

Fall Newsletter



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FALL EDUCATION EVENT and HDSA NATIONAL YOUTH ALLIANCE EVENT

SUNDAY, SEPTEMBER 22, 2019

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

DR. LEORA FOX

HUNTINGTON'S DISEASE SOCIETY OF AMERICA
MANAGER OF MISSION & RESEARCH PROGRAMS

HDSA National Youth Alliance

Come join us for an afternoon of great information and camaraderie!
Information about clinical trials, where to find resources, and advocacy!



See you on Sunday, September 22, 2019

Registration at 11:00 am

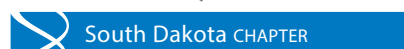
Education Event: 11:30 to 4:00 PM

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

There will be a special session for the youth about the HDSA National Youth Alliance!

All youth welcome – 9 to 29 years of age!

All youth affected by HD through families, friends, neighbors, etc. are invited to attend!



P.O. Box 2675 / Sioux Falls, SD
57101-2675

www.siouxvalley.hdsa.org

*Help for Today,
Hope for Tomorrow.*

PANEL DISCUSSION WITH USD MEDICAL STUDENTS

Featured Speaker – Dr. Leora Fox

Panel from HDSA – South Dakota Chapter

Monday, September 23, 2019

UNIVERSITY OF SOUTH DAKOTA – VERMILLION, SD

www.siouxvalley.hdsa.org

Find us on Facebook – HDSA South Dakota Chapter South Dakota

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

**Yet another Awesome Event!
\$16,500!**

5th Annual Tee Off Fore HD

Held in August at Spring Creek Golf Course
Harrisburg, SD

**A Huge Thank You to
our Golf Event
Sponsors, Players and
Volunteers!**



Check out:

<https://hdbuzz.net>

<https://hdsa.org/blog/>



**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.**

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.

Meet our new Social Worker

Hi, I am Michelle Wenge the new HDSA Chapter Social Worker in South Dakota who works with you and for you.

My life started here in Sioux Falls and I have lived a few different places in the country- Rhode Island, Oregon, Minnesota, and Florida before moving back here to live. My husband, Matt is also from here and we are caretakers for my mother who lives with us. We are also foster parents-who and how many children we have is an ever-changing number!! Lucy is our rescue cat, who used to be scared of everyone, but really is warming up to new people after 12 years of practice with us!

In addition to being your Social Worker, I am a therapist in the schools working with kids K-8th grade who have incarcerated love ones/care takers. This year, I will be in five different schools in the Sioux Falls School District. Speaking of school, I have a Masters degree in Social Work from the University of South Dakota and I am licensed in the State of South Dakota.

Fortunately, I attended convention this year shortly after being hired. I love, love, love that I saw "Family is Everything!" everywhere I looked. Family can also be chosen and I am so glad to be part of this one. I am a strong believer that ALL people matter and that our "system" has cracks that people fall through and that we ALL need support to get through this life.

I am looking forward to getting to know and meet you all.

My contact info is below:
Michelle Wenge, MSW, CSW
P: 605-214-8486
E: mwenge@hdsa.org

Love & Light, Michelle



CARE FOR THE CAREGIVER

Have you ever been told to make sure to practice self-care?

Anyone wondered what that meant and Googled it? I just did and about 3,680,000 results came up.

Self-care is important for everyone and sometimes caregivers have to be reminded to do it. A lot of people think of self-care as taking care of our external self- getting enough sleep, eating right, exercising, going to the spa, etc, etc.

Internal self-care is also very important and can sometimes be overlooked. Self-care is as simple as forgiving yourself for not getting it all done, or not getting it done exactly right. Consciously choosing to not beat yourself up and choosing to talk kindly to yourself about yourself is self-care.

Self-care can be trusting you did the best you could or trusting your instincts and the decisions you have made. Be good to you, you are the only you, you have.

Calendar of EVENTS

September 18

Founder's Day of Giving Campaign

September 22

Fall Education Event at Sanford Heath Schroeder Auditorium
Featured Speaker:
Dr. Leora Fox

September 23

Panel Discussion at USD Medical School
Vermillion, SD

October 1

Amaryllis Sales Begin.
Watch email for details.

