

Dear Families:

NNPDF is assisting Karen Quandt with a survey that she is conducting as part of her graduate work in the Nursing Program at the University of Washington.

Karen's research is designed to develop a better understanding of whether and how the gene for Niemann-Pick Type C may be associated with genes for other diseases. The goal of the research is to determine whether other diseases occur at a higher frequency in NPC families than in families from the general population. To answer this question, Karen is conducting a survey and has asked NNPDF to request participation in the survey by families of children and adults with Niemann-Pick Type C. The survey includes a family health history that asks for information on diseases and conditions of family members with NPC, their siblings, parents, aunts, uncles, and grandparents.

The survey will take between 30 and 60 minutes to complete. Taking part in it is voluntary, and all responses are completely anonymous. Your responses will not be linked to your name, email address, or any other identifying information. The survey and Karen's research have been reviewed and approved by the University of Washington Institutional Review Board.

If you would like to participate in the survey, go to the following website address:

http://www.surveymonkey.com/s.aspx?sm=tGofJA2nbnJOuke8tJ9Ntg_3d_3d.

You can stop taking the survey at any time. And please note- you will not directly benefit from taking part in this survey.

Karen Quandt will be attending the NNPDF Family Conference and will share more information about the survey then. You can also contact Karen directly at 253-862-4040 or by email at kquandt@u.washington.edu if you have questions about the survey.

NNPDF will provide assistance if needed (our contact information is on our web site at www.nnpdf.org) and Cate Walsh Vockley, a genetic counselor and NNPDF's Coordinator of Education, Referral, and Advocacy is available by phone or email if questions arise about your family history (Cate's contact information can be found at www.nnpdf.org).

We thank you in advance for your participation in Karen's study.
