

Michigan Chapter Social Worker

Hello friends,

Phoenix was great! I learned a variety of things that will benefit our family's here in Michigan. What really struck a chord with me are the most recent findings in the new clinical trials that will be conducted through the **HORIZON TRIALS**. These trials are designed to learn about new medications that are safe and tolerable for individuals afflicted with Huntington's disease.



What is the Horizon trail?

The Huntington Study Group (HSG) is conducting a trial for research on the medication **Dimebon**. HORIZON is designed to determine the safety of Dimebon 60 mg per day versus placebo and to determine whether or not there is an effect on cognitive abilities. The goal of the study is to improve on past studies resulting in positive cognitive effects on Huntington's Disease patients. The study will also assess other Huntington's disease symptoms including motor functioning and overall functioning. Approximately, 50 research centers across North America will enroll over 300 individuals. This trial is sponsored by Medivation, Inc in collaboration with Pfizer Inc.

Who can participate in Horizon?

In order to partake in HORIZON trial you must:

- Be at least 30 years old or more
- Be able to provide written informed consent
- Have clinical features of HD and have tested positive for the HD gene
- Have some difficulty with cognitive abilities
- Have a caregiver who assists/spends at least 5 days for at least 3 hours per day with you
- Be able to take oral medications and be willing to comply with study specific procedures

Not be pregnant, lactating or intend to become pregnant

What are the risks associated with participation in HORIZON?

There are mild risks associated with taking blood samples that include pain or bruising at the site where the blood is taken. Some of the side effects with this medication in a prior HD study include headache and sleepiness. Supplementary risks are explained in the consent forms.

What are the benefits?

Although there may be no direct benefits to you from participating in the HORIZON trial, you will be contributing to the growing knowledge about Huntington's disease. If significant positive benefits are observed participants will be allowed to remain on the Dimebon after the study has completed and they will continue to provide the medicine to you for an undetermined period of time.

How to sign up?

If you or a family member fits criteria listed. You can join by calling the following number or through their web site: HSG – toll free number 1(800) 487-7671, www.Huntington-Study-Group.org

Here is a helpful piece of information that could be useful in helping HD family's with care giving. It is a national website that is dedicated to help individuals in need of assistance. Other family members and friends often don't know where they can offer assistance, and the family with HD often don't like to ask for help. This web site is set up so family and friends can see where assistance would be helpful. All they need is to know what, how, or when to help. It's only a "click" away and it is easily accessible. Just go to the website listed below and set up an online calendar with your appointment, task, and any other place you could use assistance, and friends and family can sign up to help with these appointments or task. Items can be simple things like need someone to call at a certain time, stop by to make sure a HD person is okay, give meds, take someone to Dr. , sit with loved one while you are gone to an appointment, help with meals if other family member is at work, or go for a walk, the items may be small or big, but would mean a lot to a family struggling to care for a loved one with HD. Please check out the site: www.teamcaring.org

In conclusion, I hope all the family's can trust me to do the best I can do to help them with all their questions and needs. Please feel free to contact me on the helpline 1800-909-0073. I will be more than willing to talk over the phone or we can set something up for counseling or just a conversation.

Thanks,

Danny Berry – Family Service Coordinator/Social Worker