



E-mail: pompe.survey@erasmusmc.nl

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Date: November 2022

Subject: Invitation to the IPA/Erasmus MC Pompe Survey

Dear Sir/ Madam,

You are reading this letter because you may be interested in participating in the IPA/ Erasmus MC Pompe Survey ('the Pompe Survey').

The Pompe Survey collects information on how Pompe disease affects the lives of patients, and how this may change with treatment. Patients provide this information themselves through an annual questionnaire. The Pompe Survey is a collaboration between the Pompe Center of the Erasmus MC and the International Pompe Association (IPA) that started in 2002. Over the past years many patients from all over the world have participated in this annual survey. Without their help, this study would not have been possible.

Enclosed is a patient information leaflet that gives further information about the survey and why it is important to collect this information. Please take your time to read this information. If you have any questions after reading it, please do not hesitate to contact us (pompe.survey@erasmusmc.nl or +31 6 33 342 010; or contact your national patient organization through the contact details in the leaflet).

For you to participate in the survey we are required to ask your informed consent. If you decide to participate, we therefore ask you to print, complete and sign the enclosed consent form. Once we have received this signed form, you will receive the questionnaire every year.

You can complete the questionnaire through a secure internet page. Each year we will send you an e-mail with your personal link to this internet page. Therefore, we also ask you to fill in your e-mail address on the enclosed 'e-mail form'. If it is not possible for you to complete the Pompe Survey online, please use this form to send us your postal address instead so we can contact you by post.

You can return both the e-mail form and the signed consent form using the following return address. A stamp is not necessary.

Erasmus MC – Sophia
att. M. Kruijshaar, room Sb-1770
Antwoordnummer 55 (postage-free return number)
3000 WB Rotterdam
the Netherlands.

We thank you in advance for your participation. It is much appreciated!

With kind regards,

Tiffany House, Chair of the IPA

Ans van der Ploeg, Chair of the Erasmus MC Pompe Center

Enclosed: 1) Patient information leaflet; 2) Informed Consent form; 3) E-mail form