



International Pompe Association

Dear Applicants,

Thank you for your interest in the IPA's new initiative: the Pompe (Em)Power Program!

The Pompe (Em)Power Program is designed as a mentoring/young adult program intended to empower individuals that are interested in becoming involved in international patient advocacy. At this time, the IPA is accepting applications to participate in the Pilot Phase of the Program.

The inaugural event of the Pilot Phase 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. Ria Broekgaarden and I (both founding members of the IPA) will organise and facilitate the meeting. We are both skilled trainers and have a lot of experience in Pompe disease and all of the issues involved in international patient advocacy.

The meeting is scheduled for June 8th-12th, 2015 in De Rijp, the Netherlands (40km from Amsterdam). June 8th and 12th will be travel days, with the meeting being conducted from June 9th-11th.

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 are important to working towards the best interest of the Pompe 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. Community forum on the IPA website, 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.

If you are interested in applying to be a part of the Pilot Program, please complete the attached Application Form.

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

If you have any questions, please let me know.

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.

Maryze Schoneveld van der Linde
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