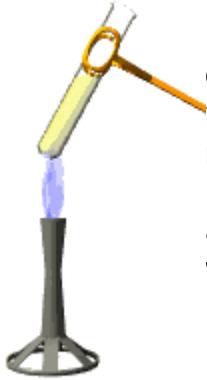


## November 1999 -

The Deater Foundation needs your help.



Dr. Khemissa Bejaoui has been working very hard at the Day Laboratory for Neuromuscular Research to find the gene that causes the disease, Hereditary Sensory Neuropathy I (HSN I), that continues in our family. This year, in anticipation that the research was getting very close to the goal, the Deater Foundation committed to pay the salary of a laboratory assistant to work exclusively on the "Deater Project", HSN I, with Khemissa Bejaoui. Salary plus benefits for this person are \$30,000 per year. This commitment is an addition to the money we have been sending to the Day Laboratory.

For several years we have been contributing \$16,000 per year toward Khemissa's salary. We do not pay for equipment, supplies nor overhead for research. Last year Khemissa wrote and received a two year \$50,000 research grant from The Neuropathy Association. Next year she will request grant money from the National Institutes of Health. Dr. Bob Brown, Director of the Day Lab, has often expressed his gratitude to the Deater family and Foundation for their cooperation and encouragement as well as for the money we provide which helps to "leverage" for additional money from the public funding sources.

Ethan Segal, the laboratory assistant hired to work on the Deater Project, graduated with a Bachelor in Neuroscience from Amherst College. He had extensive college laboratory experience and a strong recommendation from his professor of biology. He was hired July 18, 1999, with plans to work for two years and then go to Medical School. Khemissa reports that Ethan is "very serious and really nice." They work side by side; that is, Khemissa continues to do "bench work" with Ethan, as well as have him assist her in the analysis of the results.

You may remember that Dr. Garth Nicholson and his research team in Australia first identified the probable location for the HSN I disease gene on chromosome 9. Khemissa quickly confirmed that the same area was also suspect in the Deater family. Since the original discovery, much time and effort has been spent locating and identifying the genes in that area of chromosome 9. Many researchers throughout the world who are working on the human genome project have contributed information. In February Khemissa published a report on her work in Neurology. She is now preparing another paper for publication. She has been promoted to Instructor. Her

current work focuses on identifying which genes in the candidate region affect the nerves. Khemissa and Dr. Brown, met with Dr. Nicholson this summer; all agreed to share information they have and will acquire about HSN I. Another research team, interested specifically in nerve cells, is also sharing information with Khemissa. All of this collaboration speeds the research and stretches the money we send.

The ultimate goal of the research is to find a treatment for this disease. Once the disease mechanism is identified, a medication might be developed. Treatment will mean freedom from pain, for those suffering nerve pains in hands and legs. Treatment will mean increased independence for those who need help walking, or buttoning clothes. Treatment will mean greater productivity for those who might otherwise be unable to continue with their jobs. Treatment will mean not having to watch young people, our sons and daughters, nieces, nephews and cousins, follow the same path with this disease.

The Deater Foundation is committed to sending \$46,000 in a year. We need your help. You receive requests in the mail and on the phone asking for contributions to many worthwhile causes. No other contribution will affect as many people that you know, as a gift to the Deater Foundation. Please consider a weekly or monthly donation. A gift of \$6 a week, the cost of a McDonalds meal, will mean over \$300 a year to the Foundation. All donations are tax deductible and can be sent to the Deater Foundation, Inc., Box 255, White Deer, PA 17887.

The elimination of this disease will be fitting memorial to Alvin and Ellen, Ethel, Isabelle, Harvey, Russell, Tom, Betty, and Verna, and a legacy for future generations.

Sincerely,

- Carol Adams Dorward, President
- Ellen Deater Burns, Vice President
- Nancy Adams Newcomer, Treasurer