October 5

Support Group Meeting;
11am – 1pm
Dow Rummel

November 2

Support Group Meeting;
11am – 1pm
Dow Rummel

December 3

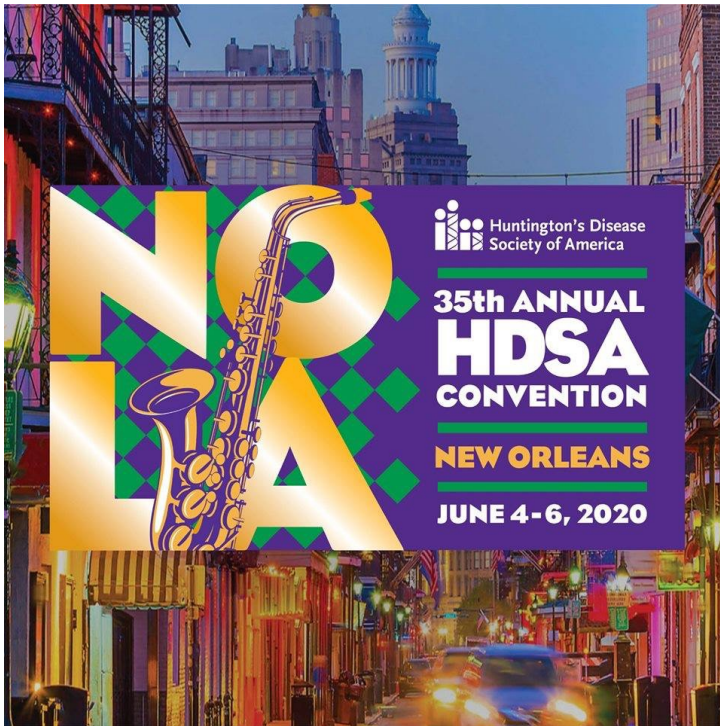
Giving Tuesday! South Dakota Day of Giving!

December 7

Support Group Meeting;
11am – 1pm
Dow Rummel

Cont. page

*Help for Today,
Hope for Tomorrow.*



Your Opportunity to Double Your Gift to HDSA

Many employers have matching gifts programs where the company will match the tax-deduction contributions you make to HDSA. Your gift doubles (or more) when your company belongs to HDSA's Matching Gift Program.

To make your gift to HDSA grow, just obtain a matching gift form from your company's Human Resources Department, enclose it with your gift to HDSA South Dakota and mail to:

HDSA South Dakota
PO Box 2675
Sioux Falls, SD 57101-2675

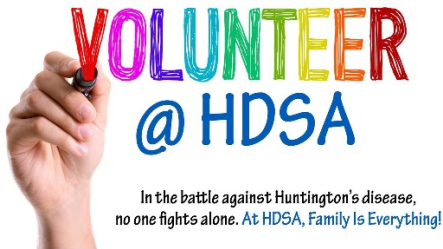
34th Annual National Convention in Boston, MA



What is Enroll-HD?

To develop better treatments for HD, we need to understand it better using observational studies of HD families. Enter Enroll-HD - a **worldwide observational study for Huntington's disease families**. Enroll-HD is sponsored by the CHDI foundation, a non-profit organization focused solely on speeding the development of new effective treatments for HD.





Get Involved

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 --- if interested in helping us execute our HDSA mission.

Please email either:

Brad Lingen
brad.lingen@gmail.com

Doreen Heickes
dmhoeck22@hotmail.com

if you would like to volunteer!

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 Members of Congress 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 2770/S. 1476) 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>

Pass the #HDParityAct

JOIN THE FIGHT @ HDSA.ORG/TAKEACTION

Louise Vetter

President & CEO
 Huntington's Disease Society of America



"The Huntington's Disease Parity Act is a crucial bill to improve the lives of everyone affected by HD and their families. Right now, HD families must wait two years to access Medicare benefits after being qualified as disabled. In two years with HD, an individual can go from being functional to completely bed-ridden and under 24-hour care. This is unacceptable and the bill MUST be passed."



NATIONAL YOUTH ALLIANCE (NYA)

There is one (1) NYA Retreat remaining for 2019! Retreats are free with the proper registration.

New Orleans September 27-29

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>

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.

Calendar of EVENTS*Continued.....***January 4**

Support Group Meeting;
11am – 1pm
Dow Rummel

February 1

Support Group Meeting;
11am – 1pm
Dow Rummel

March 7

Support Group Meeting;
11am – 1pm
Dow Rummel

April 4

Super-Sized Group
Meeting; Dow Rummel

May 2

12th Annual Team Hope
Walk/ Run Sertoma Park

May 9

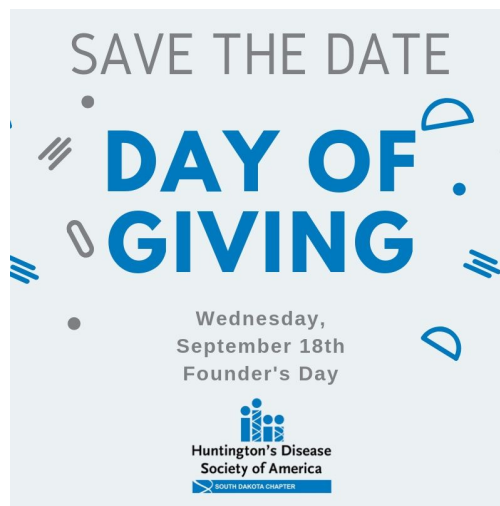
Support Group Meeting;
11am – 1pm
Dow Rummel

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

**Stay Connected**

Website: siouxvalley.hdsa.org

Watch your email for updates
regarding:

**Amaryllis Campaign
Support Group
Day of Giving
National Convention**

and much, much more!



