



1-1-98

Happy New Year everyone!!!! We hope that a safe and enjoyable holiday season was had by all. We are excited to have begun the CARE-HD clinical research trial. It has given me the opportunity to meet the brave and generous people participating in the study. I have been learning quite a bit, and feel privileged to be a part of the community working towards the cure for Huntington's disease. I'd like to share with you some of what we're doing at the University and hope that everything going on will excite you as much as it does us.

Clinical research: CARE-HD and the HD Clinic

CARE-HD: Enrollment has ended in the nationwide study. Members for the study have been selected, and research has begun! Everyone is excited and pleased with how smoothly this project has gotten underway. I would like to extend a great thanks to all of you for being screened and for allowing us to work with you for the search for HD treatments. Your support along with the support of your families is much appreciated by everyone here at Dr. Paulsen's office. In turn, we also want to be sure that that you consider us a resource as well, and know that our office can be contacted for any assistance we might provide.

HD Clinic: We have recently been approved to begin seeing patients at the University Hospital in a clinic designed specifically for the treatment of Huntington's disease. A team approach is used at the University of Iowa Hospitals and Clinics to provide a full range of Huntington's disease services. The staff includes professionals from Neurology, Psychiatry, Genetic Counseling, Nutrition and Speech Therapy. The Huntington's Disease Clinical Research Program will serve as a monthly clinic and provides a full range of Huntington's disease services. Aside from offering patient visits and follow up care, this clinic will serve as a resource for anyone needing information pertaining to HD. A team of neurologists, psychiatrists, nutritionists, and genetic counselors are working together to provide the well-rounded approach needed for the complete care of individuals with Huntington's disease and their families.

On-going research: neuro-imaging studies and the HD Registry

In our attempt to continually provide research towards the understanding of and cure for Huntington's disease, Dr. Paulsen is advancing our efforts with her work on two other programs. The first, not yet underway is a neuro-imaging study. Similar to a CAT scan (an X-ray of the brain), this study uses PET scans to look at the actual functioning of the brain to see if the parts normally affected by Huntington's disease are still working. By doing so, we gain insight in to the brain's functional abnormalities, and can better understand the behavioral changes which take place as the disease progresses. Investigators hope to determine if these PET scans can reveal abnormalities before the display of the clinical signs of Huntington's. The answer to this question may result in the use of PET as a standard diagnostic tool for HD.

Secondly, Dr. Paulsen has also been approved to maintain a Huntington's Disease Registry. This registry will serve as a database collected solely for Huntington's disease research. It will be compiled of the names of all interested parties wishing to be involved in our research. It can be used as a resource for other doctors and researchers as well as for patients and their families who maintain an interest in the University's research. To be a part of this registry, simply return the enclosed consent forms in the envelopes we sent. Postage is not necessary.

Huntington Study Group

This year's annual Huntington Study Group meeting was held in Santa Fe New Mexico. It was very informative and enjoyable. The nation's leading experts on Huntington's disease joined to share ideas and the results of their research. Everyone learned a lot and left feeling even more united to the cause. It was especially exciting for me to meet many of the people whose work I have read and admired.

Early Cognitive Assessment in HD in Venezuela

Dr. Paulsen has just found out that she has been awarded another grant to investigate early cognitive changes in Huntington's disease. This study will be helpful in the understanding of the disease and will be useful in determining methods of predicting onset. This is important so that when a medication is found that slows symptom progression, it can be started at the very best time for each patient. Dr Paulsen will conduct this study in Venezuela with a team from the Hereditary Disease Foundation and Columbia University. They along with Dr. Paulsen have been visiting Venezuela for years now and we are all excited that it is finally being funded and getting some federal attention.

Please contact Dr. Jane Paulsen or myself with any questions you might have. It is important to us here at the University of Iowa that you know all that your time is appreciated. You are contributing to the search for a cure Huntington's disease. With every study, each trial and exploration, we come closer to finding the answers that will fight this disease. Generations will have your efforts to thank and we would like to begin this New Year saying thank you to the CARE-HD participants and their families. Best of Luck to everyone in 1998.

-Liz Agresta

Research Assistant



The University of Iowa – Hospitals and Clinics