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Dear NNPDF ASMD Patient and Family Community,

The National Niemann-Pick Disease Foundation (NNPDF) is pleased to advise our Niemann-Pick Disease Type A/B & Type B (aka: Acid Sphingomyelinase Deficiency ~ ASMD) Disease patient's & family community that Sanofi Genzyme has received FDA authorization to begin recruiting for the phase 2/3 clinical trial of Olipudase Alfa for adult patients in the United States (U.S.).

The first U.S. clinical trial site will be at Emory University in Atlanta, Georgia under the direction of Dr. William Wilcox and will begin recruiting for adult patients diagnosed with ASMD (NPD Type B) who are 18 years or older in age.

The official name of this trial is: "A Phase 2/3, Multi-center, Randomized, Double-blind, Placebo-Controlled, Repeat Dose Study to Evaluate the Efficacy, Safety, Pharmacodynamics and Pharmacokinetics of Olipudase Alfa in Patients With Acid Sphingomyelinase Deficiency" and has been assigned the clinical trial number of: **NCT02004691**. To learn more about this trial, please consult with your physician and refer to the web site titled: <https://clinicaltrials.gov/> and enter the clinical trial number noted above.

The NNPDF Central Office has included the Sanofi Genzyme press release from July 6, 2016 with more specific details pertaining to the trial for your review.

Sanofi Genzyme will be adding more clinical site locations in the United States as they are initiated and are slated to be announced shortly. The NNPDF will make further announcements to our ASMD community as they are established. Please watch the NNPDF website at www.nnpdf.org, the Niemann-Pick Disease Awareness pages on Facebook and the clinicaltrial.gov page for up-to-date notifications.

As always, should you have any questions regarding this mailing and announcement, please feel free to contact the NNPDF Central Offices at nnpdf@nnpdf.org, we are happy to assist you.

We WILL Persevere in our Quest for a Cure!

Sincerely,

Chris Klauer
Family Services Coordinator
National Niemann-Pick Disease Foundation

The National Niemann-Pick Disease Foundation (NNPDF) does not engage in the practice of medicine. It is not a medical authority nor does it claim to have medical knowledge. For all information related to care, medication or treatment, the NNPDF recommends consulting a physician to determine if information presented is applicable. It should also be noted that choosing to participate in a clinical study is an important personal decision. Talk with your doctor and family members or friends about deciding to join a study.