

Fall Newsletter



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FALL EDUCATION EVENT & HDSA NATIONAL YOUTH ALLIANCE EVENT

SUNDAY, SEPTEMBER 23rd, 2018

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

DR. GEORGE YOHLING

HUNTINGTON'S DISEASE SOCIETY OF AMERICA
SENIOR DIRECTOR MISSION & SCIENTIFIC AFFAIRS

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 23, 2018

Registration at 11:30 am

Education Event: Noon 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. George Yohrling

Panel from HDSA – South Dakota Chapter

Monday, September 24TH

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 Teva.



South Dakota Chapter HDSA /
P.O. Box 2675 / Sioux Falls, SD
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www.siouxvalley.hdsa.org

*Help for Today.
Hope for Tomorrow.*



HDSA SD Chapter is registered to be part of the first ever 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 on #GivingTuesday, November 27, 2018.

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

TEAM HOPE WALK/RUN

Our 2018 Team Hope Walk/Run was a success! Thank you to our families, friends, sponsors and participants for your continued support! Over \$45,000 was raised to support the mission.

A Special Thank You to the generous Team Hope Walk Run Sponsors below:



Mission Statement

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

Vision

A world free of Huntington's disease.



Gold Sponsors		
First PREMIER Bank	PREMIER Bankcard	
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Event Sponsors		
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Roche huntingtin-lowering drug gains PRIME Status from EMA

Posted on August 7, 2018 by Dr. Leora Fox

On August 4th, Roche Pharmaceuticals announced that their huntingtin-lowering therapy [was granted PRIME status](#) from the European Medicines Agency (EMA). The EMA is the European equivalent of the United States Food and Drug Administration (FDA). In Europe, PRIME ([PRiority MEDicines](#)) designation means that the EMA has agreed that this drug, RG6042 ([formerly IONIS-HTTRx](#)) could potentially fill an urgent need to combat HD. For this reason, the EMA will make it a priority to evaluate any future clinical findings at a faster rate.

PRIME status does not mean that the drug is now available to the public. But it's exciting nonetheless – it's a commitment from the EMA to prioritize HD. This means that the clinical trial approvals and eventual data review will move faster, once there is more information on effectiveness in humans. The Phase III trial of this drug will take place as planned, and we are cautiously optimistic that it will begin by the end of the year, in both Europe and the USA. HDSA still does not have information about what exactly the trial will look like, including specific sites and timing, but we will continue to work closely with Roche to share any information across our networks as it becomes available.

#HDTips

WAYS TO KEEP YOUR BRAIN IN SHAPE

EAT A HEALTHY DIET

STAY PHYSICALLY ACTIVE

TRY PUZZLES

READ A BOOK OR MAGAZINE

STAY SOCIALLY ACTIVE



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Society of America

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HDSA.org (800) 345-HDSA

Calendar of EVENTS

September 8

Support Group Meeting
11am to 1pm
Dow Rummel

September 23

Fall Education Event at
Sanford Heath Schroeder
Auditorium
Featured Speaker:
Dr. George Yohrling

September 24

Panel Discussion at USD
Medical School
Vermillion, SD

October 6

Support Group Meeting;
11am – 1pm
Dow Rummel

November 3

Support Group Meeting;
11am – 1pm
Dow Rummel

December 1

Support Group Meeting;
11am – 1pm
Dow Rummel

Website:

siouxvalley.hdsa.org/

ME
WE

Family is everything.



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HDSA's National Youth Alliance (NYA)

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.

The NYA provides a wide variety of ways for the youth of HDSA to become motivated:

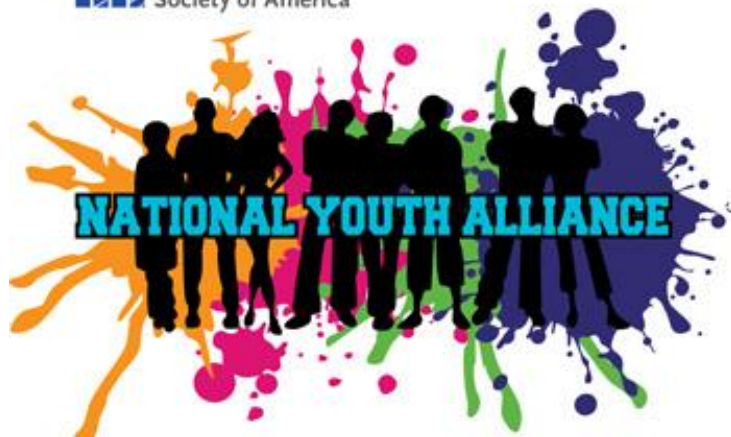
- By increasing the amount of local youth support groups nationwide we are able to ensure our members are getting the support they need locally
- Educating the youth at Education Days, Symposiums and Conferences locally as well as on the national level at NYA Day and Convention
- Advocacy training and proactive efforts from meetings with the Senate and Congress at home to Capitol Hill in Washington D.C.
- Fundraising for our NYA Convention Scholarship Fund
- Providing updates on NYA activities, initiatives, and fundraising efforts in the We Are the NYA newsletter

Sharing the experiences and observations of young people from all walks of life affected by Huntington's disease through our website's Faces of NYA section.



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.



