to a generous educational grant from Teva Pharmaceuticals.
- The NYA is also providing transportation reimbursement up to \$350 for attendees! Reimbursement rates vary depending on accessibility. Reimbursements can be provided for airfare, gas or train fare. Airfare and train fare reimbursed for coach class tickets only.

What if I live far away?

- Not a problem! HDSA has hotel rooms reserved for youth and their parents who have to travel to attend the Retreat.
- The cost of hotel rooms (including taxes) are paid for by HDSA

<https://fs22.formsite.com/hdsa/NYA2019/index.html>



HDYO – HUNTINGTON'S DISEASE YOUTH ORGANIZATION

The 2019 North American Youth Camp has been set for August 11-15, 2019 in Julian, CA (just outside of San Diego).

- Camp is FREE to attend. HDYO covers cost of flights and camp
- Anyone between the ages of 15-23 can apply (if you know of young people just outside that range give me a shout and we can discuss their particular circumstances)
- Camp is for young people at-risk, tested (both negative or positive), a caregiver or not-at-risk family member. We can also take young people in the early states of JHD on a case-by-case basis.

<https://en.hdyo.org/eve/events/584>

Applications will close on April 30, 2019. Space for about 45 campers this year.

Calendar of EVENTS

Continued.....

August 3

Support Group Meeting;
11am – 1pm
Dow Rummel

August 24

TEE OFF FORE HD
Spring Creek Golf Course
Harrisburg, SD

September 7

Support Group Meeting;
11am – 1pm
Dow Rummel

September 23-24

Fall Education Event
Schroeder Auditorium
Sanford Medical Center
Sioux Falls, SD

Panel Discussion at USD
Medical School
Vermillion, SD

AmazonSmile

Shop AmazonSmile and Amazon will make a donation to the Huntington’s Disease Society of America Sioux Valley Chapter (soon to be updated to South Dakota Chapter).

Up to 0.5% of your purchase will benefit HDSA.

www.smile.amazon.com



May is HD Awareness Month

May is HD Awareness Month and a great time to educate people outside the HD community about the disease and how they can join us in our efforts to provide “Help for Today and Hope for Tomorrow” to everyone affected by HD. Watch your emails for more information.



SAVE the DATE

5th ANNUAL TEE OFF FORE HD

Saturday, August 24, 2019
Spring Creek Golf Course



Stay Connected

Website: siouxvalley.hdsa.org

Watch your email for updates regarding:

- Team Hope Walk**
- Support Group**
- National Convention**
- Education Events**

and much, much more!

The Huntington's Disease Society of America

HDSA 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.

HDSA's network of chapters, affiliates, 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.

WHAT IS HUNTINGTON'S DISEASE?

HD 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.

Every child of a parent with HD has a 50/50 chance of inheriting the faulty gene.

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

There is no cure...yet.



CREATE for HD!

Cindy Trager has "created" a wrap-around event called CREATE for HD! This is the 3rd annual event that she has organized to generate dollars for her TEAM HOPE WALK team! This year, the CREATE for HD event was on Saturday, March 16th at JJ's Wine & Spirits!

The CREATE for HD event and "Team Cindy" raised about \$900.00 for the 11th annual TEAM HOPE WALK!

Don't forget the TEAM HOPE WALK/5K & 10K is on Saturday, May 4th at Sertoma Park in Sioux Falls, SD.

#HDTips

Climbing stairs is a task that can become difficult & dangerous for a person with Huntington's disease.

Caregivers can help by reminding to:

1. Stop & think about climbing the stairs.
2. Grab the handrail.
3. Go slowly.



Huntington's Disease Society of America
For more support & resources visit **HDSA.org**



South Dakota Chapter
HDSA
 PO Box 2675
 Sioux Falls, SD
 57101-2675
 Phone # contacts below.



South Dakota Chapter Board of Directors

President: Debbie Stadley Augustad / 612-816-0145 / debstadley@gmail.com
Treasurer: Doreen Heikes / 605-201-7898 / dmhoeck22@hotmail.com
Secretary: Brad Lingen / 701-640-8446 / brad.lingen@gmail.com
Michael Hight / 605-212-8645 / hightm@gmail.com
Cindy Trager / 605-941-3173 / cst6319@hotmail.com
Clint Jones / 816-262-6634 / wcyjones2@gmail.com
Mallory Kloucek / 605-380-8464 / mjflan2010@gmail.com
Honorary Board Member – Kevin Sandbulte

Resources

Social Worker
South Dakota Chapter
 Rebecca Donaldson
 605-214-8486
rdonaldson@hdsa.org

**Sanford Huntington's
 Disease Clinic**

- Dr. Matos
 Neurologist
- Lior Borovik
 Genetics Counselor
- Diane Johnson
 Mitchell – Family
 Therapist
 Sanford Health -
 Sioux Falls, SD
 605-312-3499

Content for the HDSA
 South Dakota Chapter
 Spring 2019 Newsletter
 was provided by
 Rebecca Donaldson,
 Becky Mutziger, Debbie
 Augustad and
www.hdsa.org.



March 25, 2019

HD Night at The Barrel House! Dine at the Barrel House in Sioux Falls, SD on March 25th. 10% of all sales on Monday, March 25th will be donated to our HDSA South Dakota Chapter. The Barrel House is located 4701 E. 54th Street – Sioux Falls, SD.



March 28, 2019

PizzaRev will be featuring our HDSA South Dakota Chapter on Thursday, March 28th. Mention our HD Chapter and 20% of those sales will be donated to our HDSA South Dakota Chapter. PizzaRev is located at 3901 W. 49th Street – Sioux Falls, SD.