



HDSA Omaha Affiliate

Winter Newsletter

31 January 2019

Volume 1, Number 1

Calendar of Events *Save the Date!*

February 7, 2019

Support Group
6-7pm
Pathways to Compassion

March 14, 2019

Support Group
6-7pm
Pathways to Compassion

April 11, 2019

Support Group
6-7pm
Pathways to Compassion

April 27, 2019

Strike Out HD Bowling Event
1-3pm
Scorz Sports Center
<https://hdsa.donordrive.com/event/1615>

May is HD Awareness Month!

Check our [website](#) for a list of HD awareness activities going on throughout the month of May!

May 9, 2019

Support Group
6-7pm
Pathways to Compassion

May 17, 2019

UNMC's Annual Patient & Caregiver Symposium
8am – 12pm
Scott Conference Center at UNO
[Register online now](#)

First Patient Enrolled in Generation HD-1 Clinical Trial

Just over a month after releasing information on the locations chosen to participate in the Generation HD-1 clinical trial, Roche/Genentech announces the first patient has entered the study.

This pivotal, global Phase III study will investigate the efficacy and safety of RG6042 (formerly known as IONIS-HTT_{Rx}). This will be a 2-year study in people with early diagnosed HD. It will involve monthly lumbar punctures (spinal injections) to deliver RG6024 or a placebo, as well as clinical tests and scans to understand the effect of the drug on HD symptoms. If this clinical study is successful, it is the hope that RG6024 will be approved by health authorities and made available for the treatment of manifest Huntington's Disease.

Around 660 people ages 25-65 will be recruited at approximately 90 sites across the world, including 20 sites in the US and 6 in Canada. For a list of the sites and the complete update letter from the Roche & Genentech HD team, visit www.hdsa.org.

Join us at our monthly HD support group!



We are pleased to welcome Social Worker Cindy Schreiber as our new support group leader!

Cindy joins us with an extensive background in hospice care. She also has experience working with partial hospitalization programs. These consist of day-long group therapies, some educational and some support, this is where she fell in love with group settings. *"The benefit of being with others who are going through the same or similar struggles is immeasurable,"* Cindy says.

Currently Cindy works on the Psychiatric unit at Nebraska Medicine, which has allowed her to explore her passion for mental health. *"I lead group therapy daily. Our patients find comfort in shared experiences with others. I hope that my experience in medical social work and group therapy have adequately prepared me to lead your HDSA group, which I am privileged to be a part of."* - Cindy Schreiber, LSCW.

The Omaha HD support group meets the second Thursday of every month from 6-7pm at Pathways to Compassion; 287 N. 115th Street Omaha, NE 68154.



Visit our Website at
Omaha.hdsa.org

Board Members:

- Lindsay Rice
- Tiffany Burkholder
- Ann Wehner
- Nick & Carla Miller
- Noel Paventi
- Jason & Tina Sempeck

Contact us:
HDSA Omaha Affiliate
PO Box 27538
Omaha, NE 68127

Email:
Omaha@hdsavolunteer.org



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Mission Statement

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

*Help for Today,
Hope for Tomorrow.*

**34th Annual HDSA National Convention June 27-29th
in Boston, MA**



Registration is now open for the 34th annual HDSA Convention. Visit hdsa.org for and outline of the convention, registration information and instructions.

If this is your first time attending convention, consider applying for a national convention scholarship for a chance to be awarded a full or partial scholarship to attend this year's convention. Applications must be submitted no later than April 10, 2019. Visit hdsa.org to apply! This event is the highlight of the year for HD families, volunteers and HDSA staff. It is a wonderful three days of education, family, fun, and camaraderie!

HDSA Center of Excellence at Nebraska Medicine

We consider ourselves incredibly lucky to have one of the 43 HDSA Centers of Excellence right here in Omaha!

The center is composed of a multi-disciplinary team of specialists who collaboratively develop the best care plan for you or your loved one in all phases of the disease.

Center location: 4239 Farnam Street, Suite 105, Omaha, NE 68198
Phone for appts: 402-559-8600.

Clinic Coordinator: Regan Iske riske@nebraskamed.com



We are looking for volunteers to help carry out our awareness 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 – simply an interest in helping us execute our HDSA mission.

If you are interested in volunteering on a committee, at an event, or serving on our affiliate board, please contact, Lindsay Rice, at Omaha@hdsavolunteer.org