RESEARCH STUDY: SPEECH, LANGUAGE AND SWALLOWING DIFFICULTIES IN POMPE DISEASE

VOLUNTEERS WANTED FOR A RESEARCH STUDY

WHO? Parents or legal guardians of infants and children of all ages with Pompe disease.

WHAT: Part 1: Complete an online (or mailed) survey/questionnaire about your child’s speech, language and swallowing function.

Part 2: Sign a Medical Records Release for your child with Pompe disease. We will request, collect and review information in your child’s medical records. Parents are not required to participate in Part 2 of this study.

WHERE: Participants do not need to travel anywhere for this study.

CONTACT: If you would like to know more information about this study you may contact the Principal Investigator, Alana Cecchi, B.S., at Cincinnati Children’s Hospital at (513) 803-0589 or alana.cecchi@cchmc.org.

If you decide to participate after reading this flyer, you can access the survey from the link listed below.

http://www.surveymonkey.com/s/Pompesurvey_CCHMC_Dec2010