HDSA SD Chapter is registered to be part of the South Dakota Gives campaign. Nonprofits and communities from across the state are uniting to celebrate generosity in the great state of South Dakota. Mark your calendars now for the South Dakota Day of Giving December 3, 2019.



**Huntington's Disease
Society of America
Free Online Support Groups**

Connect with other members of the
Huntington's disease community to help
navigate you and your family's journey with HD.

For more info visit
HDSA.org/osg

ONLINE SUPPORT GROUPS

The Huntington's Disease Society of America provides FREE, professionally-run Online Support Groups for you to get the help you need from the comfort of your home.

Go to <https://www.supportgroupcentral.com> for the full schedule and to register.

HDSA & CHDI FOUNDATION LAUNCH HD LEGACY TO PROMOTE BRAIN DONATION AND HD RESEARCH

(published on www.hdsa.org)

In response to a growing need to study exactly what Huntington's disease (HD) does to the human brain, the Huntington's Disease Society of America (HDSA) and CHDI Foundation are pleased to announce a new collaboration called HD LEGACY to support brain and other organ donations from families affected by HD who would like to make a vital contribution to research.



This new program encourages the donation of brain and other tissues from HD gene-expansion carriers, at-risk individuals, and healthy family controls. The Harvard Brain Tissue Resource Center (HBTRC) will assist interested families throughout the process, and families will bear no costs associated with the donation. To learn more you can call the HBTRC at 1-800-272-4622, visit <https://hbtrc.mclean.harvard.edu/donate/>

"The decision to donate one's body to science is an amazingly selfless act," said Louise Vetter, President and CEO at HDSA. "Participating in HD LEGACY is truly a gift for future generations. The brains and other organs donated through this program will leave a 'legacy' of hope, inspiring new knowledge that will someday stop HD in its tracks."

"Science still has a quite rudimentary understanding of how the human brain works," said Robi Blumenstein, President of CHDI Management, Inc. "Researchers need more brain donations from HD-affected individuals to better understand how HD affects the human brain, what happens to the different cell types and circuits that make up the brain over time. HD LEGACY will give us new insight into how to intervene therapeutically."

Sabina Berretta, MD, Director of the HBTRC added "As an investigator on the pathophysiology of brain disorders, I am infinitely grateful to all brain donors and their families for the precious gift they entrust to us. A brain donation truly is a 'gift of knowledge' to the research community and, more broadly, to our society. Investigations on the human brain open a unique window into the changes that occur at the cellular and molecular level, which is an essential step toward effective therapeutic interventions. The HBTRC is proud to partner with CHDI and HDSA to support tissue donations from families affected by HD".

Continued on next page....

**Here's
the Deal**

HDSA's new interactive conversation series, **Here's the Deal**, tackles important topics to help you navigate through your HD journey. Episodes will air on [HDSA's YouTube channel](#) and will

include discussions about isolation, testing, relationships, family planning & much more.

Hosted by HDSA's Jennifer Simpson, **Here's the Deal** allows members of the HD community to submit questions & some will be featured in the upcoming episode.



Huntington's Disease
Society of America

HD Trialfinder

The only way to fill this bottle with a treatment for **Huntington's disease** is if families enroll in clinical trials.

Please visit
www.HDTrialFinder.org
to enroll in a trial near you.

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



Resources

Social Worker
South Dakota Chapter
Michelle Wenge
605-214-8486
mwenge@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
Fall 2019 Newsletter
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South Dakota Chapter Board of Directors

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Jay Waagmeester / 712-470-0504 / jwaagmee@centrallyon.org

Honoray Board Member – Kevin Sandbulte

Continued from page 8....

HD is a fatal genetic disorder that causes the progressive breakdown of nerve cells in the brain. It deteriorates a person's physical and mental abilities during their prime working years and has no cure. Each child of a parent with HD has a 50/50 chance of inheriting the faulty gene that causes HD. Today, there are over 33,000 symptomatic Americans and more than 200,000 at-risk of inheriting the disease. The symptoms of HD are sometimes described as having ALS, Parkinson's and Alzheimer's – **simultaneously.**

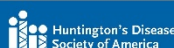
The decision to participate in HD LEGACY is an intensely personal one. All discussions with the Harvard Brain Tissue Resource Center are strictly confidential and registration in the program is non-binding.

#HDTips

There are many simple changes and modifications that can be made in the home to increase safety and comfort for the person with HD.

In the Bathroom

- Put a non-skid mat in the tub or shower
- Change to 'soap on a rope' or a wall mounted soap dispenser
- Get a shower bench or chair
- Install safety bars



For more support & resources visit
HDSA.org

#HDTips: INFORMING THE SCHOOL

The school is the center of your child's day and the people who work there care about your child. Informing a few people at the school about the diagnosis of HD in the family will help to create a supportive and understanding atmosphere for your child.



FOR MORE RESOURCES VISIT
HDSA.ORG