Appendix IV: Recruitment Announcement

for inclusion in the NORD newsletter

A graduate student in the PhD program at Wurzweiler School of Social Work is recruiting volunteers for a research study. Participants must be parents who provided most of the care for a child who had a delayed diagnosis of more than six months' duration after the symptoms were first noticed, and who was eventually diagnosed with a rare disorder (fewer than 200,000 persons in the United States have that disorder). At this time we are not including instances of a child with ADD or austim spectrum disorders or any birth injuries, or who is not living at home, and we are not able to include those families whose child is deceased. Participants will have a telephone interview of approximately one and a half hours, and will complete a questionnaire online of 55 questions. The interview questions ask about your response to the time of searching for a diagnosis, and your response to obtaining a diagnosis. The questions online simply require one check for each answer. There is no financial compensation for participation. The risk to participation is an emotional reaction to remembering and talking about your experiences. The benefits include the knowledge that you are making a contribution to those who face these experiences in the future. Results of the study will help professionals to provide better care to families facing these difficult experiences. If you are interested, please contact Rachel Reeder, MSW, MSN, CNM at 973-641-8957 or rachelcnm@aol.com. Thank you.