



IPA's Pompe M-Power Pilot Project Recipient of Genzyme's 4th Annual PAL Award

For Immediate Release

October 1, 2014

The International Pompe Association (IPA) is excited to announce that it has been selected as a recipient of Genzyme's 4th Annual PAL Awards program for its **"Pompe M-Power"** Pilot Project.

The Genzyme PAL Awards grants program was launched in 2011 to encourage bold new ideas and programs to support the LSD community worldwide. The PAL program funds innovative projects in disease awareness and education, community mobilization, non-profit development and good governance activities, patient care and support programs.

"The IPA's Pompe M-Power Pilot Project is the first step in launching the international 'Pompe M-Power' program, which will identify, educate, and mentor the future Pompe leaders in our Community. We appreciate Genzyme and the PAL Award Review Committee's recognition of this important project and look forward to beginning this work with our Pilot Program in the second to third quarter of 2015," says Tiffany House (IPA Chair).

About the Pompe M-Power Project

The Pompe M-Power Project is designed as a mentoring/young adult program intended to empower individuals that are interested in becoming involved with international patient advocacy. The program will be open to individuals from 18 to 30 who have a connection to Pompe disease. This connection can be direct (i.e. they are a patient) or indirect (i.e. they are a parent, sibling or partner of a patient).

Currently there is not a program in place to identify and guide those who have expressed an interest in learning how to become international advocates, and there is a need to bring together interested parties to educate and train them regarding advocacy on an international level. Gaining a clear understanding of the needs of a global community and how to effectively advocate on an international level is different from being focussed solely on local or national issues, and special skills are required.

With the support of the Fourth Annual PAL Award, the IPA will launch the Pompe M-Power Pilot Project. The goals of the Pilot Project are: (1) to educate and train young people with Pompe disease to become international patient advocates, and (2) to take the best practices and lessons learned from the Pilot Program to launch similar Programs in other regions, with the ultimate goal of having an international meeting in the future with representatives from all of the regional Programs.

The Pilot Program will be launched in the Netherlands in mid-2015 with a face-to-face meeting and workshop where attendees will spend four (4) nights and three (3) days getting to know each other and learning skills that will assist them on the path to becoming international patient advocates.

The IPA looks forward to working with the international Pompe community to make the Pompe M-Power Program a success!

Contact information

For more information on the IPA's "Pompe M-Power" Program please contact Maryze Schoneveld van der Linde at maryze@xs4all.nl

About Pompe Disease

Pompe disease, also termed glycogen storage disease type II or acid maltase deficiency, is an inherited lysosomal storage disorder with an estimated frequency of 1 in 40,000 births. The disease is characterized by a total or partial deficiency of the enzyme acid α -glucosidase. Deficiency of acid α -glucosidase leads to accumulation of lysosomal glycogen in virtually all cells of the body, but the effects are most notable in muscle. Pompe disease is a spectrum disease with classic infantile onset at the severe end of the spectrum and the late onset at the other end of the spectrum. Disease symptoms may include: heart involvement; breathing problems; difficulty walking; inability to walk or stand; inability to raise the arms; muscle pain; fatigue; and scoliosis. Pompe disease causes severe disability and can be fatal when not treated in time.

About the IPA

The International Pompe Association (IPA) is an international federation of Pompe disease patient's groups that seeks to coordinate activities and share experience and knowledge between different groups and individual patient advocates from around the world. The IPA was founded in the Netherlands in 1999 and is the first, and only, international Pompe organization and serves as a model for other disease groups. There are currently sixty (60) countries that are affiliated with (or contacts for) the IPA. For more information on the International Pompe Association, please go to www.worldpompe.org