



FOUNDATION FOR PATIENTS WITH FABRY DISEASE NEW MEMBER OF FABRY INTERNATIONAL NETWORK

1st September 2014

Károly Fogarassy
Foundation for Patients with Fabry Disease
Zalaegerszeg u. 18. Fsz.2
Budapest

FIN Membership Number: **HUN0192014**

Dear Károly,

RE: WELCOME TO THE FABRY INTERNATIONAL NETWORK

I warmly welcome you and thank you for becoming a member of the Fabry International Network (FIN), an independent, non-for-profit Organisation based in United Kingdom. Your membership reflects your commitment to your Fabry Patients and the Fabry community around the world.

Today, FIN has a network of 47 Fabry Patient Associations in 35 countries. FIN was established in 2005 with a vision of a world where every person affected by Fabry disease has the best quality of life possible through early diagnosis, treatment and cure.

Fabry International Network is the only organisation that connects all Fabry Stakeholders with a purpose of collaborating, communicating and promoting best practices to support those affected by Fabry disease. Stakeholders are FIN members: Patient Organisations around the world; FIN Industry Partners: GSK, Genzyme, Shire and Amicus Therapeutics; FIN Medical Advisory Board and any organisation that is linked to Fabry disease. Through this unique partnership, FIN is able to look after the interests of over 10,000 Fabry patients worldwide.

Through your FIN membership, you will be able to:

- **Connect with the Fabry community.** Please use the Patient Organisations' links on our website www.fabrynetwork.org should you wish to connect with other Associations.
- **Communicate your latest news using our Newsletter.** We publish a quarterly newsletter that is sent to all our members and partners.
- **Connect with our Industry Partners.** We will communicate to all our members the latest news from the Pharmaceutical Industry.
- **Attend teleconferences and face-to-face meetings** with FIN Board of Directors, Industry Partners and FIN Medical Advisory Board (MAB).

FIN is governed by a group of trustees: Christine Lavery, President (UK), Jack Johnson, Vice President (USA), Lut De Baere, Director (Belgium), Anna Meriluoto, Director (Finland). The FIN Office is in Amersham UK and is manned by Nawel van Lin, Global Development Officer who works remotely from the Netherlands. We all look forward to personally welcoming you to FIN in the near future.

Should you need any more information or assistance, Please contact Nawel on + 31 486 83 00 23 or nawel@fabrynetwork.org.

Welcome again to the Fabry International Network.

Yours Sincerely,

A handwritten signature in cursive script, appearing to read "Christine Lavery".

Christine Lavery MBE
President
Fabry International Network
CEO MPS Society UK