



05-98

Spring has FINALLY arrived. We hope that everyone is doing well and enjoying the fair weather. A lot has been happening here at the University of Iowa and we are glad to stay in touch with all of you.

CARE-HD is approaching its eight-month visit (can you believe it?). This visit is a bit more extensive than the others and will prove especially useful in monitoring the study's progress.

Dr. Jane Paulsen has returned from a successful trip to Venezuela where she conducted follow-up testing on several hundred Venezuelans with HD. Her collaborative efforts with the Hereditary Disease Foundation provide valuable research toward the understanding of HD and its treatment.

The Huntington's Disease Clinic is also up and running. We have had two months of successful clinic visits and feel this is a great way to stay connected to the individual needs of Huntington's patients. Should you have friends or family wishing to be involved with the clinic or to schedule an appointment, they can phone me for assistance (319-353-4307).

A new study is also in the works. The objective of this study is to look at HD people who are gene carriers but do not have symptoms. We hope to study these at-risk individuals to best determine how to distinguish when the disease starts. In this manner we will be able to decide when to initiate drugs to delay onset. This is an exciting new project and all at-risk and interested individuals should contact me for further information.

Dr. Paulsen's lab has also been discussing the possibility of beginning monthly support group meetings where we can gather as a community and share our ideas and concerns. This idea is still in the planning stage but we will be sure to keep all of you informed as things get underway.

Upcoming Events: The HDSA thirteenth annual convention will be held in Denver, Colorado on June 19-21, 1998. Dr. Jane Paulsen is a guest speaker and will be presenting on HD Management in relation to care, medications and treatment. She also presents on experimental treatments for HD in clinical research. She is looking forward to this and will be sure to keep us all informed upon her return.

IN bookstores this May, The Faces of Huntington's, anthology compiled by HD family member Carmen Leal-Pock. A percentage of the book's proceeds will go to support HD programs. Books can be ordered for \$15.95. Send check payable to Living Hope Inc., P.O. Box 952163, Lake Mary, Fl. 32795-2163.

OUT on Video: "Huntington's Disease: Living with Knowledge" written and narrated by Dr. Jane Paulsen and produced by the Sioux Valley HDSA chapter, can be ordered by sending a \$25.00 check (includes shipping and handling) made payable to the Sioux Valley Chapter, PO Box 1311, Sioux Falls, SD 57101-1311. All proceeds go to HD.

ON the web: check out the web site created by Renette Davis, in Chicago Ill. It is one of my favorites and includes lots of important information for people with HD and their caregivers. It has great stuff on nutrition, and contains super recipes. It has poems and stories as well as up-to-date links to medical information and conference reports. Renette welcomes contributions from others. The web site address is

<http://www.lib.uchicago.edu/~rd13/hd/>, and here's a taste of what's out there: ENJOY!!

A soft dessert that is WONDERFUL

1 box yellow cake mix. I use Duncan Hines Lemon without pudding. Don't prepare as cake mix

1 stick melted butter or margarine

1 egg

Mix together and spread in bottom of 13 x 9 pan - will be thick!

Bake at 350 for 35-40 minutes - not as long if it is a dark base pan.

Top Layer - Mix and pour over bottom layer:

8 oz. cream cheese (add lemon juice or lemon extract)

1 box powdered sugar

2 eggs

Really easy.

Enjoy the weather, we look forward to seeing you all soon! From the CARE-HD team at the University of Iowa Hospitals and Clinics, Iowa City, Iowa.

Newsletter produced by Liz Agresta.

