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!

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

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/

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.

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.
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

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

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.
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

HDSA MISSION

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


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.

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/.

“There is a 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”.

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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.
South Dakota Chapter Board of Directors

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Honorary Board Member – Kevin Sandbulte

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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.