#HDTips

Managing Caregiver Stress...You might try:

- ◆ Prioritizing & making lists.
- ◆ Establishing a daily/weekly routine.
- ◆ Identifying specific things that trigger outbursts in your loved one & work to reduce them.
- ◆ Asking for help from friends, family & community.
 - ◆ Learning about caregiving resources.
 - ◆ Being kinder to yourself.





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 on a committee, at an event, or serving on our chapter board, please email one of our current board members. Contact information on last page.



Huntington's Disease Parity Act

The HD Community had a huge win with the recent updates to the Social Security Disability guidelines for Huntington's disease. But, we still have to wait two years to access Medicare.

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.

Take Action Now!

[Get Ready to Rock the Vote!](#)

Make sure your voice is heard this November by registering to vote!

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

Send your Senator a message to co-sponsor S 1197 Today!

[Your Representative Needs to Know...](#)

Don't Wait Another Day! Join the Fight Today To Pass the HD Parity Act!



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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#HDTips

Why Join an HDSA Support Group?

- ⇒ Connect with others who understand your journey
- ⇒ Build relationships with people that can help
- ⇒ Hear the experiences of others even if you are not feeling quite ready to share your own
- ⇒ Add to the support you may already receive
- ⇒ Seeking support is not a weakness



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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.

Prenatal Testing

For families wishing to have a child who does not have the gene that causes HD, there are a few options. Pre-genetic diagnostic (PGD) testing can be used with In Vitro Fertilization (IVF) to make sure that any fertilized egg implanted does not have the abnormal gene. This can be done without informing the at-risk patient whether or not they have the gene that causes HD. If a woman is already pregnant, she can receive testing for the fetus with a chorionic villus biopsy at 10-11 weeks or via amniocentesis at 14-18 weeks.

*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.

OUTSTANDING BOARD DEVELOPMENT AWARD – SOUTH DAKOTA CHAPTER

The South Dakota Chapter was awarded the 2017 Chapter of the Year at the 33rd Annual National Convention in Los Angeles, CA. There are 54 chapters and affiliates in the United States.



4th Annual Tee Off Fore HD Golf Event

Saturday, August 25th at Spring Creek Golf Course
Harrisburg, SD.

We had a great day on the course! Awareness was built amongst our golfers and we raised \$15,000 to help support our HD mission.

A Huge Thank You to
our Golf Event
Sponsors:

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SILVER SPONSORS



Thank you to all our great sponsors!



Social Work/Caregiver Corner

By: Rebecca Donaldson, Chapter Social Worker

It is hard to believe that I have been the HDSA South Dakota Chapter Social Worker for 6 months! It has been wonderful getting to know many of you, and I look forward to continue working with the HD community. In this newsletter, I wanted to highlight our monthly support group and briefly discuss the benefits support groups can have on families, caregivers and individuals with HD. Not only are support groups utilized to receive support from others, groups provide updates, learning opportunities and provide a safe space to both feel and heal. *"Caregiving for people with neurodegenerative disease (e.g. Alzheimer's disease (AD); frontotemporal dementia (FTD)) is provided primarily by the family care system"*. HD is also another neurodegenerative disease that often has a large family care system. Support groups allow caregivers the opportunity to discuss their personal experience while also learning from other's experiences. By having a family care system, caregivers are not alone in benefiting from support groups. Family members close to the family, family friends, and individuals with HD also benefit by taking what they need from the group and leaving the rest. Each person has a different role and may require various needs from the group, but the beauty of support groups is that all of these needs can be met. If you have any questions, concerns or want to know more about the benefits of support groups, please reach out to me!

Most of you are aware that the SD Chapter support group meets the 1st Saturday of the month at Dow Rummel in Sioux Falls. All are welcome! As we move into Fall and Winter, weather is often a barrier to attending groups. I am currently working on a way to accomplish live video chat during our support group meetings. This will allow those who come from out of town the opportunity to participate if they are not able to attend the meeting in person. This allows connection with others on a local level. In addition to our monthly support group, HDSA offers several different online support groups including caregivers, parent caregiver, at risk/not tested, and newly added 25-45 tested +/-no symptoms. These online groups utilize video and audio with the option to turn either off during the group. You are also not required to use your real name if you prefer anonymity. 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 if you are interested in participating. I look forward to seeing many of you at future support group meetings!

Reference:

Thecla Damianakis, Kimberley Wilson & Elsa Marziali (2018) Family caregiver support groups: spiritual reflections' impact on stress management, *Aging & Mental Health*, 22:1, 70-76, DOI: [10.1080/13607863.2016.1231169](https://doi.org/10.1080/13607863.2016.1231169)

South Dakota Chapter HDSA

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Resources

Social Worker South Dakota Chapter

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Sanford Huntington's Disease Clinic

- Dr. Matos
Neurologist
- Lior Borovik
Genetics Counselor
- Diane Johnson
Mitchell – Family
Therapist
Sanford Health -
Sioux Falls, SD
605-312-1000



South Dakota Chapter Board of Directors

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Honorary Board Member – Kevin Sandbulte

**Mark Your
Calendars for
Convention
2019
June 27-29**



National Convention Los Angeles, CA June 2018

Pictured:
Debbie Augustad
(Past Chapter President & Board Member)
Becky Mutziger
(Chapter Co-President)
Rebecca Donaldson
(Chapter Social Worker)

