



International Pompe Association

Dear Patientorganisation,

Like many other patient organisations the IPA submitted the 'Pompe M-Power' Pilot Project proposal to Genzyme's 4th annual PAL Awards program. It was the first time the IPA participated in this PAL program that funds innovative projects. We are therefore excited and grateful that our project was selected to receive a PAL Award.

The Pompe M-Power Program is designed as a mentoring/young adult program intended to empower individuals that are interested in becoming involved with international patient advocacy. The Pilot Project will be held in Europe.

The inaugural event of the Pilot Program will be a face-to-face meeting in the Netherlands 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. Two founder-members of the IPA will organise and facilitate the project. Both are skilled trainers and have a lot of experience in Pompe disease and all the issues involved.

Participants will be encouraged to engage in discussion topics presented to them and helped to share their own thoughts, questions, and ideas. The IPA believes that open discussion and debate is important to working towards the best interest of the Community, and this message will be stressed throughout the Program. Participants will also be encouraged to identify their personal strengths and weaknesses, as well as those of the whole group, so that by working together, a stronger group is formed. As the slogan for International Pompe Day states: Together We Are Strong. This message will be emphasized to participants and an educational team-building activity will be arranged to allow participants get to know each other better, and to reinforce discussion topics related to networking and the importance of working together.

After the initial face-to-face meeting in the Netherlands, attendees will continue to communicate and work together through a variety of mediums (i.e. Skype, email, etc.). Participants will also be encouraged to organize activities in their own countries for other young adults. The groundwork for this will be laid during the face-to-face meeting by discussing the "Train the Trainer" principle. This Pilot Program will be the first step in encouraging and guiding young adults interested in international patient advocacy.

Participation criteria are:

- Direct connection to Pompe disease (i.e. patient) or indirect connection (i.e. parent, sibling, partner)
- Age: eighteen (18) to thirty five (35)
- English-speaking from Europe or surrounding countries (Russia, Turkey, Israel, Northern Africa, South Africa)
- Able and willing to travel to the Netherlands for face-to-face meeting (can be assisted by a caregiver)
- Able and willing to be an active participant in the Program
- Commitment to becoming active in national organization activities and to spread awareness amongst other young adults.

The IPA reaches out to your patient organisation to enquire your interest in having one of your members to participate in the Pompe M-Power Project. The IPA does fund travel and staying costs. In case a personal care taker is needed, travel and staying costs too are funded for the personal care taker.

The deadline to submit applications is Friday, February 20, 2015

We hope to hear from you and to have one of your eligible members to take part in our project to support the global Pompe Community now and in the future.

With kind regards,

On behalf of the International Pompe Association
THE NETHERLANDS

A handwritten signature in blue ink, appearing to read 'Maryze', with a long horizontal line extending to the right.

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