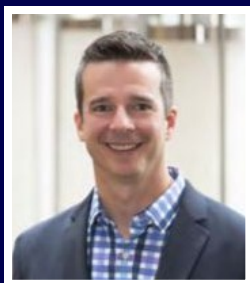


HDSA Minnesota Chapter Highlights

SPRING 2019

Research Report

by George Yohrling, Ph.D., HDSA's Senior Director of Mission and Scientific Affairs



Hope shines brighter than ever that future generations may one day be free of Huntington's disease.

It has shaped up to be a year unlike any other for the HD community. In 2018,

HDSA commemorated 50 years of service to the HD community and this year also marked the 25th anniversary of the identification of the huntingtin gene. The year culminated with the announcement from Roche/Genentech that the first ever Phase 3 clinical trial to test a huntingtin-lowering drug will begin in 2019 and will include sites in the U.S.

The study will be called the GENERATION-HDI study. The study name and Roche/Genentech team are inspired by HD families with the hope that "this will be the last generation to suffer" from the ravages of this hideous disease. News of this study has grabbed the attention of the global HD community. While the light of hope now shines brighter for all of us, we must not lose sight that much work remains before a finish line comes into sight.

GENERATION-HDI and other HD trials will be long and require an unprecedented amount of commitment from not only HD families, but also the clinic staff that will run these studies.

We know that the demand to participate in GENERATION-HDI will outpace available spots, and this will undoubtedly be devastating news to many families. However, we are fortunate that there are many other companies currently testing or making plans to test innovative HD treatments.

On December 19th, Roche/Genentech announced the US and Canadian locations for GENERATION-HDI to test efficacy of the huntingtin-lowering therapy RG6042. This will be a two-year study in people with early diagnosed HD. It will involve monthly lumbar punctures (spinal injections) to deliver RG6042 or a placebo, as well as clinical tests and scans to understand the effect of the drug on HD symptoms. Around 660 people age 25-65 will be recruited at approximately 90 sites across the world, including 20 sites in the U.S. (see list below) and six in Canada.

As I look back on 2018, I am overwhelmed by the progress that has been made by the HD research community. When the calendar turns to 2019, I know that the HD families around the world will be ready to answer the call for brave research volunteers to get these disease-modifying trials complete quickly. The scientific breakthroughs of this past year give me hope that 2019 will bring generations of HD families a step closer to seeing the finish line.

Thank you for all you do!

Help for Today.
Hope for Tomorrow.



HDSA is a national, voluntary health organization dedicated to improving the lives of people with Huntington's Disease and their families.

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Shopping on Amazon?

Use Amazon Smile to have part of your purchase come back to our chapter! Go to smile.amazon.com and search for HDSA MN Chapter or go to <https://smile.amazon.com/ch/41-1794522>

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Expected Sites for GENERATION-HDI Studies in the U.S.

ALABAMA, Birmingham
University of Alabama

ARIZONA, Phoenix
Barrow Neurological Clinic

CALIFORNIA, Davis
University of California, Davis

CALIFORNIA, Palo Alto
Stanford University

CALIFORNIA, Pasadena
Arcadia Neurology Center

CALIFORNIA, San Diego
University of California, San Diego

COLORADO, Englewood
Rocky Mountain Movement Disorders Center

FLORIDA, Tampa
University of South Florida

ILLINOIS, Chicago
Northwestern University

MARYLAND, Baltimore
John Hopkins University

MASSACHUSETTS, Boston
Beth Israel Deaconess Medical Center

MISSOURI, St. Louis
Washington University

NEW YORK, Amherst
Dent Institute

NEW YORK, New York
Columbia University

PENNSYLVANIA, Pittsburgh
University of Pittsburgh Medical Center

TENNESSEE, Nashville
Vanderbilt University Medical Center

TEXAS, Houston
University of Texas Health Science Center

UTAH, Salt Lake City
University of Utah

WASHINGTON, Kirkland
Evergreen Health

WASHINGTON, D.C.
Georgetown University

HDSA Launches Youth Social Worker Program

The Huntington's Disease Society of America (HDSA) is expanding its youth programming with the launch of its new HDSA Youth Social Worker Program. Over the next three years, HDSA will recruit and train Social Workers within its Huntington's disease (HD) network to serve young people and respond to the unique needs of children, teens and young adults impacted by HD. "We are always working to develop new ways to provide meaningful resources for youth impacted by Huntington's disease," said Louise Vetter, HDSA's President & Chief Executive Officer. "In complement to the HDSA National Youth Alliance and our ongoing partnership with HDYO, HDSA's new Youth Social Worker Program will help us serve the needs of the youngest members of HD families and connect them to HDSA's vast community of support and resources."

