

# April 1999 -

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## Research Developments

### Ellen Burns, Vice President

Khemissa reported in January on her work during the preceding few months. We are happy to report that two people have been hired to assist Khemissa in her work. Dr. Chenyan Wu is helping with several projects at the Day Lab and is being assisted by laboratory technician Lianchun Wu. They are working in Buffalo at the Roswell Park Cancer Institute to make use of the special robotics and other resources there.

Khemissa had already examined and excluded all the known genes in the area of Chromosome 9 that have been identified as containing the gene causing our family disease. Now she is working on identifying other (novel) genes that are in this region. To do this, she must use known artificial chromosomes and match them up, like pieces of a puzzle, to cover the area that is suspect. She has just completed this task! This is a big step forward.

The researchers can now estimate the size of the responsible region to be less than 2.5 million base pairs. Although that sounds like a big number, when we started this search, we were looking at 3 billion base pairs! Our region may contain as many as 80 genes.

Khemissa is prioritizing the search by identifying genes that are expressed in the sensory nerves. She is studying the pattern of tissue expression of the various genes in the region.

The work is progressing well, and we are anticipating that Khemissa will share additional exciting news at the reunion this year.

## Treasurer's Report

Nancy Newcomer, Treasurer

Nancy newcomer, Treasurer, reports the following regarding the treasury of Deater Foundation, Inc.:

1998 Finances	
Balance as of 1/1/1998	\$38,071.79
1998 Contributions	12,750.00
1998 Interest	<u>615.06</u>
Total Income	\$51,436.85
1998 Expenses (Feb. & July)	-16,000.00
Balance as of 12/31/1998	\$35,436.85

## Grant Awarded

A grant (written by Dr. Bejaoui) was approved by the Neuropathy Association. Khemissa wrote this grant (her first grant application, too) for the Deater project which was awarded one of four grants given by the organization for \$25,000 a year for two years!

Congratulations to Dr. Bejaoui for her success in winning this grant that will benefit the research being done on the Deater disease!

## Publication of Article

Dr. Bejaoui wrote an article regarding genetic research which was published in the February issue of Neurology. Neurology contains an article entitled "Confirmation of linkage of type 1 hereditary sensory neuropathy to human chromosome 9q22" by Dr. Khemissa Bejaoui (and others). Ellen Burns' and Larry Deater's names are included in this article.

Once inside the Neurology site, follow these steps to read the entire article:

1. click on Contents
2. select February 1999 (Vol. 52)
3. select "Confirmation of Linkage"
4. click on HTML File

*Note as of August 2001: The full article is only available for Neurology subscribers. However, feel free to read the abstract.*

## The Australian Study

It is interesting that Dr. Nicholson's group is still involved in a similar genetic study in Australia.

## Final Note From Ellen

Please consider giving to the Deater Foundation. It is an investment in future generations of our family. The large size of our family has been to our advantage in research. The large size of our family can assure that the burdens of the disease are not carried by only a few individuals. If each of us gives a few dollars, five or ten dollars a month, or more if we can afford it, the dollars will add up to support for Khemissa and the other researchers. The contributions of the Deater Foundation to the Day Lab, although not large in research expenditures, have acted as "seed money" to stimulate contributions from other organizations. Perhaps most importantly, the contributions from the family have impressed upon Dr. Brown and Dr. Bejaoui the determination of the family. Dr. Brown has an international reputation for the work he has spearheaded for ALS (amyotrophic lateral sclerosis), also known as Lou Gehrig's disease. Yet he continues to work (12 years now) to find a cause and cure for the disease affecting our family. Khemissa has spent many more years than usual in a "post doctoral" position in the Day Lab, instead of moving on to improve her career and her finances, because of her dedication to the family. We are blessed to have these doctors doing this work. We are quite certain that every person who has the gene for the disease will develop the disease at some point. Each child born to a person with the gene has a 50-50 chance that he or she will have the disease. I pray for the day that we, together, find a treatment and a prevention for HSN-1, so that the "Deater Disease" will be no more.

If you have any questions, comments, or suggestions about our newsletter, the medical report, etc., or if you are interested in contributing to the Deater Foundation, send your e-mail message to: [tcdor34@enter.net](mailto:tcdor34@enter.net).

**55th Annual Deater Reunion -  
Saturday, July 17, 1999  
At the grove in the Stull**