

# The Fabry International Network (FIN)

[www.fabryintnetwork.com](http://www.fabryintnetwork.com)



## FIN: Who & What

Any organization worldwide that represents Fabry patients, families and caregivers can become a member of FIN.

FIN was founded as a non-profit organization in Dec. 2005 in the Netherlands under Dutch law.

Currently, there are 19 Fabry country organizations:

- North America: USA, FSIG; Canada, CFA
- South America: Brazil, ABRAF
- Europe: Belgium, BOKS; Denmark, DFPA; Finland, FFA; France, VML; Germany and Lithuania, ind. Patients; Italy, AIPAF; Netherlands, FSIGN; Norway, FPN; Poland, PFFA; Portugal, APL; Spain, ADAC; Sweden, SFA; Switzerland, Fabrysuisse; UK, MPS
- Australia: FSGA

## FIN Objective Statement

The primary aim of the Fabry International Network (FIN) is to facilitate collaboration between organisations to support those affected by Fabry disease.

It seeks to do this primarily through enabling communication, promoting best practice and acting as an independent forum for Fabry Associations.

## FIN Vision

A world for Fabry patients, families and caregivers where...

- Knowledge is shared
- Groups are successful ('it's a good news news story')
- Hope is instilled in all
- High expectations of scientific/medical advancements are met
- Physicians are well informed
- There has been progression from ERT to a cure
- All have an improved quality of life

## FIN Medical Advisory Board (MAB)

- Dr. Michael Beck  
Children's Hosp., Univ. of Mainz, Mainz, Germany
- Dr. Johannes (Hans) Aerts  
Chief Scientific Officer, Dept. of Medical Biochemistry, Univ. of Amsterdam, AMC, Amsterdam, The Netherlands
- Dr. Annick Raas Rothschild  
Specialist in Medical Genetics and Pediatrics, Hadassah Medical Center, Genetic Counseling Clinic, Jerusalem, Israel
- Dr. Stephen Waldek  
Consultant Renal Physician, Dept. of Nephrology, Hope Hospital, Manchester, United Kingdom

## FIN Participation and Support

- Fabry country organization representatives (patients, families, caregivers)
- Members and volunteers (committees)
- Medical community (medical advisory board, physicians, nurses, counselors, others)
- Industry and sponsors
- Researchers
- Government representatives
- Others

## FIN Values

- Transparency:
  - Guidelines for distribution of information (website/newsletters)
- Independence and neutrality:
  - From pharmaceutical, companies and financial sponsors
  - From any specific treatments, i.e. ERT, gene therapy, oral, other
  - From government institutions
  - From any special interest groups, i.e. physicians, culture, religion
- Patients' and caregivers' needs first
  - Recognize differences in patients' priorities, opportunities and choices within different countries and regions
- Integrity
  - Code of conduct (a set of rules)
  - High ethical standards; open to inspection and no decision in secret
  - Democratic; elected board of directors
  - Use consensus (unity) and collaboration in decision making
- Knowledge, education and learning from others
- Collaboration with other stakeholders
- Relationships
- Objective equality
- Justice and mercy for all members (reg. culture, religion, race, etc.)
- Balanced communication
- Open minded
- Humility
- Accountability
- Leadership by example

## Is your Fabry Organisation a FIN member?



If not, can you join FIN's efforts?



## FIN Objectives

- Support and educate individual country organizations via a global network to improve lives of Fabry patients, families and caregivers
- Develop positive and strong relationships with all stakeholders worldwide (patients, industry, medical experts, governments and others)
- Encourage and support research
- Establish a worldwide medical advisory board
- Ensure regular communication between country organizations, Fabry patients, their families and care givers, and other stakeholders
- Provide global meetings of all FIN member representatives

## FIN Board of Directors

- President: Rune Sedal, Norway, FPN
- Vice-President: Erica Schenk, Netherlands, FSIGN
- Treasurer: Kees Bosman, Netherlands, FSIGN
- Secretary: Adrian (Ed) Koning, Canada, CFA
- Board Members: Marlene Koning, Canada, CFA; Christina Graef Christensen, Denmark, DDF
- Past President: Rob van der Laan, Netherlands, FSIGN

The Board meets regularly via teleconference

## Long Term Plans and Objectives

- Reduce division between all stakeholders in the worldwide Fabry community
- One international meeting supported by Shire, Genzyme, Amicus, Protalix and other sponsors
- Move toward one international registry open to all research parties

## Current FIN Sponsors

