

Get Involved with Philly Cure HD

We hope you will consider getting involved with us. You can utilize the services of our HD Care Consultant, participate in one of our Huntington's disease social gatherings, assist with our fundraising activities, help with some of the planning and leadership needs of our organization and/or make a donation in support of all we do!!

Please feel free to contact us with any questions about what we do or how you can get involved.

For more information visit our website at www.phillycurehd.org

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find us on facebook at Philly Cure HD, Huntington's disease

What We Do

Throughout the year we host several social outings for the HD community as well as offer a number of educational events.

"I'm glad I have the support of others who understand HD"

Hereditary Disease Foundation.

We offer the services of a full time HD Care Consultant to individuals and families affected by Huntington's disease. These services include providing information, education, and referrals to community resources, as well as needs assessments and development of coping strategies for the living with HD including:

- understanding Huntington's disease
- consideration of genetic testing
- finding and utilizing the support of medical, government and community resources such as neurologists, Social Security Disability and in home supports.
- long term planning such as living wills, powers of attorney.
- coping with uncertainty, a chronic progressive illness, discrimination, financial challenges, etc.

"No one coping with HD has to do it alone."

Philly Cure HD supports Huntington's disease research through yearly donations to the



Philly Cure HD is dedicated to improving the lives of those local individuals affected by Huntington's disease and their families by

- ⊕ Providing counseling, future planning, and referrals for assistance
- ⊕ Fostering a strong HD community
- ⊕ Educating families and the greater community regarding HD
- ⊕ Supporting HD research

What is Huntington's disease?

Huntington's disease is an incurable, hereditary brain disorder. It is a devastating brain disorder for which there is no currently 'effective' treatment. Nerve cells become damaged, causing various parts of the brain to deteriorate. The disease affects movement, behavior and cognition - the affected individuals' abilities to walk, think, reason and talk are gradually eroded to such a point that they eventually become entirely reliant on other people for their care. Huntington's disease has a major emotional, mental, social and economic impact on the lives of patients, as well as their families.

Credit <http://www.medicalnewstoday.com/articles/159552.php>

How Huntington's disease Affects Families?

When there is Huntington's disease, HD, in a family every member of that family is affected in different ways. For those of us not living with HD here is what four HD family members say about their experiences and feelings.

Someone at risk for Huntington's disease "I wonder what my father's quality of life will be like as Huntington's disease takes away more and more of his ability to work, to manage all the household chores, and much more. Then being at risk myself for HD means I have a 50-50 chance that I have inherited the faulty gene. I don't know when to tell the men that I date that I might get sick and die from Huntington's. I wonder if I should have children as they too might inherit HD. I wonder who will help me if I become symptomatic."

"Do I have HD?"

Someone who has inherited Huntington's disease

"I wanted to plan for retirement, not for moving into a nursing home when I am middle aged. I wonder will I still be able to walk my daughter down the aisle when she gets married. Will I be able to see my grandchild play in the little league. I had always dreamed of seeing the Rocky Mountains but now that my symptoms have started I don't think I will get there. Now I am just hoping that I don't lose the ability to walk too soon. I dread the day when I will have to use a wheelchair."

"I worry about my future."

For a woman whose husband is HD symptomatic "I hated seeing what HD did to his mother. I watched my husband for years wondering if his symptoms were starting. He would trip up the steps. He would forget his dental appointment. I wondered if these were the first signs. He just recently got fired. It was probably because of early HD symptoms. I hope his Social Security Disability application is approved on the first try. Will I have to stop working to care for him? He gets so anxious so easily and he takes it out on me."

"How will I manage?"

For a man whose wife died 10 years ago from HD

"Long before her own death my wife lost her father and an aunt to HD. Since her death my wife's sister as well as a cousin and a nephew have died from HD. I've prayed that HD wouldn't come to our children but now I think I am seeing early

"I don't want HD to affect anyone else in my family"

symptoms in my daughter. I also worry about and watch my son. I don't think I can bear any more losses. I wonder if I will I watch my children die from HD. I also worry about my grandchildren."

What is our hope for Huntington's disease?

We have hope that more and better treatments will be found and that someday soon they will know how to cure Huntington's disease.

There is more and more research into and understanding of the mechanism of the faulty HD gene. We currently have one FDA approved medication that may help with the involuntary

"We have hope in research."

movement associated with Huntington's disease. There are a number of drugs

currently being tested and soon some of them will be proven successful and approved by the FDA for us to use.

In the meantime we struggle daily with living with HD in our families. We find it important to create our HD community where we can educate and support each other while at the

"We are building a strong supportive HD community."

same time we can help fund the research that is ultimately going to make a world of difference for every HD affected individual and their families.

Please join us in our efforts.