



National Niemann-Pick Disease Foundation, Inc.
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May 16, 2016

RE: NNPDF hosted VTS-270 (Cyclodextrin) Clinical Trial Informational Patient Webinar
DATE: Tuesday, May 31st, 2016
TIME: 5:00 pm PST; 6:00 pm MST; 7:00 pm CDT; 8:00 pm EDT
PARTICIPANTS: All Niemann-Pick Disease Type C families & patients
REGISTER AT: <http://tinyurl.com/j991b9>

The National Niemann-Pick Disease Foundation (NNPDF) is pleased to advise our Niemann-Pick Disease Type C (NPC) family membership and patient community that we will be hosting a VTS-270 (Cyclodextrin) informational webinar. The goal of this informational webinar is to provide updates from the family and patient perspective as to their personal experiences associated with participation in the experimental therapies/treatments of VTS-270 (aka: Cyclodextrin). Updates will be provided from a panel of NPC parents who currently have a loved one receiving VTS-270 either via:

- I. The NIH Phase I clinical trial
- II. The Vtesse VTS-270 Phase II/III Clinical Trials/individual Investigational New Drug (i-IND).

You can register for this webinar by going to <http://tinyurl.com/j991b9>. Once there you will be prompted to fill in your first and last name and an email address. The system will then email you a link so that on the day of the webinar you can log in. Additional information pertaining to the specifics of the webinar will be posted at: www.nnpdf.org

Please note that our webinar system will only allow 100 people to take part. It is a first come first serve type of webinar. Meaning that even though you register if you do not log in before the 100 seats are taken you will not be able to attend. Please do not worry though we will be recording this webinar for later viewing.

In addition, please find a flier pertaining to a second webinar to take place this Friday, May 20th which we would appreciate you forwarding to your treating physician. This is for physicians to hear an update from Dr. Denny Porter regarding the NIH Phase 1/2 trial.

If you have any questions regarding signing up for the webinar please email Chris Klauer at nnpdf@nnpdf.org.

We will **persevere** for a **cure**!

Sincerely,

Nadine M. Hill
Executive Director