

# HDSA Minnesota Chapter Highlights

FALL 2018

## Update on HD global development program

This is an excerpt from the Sept. 16 Roche Global HD community letter. For the full article, visit [hdsa.org](http://hdsa.org)

Dear Global Huntington's Community,

Thank you for your ongoing support and interest in the investigational medicine RG6042 (formerly known as IONIS-HTTRx) for Huntington's Disease (HD).

Over the past months we and our partner Ionis Pharmaceuticals have been heavily engaged with communities around the world (patient groups, medical professionals, Health Authorities and payers) to collaborate and build the RG6042 global development programme and upcoming studies. We are eager for RG6042 to advance into further clinical development.

All 46 participants who took part in the Phase I/IIa study are continuing to receive RG6042 as part of an 'open-label extension' study run by Ionis. This study assesses the safety and tolerability of longerterm dosing of RG6042 and is being conducted at the nine sites involved in the Phase I/IIa study in Canada, Germany and the United Kingdom.

Two additional clinical studies, run by Roche, are planned to start by the end of 2018.

**The HD Natural History Study:** This 15-month observational study aims to further understand the role of mHTT in disease progression. There is no drug treatment in this study, as the goal is to understand the natural progression of HD. This study is expected to start towards the end of 2018.

**GENERATION HDI:** This will be the world's first Phase III study testing a molecule designed to lower huntingtin protein. The study design will be submitted to Health Authorities and Ethics Committees/Institutional Review Boards (IRBs) this year. The GENERATION HDI study will evaluate the efficacy and safety of RG6042 treatment given once per month or once every two months (bi-monthly) over a period of 25 months (approx. two years). This global study will enrol up to 660 patients with manifest HD at 80-90 sites in approximately 15 countries around the world. The study is expected to begin at the end of 2018 with patients starting to enrol by early 2019. Participants will be randomised to one of three treatment study arms: RG6042 monthly, RG6042 bi-monthly or placebo monthly. This means for every two

participants randomised to RG6042, one will receive placebo. The study is designed to test the potential effects of RG6042 compared to placebo, whilst limiting the number of people who will be given placebo. The study is "double-blinded," meaning neither the participant nor his/her investigator or site staff will know which study arm the participant is assigned.

Our team is working with urgency to start the HD Natural History and GENERATION HDI studies and we understand that you are eager for more detailed information, such as specific sites, countries and dates.

Study site/country information will be shared on a progressive basis. Once a site is nearly ready to enrol patients, we will update the information on [clinicaltrials.gov](http://clinicaltrials.gov) and on North America's [HDTrialFinder.org](http://HDTrialFinder.org).

The urgency in which families are seeking a medicine that can slow or stop the progression of HD is deeply felt and shared by our team. Because the need in HD is greater than the capacity of our development programme, we recognise that not every person, nor every capable HD clinic or centre, interested in participating in these clinical studies will be able to participate. Please understand the studies are designed to provide Authorities with the required data so that the benefit-risk of RG6042 can be determined as quickly as possible.

Our team is committed to addressing the scientific questions and promptly completing the RG6042 studies with appropriate rigour. The ultimate goal is that this investigational medicine can be approved by Health Authorities, and made accessible to the broader HD community – a goal that we share with you, the global HD community.

We look forward to providing you updates later this year, and we thank you for your continued partnership.

Sincerely,

**Mai-Lise Nguyen**, on behalf of the Roche HD team Patient Partnership Director, Rare Diseases Roche Pharma Research & Early Development / Roche Innovation Centre Basel, Switzerland

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.

### HDSA Minnesota Chapter

Brianna Wallen Lindell, Chapter President

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### HDSA Center of Excellence at the Hennepin County Medical Center

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Interested in becoming a  
volunteer?

Contact Brianna Wallen Lindell at  
(952) 334-2211 or  
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# Long-Term Care Options for Huntington's Families

Here in Minnesota, we are lucky to have many great long-term care options for our HD patients when extra care is needed. Below are a few of the options that are available to us. Please reach out to any of the contacts below for more info or to our social worker, Jessica, for follow-up questions at 612-371-0904 or [jmarsolek@hdsa.org](mailto:jmarsolek@hdsa.org).

## Tadd's Lighthouse

Tadd's Lighthouse is a family-owned and run organization that combines the love and support of family with highly trained and dedicated staff. Since 2008 we have been recognized as a leader in providing long-term care to individuals with Huntington's Disease.

We currently have six foster care homes that are custom-designed to be 100% handicap accessible to meet the long-term needs of our residents. Locations include: Buffalo, St. Cloud, and surrounding areas.

We treat our residents and employees as extensions of our own family. We believe in cultivating an environment that combines industry-leading expertise with warm, compassionate care. At Tadd's Lighthouse, you'll not only receive expert long-term care—you'll get the love and support of a family. Because when you're with us, you are family.

It's one thing to say, but we'd prefer to show you personally. Send us an email ([jacob@taddslighthouse.com](mailto:jacob@taddslighthouse.com)) or call us at (612) 643-5363 to talk about your needs, arrange a site visit, or inquire about employment opportunities. You can also check us out on the web at [www.taddslighthouse.com](http://www.taddslighthouse.com).



## 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](mailto:jmarsolek@hdsa.org).

### Richfield, MN

Oak Grove Lutheran Church  
7045 Lyndale Ave. S.  
Every third Saturday, 10:30 a.m.-12 p.m.  
Facilitators: Jessica Marsolek, Nina Ross

### Rochester, MN

Location TBD  
Every third Saturday, 3 p.m.  
Facilitator: Jessica Marsolek  
RSVP required to Jessica at  
(612) 371-0904 or [jmarsolek@hdsa.org](mailto:jmarsolek@hdsa.org)

## Sonshine & Hope

Sonshine & Hope, Inc. is a Huntington's family business that opened the first two residential group homes in the country for Huntington's & other disabilities. The owner's husband & father, and several of their friends, had HD. S&H has 2 beautiful handicap-accessible ramblers located a mile apart in Burnsville, MN.



We are Adult Foster Care, licensed through Dakota County & DHS, and we accept residents from other counties as well. We serve adults from mostly age 40+, generally on TBI & CADI waivers. Our loving, trained staff offers 24/7 person-centered care and daily programs and outings. Each home has a van to transport residents for doctor appointments and outings. Visit our website for more details and pictures at [www.sonshineandhope.com](http://www.sonshineandhope.com)

Contact Angie Priebe at [apriebe7@icloud.com](mailto:apriebe7@icloud.com) (612-203-2284) or Dianne Priebe Brunsvold at [dpriebe@me.com](mailto:dpriebe@me.com)

## Good Samaritan Society

Good Samaritan Society Specialty Care center is a 96-bed rehab and long-term facility. 32-bed unit offering music therapy, chaplain services, Occupational, Physical and Speech therapy. On-site services include a beauty shop, hearing, vision & dental. Dr. Nance oversees all and visits monthly. Serving the HD community since 1993.



Contact Gwen Johnson at 612-332-4262

## Upcoming Events

For event updates, visit [www.minnesota.hdsa.org](http://www.minnesota.hdsa.org) or [www.facebook.com/hdsamnchapter](https://www.facebook.com/hdsamnchapter)

### Spring 2019

Fun Outta the Sun Bowl-a-Thon

### Summer 2019

HDSA National Convention | June 27-29, Boston  
Twin Cities Team Hope Walk & 5K Fun Run  
Duluth Team Hope Walk

### Fall 2019

Ride for Hope Motorcycle Run  
Education Day

## In Memoriam



Ned Bartlett  
Joe Lutwitz