Beginning on a part-time basis, the Youth Social Workers will provide case management, counseling and resources to young people nationwide impacted by HD. HDSA's first two Social Workers to join the program are Katie Dykman, LISW and our very own Minnesota Chapter Social Worker, Jessica Marsolek, LGSW. Since becoming the MN Chapter Social Worker, Jessica has worked with the Minnesota Chapter board and volunteers to connect with the youth in our local families by offering youth meet ups and youth tracks at the education day. She is hopeful that with the expansion of youth support for HD families, and easier ways for youth to connect via social media, youth from the midwest will feel comfortable reaching out to her if they need someone to talk to or to want to connect with other youth who are living in an HD family. Jessica works full-time as a school social worker and has loved serving HD families in Minnesota for the past 13 years. She has always had a special place in her heart for the children and young adults of the families she supports.

Jessica can be reached at: 612-371-0904, jmarsolek@hdsa.org and she can be found on Facebook by searching "Jessica Marsolek HDSA."

HDSA's National Youth Alliance (NYA) is a powerful network of children, teens and young adults between the ages of 9-29 who are impacted by HD in the United States. The NYA includes all youth members of the HD community, including those who are at-risk, gene positive, gene negative, impacted by Juvenile-onset HD, caregivers and friends of those affected by HD. In addition to the new Youth Social Worker program, the NYA coordinates free Youth Retreats around the country, hosts an NYA Day at the Annual HDSA Convention, and manages its own Convention Scholarship Program which enables NYA members to attend the HDSA Convention at no cost.



The HDSA Youth Social Worker Program is generously funded by The Griffin Foundation. "Griffin Foundation focuses on expanding care and outreach to HD patients and families," said Jack Griffin, Chair of The Griffin Foundation. "This Youth Social Worker Program will be an important and much-needed piece to achieve this goal."

Upcoming Events

For more information, visit hdsa.org/mn

Fun Outta the Sun Bowl-a-Thon

Saturday, April 6, 12-2pm | Park Tavern Bowling, 3401 Louisiana Ave., St Louis Park

Wild Food Fandango

Sunday June 9, 1pm – 9pm | Keg and Case West Seventh Market, 928 7th Street W., St. Paul

Duluth Team Hope Walk

Saturday June 15, 9:30am-1pm | Leif Erickson Park, 1301 London Rd, Duluth

HDSA National Convention – Boston MA

June 27 – 29 | Boston Marriott Copley Place, 110 Huntington Ave, Boston MA

Twin Cities Team Hope Walk & 5K

Saturday July 13, 8:30am-1pm | Purgatory Creek Park, 13001 Technology Dr., Eden Prairie

Minnesota United Game

Saturday July 27, 7pm | Allianz Field, 400 Snelling Ave N, St Paul

Motorcycle Ride for Hope

Saturday August 24, 9:30am-11pm | Harley Davidson, 1355 98th Ave NE., Blaine

MN Chapter Education Day

October

Support Groups

Support group meetings are for people who are at risk for HD, persons with HD, and families of people with HD. For more information, including how to start a support group in your area, contact Jessica Marsolek, LGSW, at (612) 371-0904 or jmarsolek@hdsa.org.

Twin Cities

Every third Saturday, 10:00am

Oak Grove Lutheran Church

7045 Lyndale Ave. S., Richfield

First half of the meeting is together. The second half is broken out between impacted and support.

Rochester

As planned

Please contact Jessica Marsolek at (612) 371-0904 for specifics

In Memoriam

Ned Bartlett
Joe Lutwitz

