

Fabry International Network (FIN)

INTERACTION AND RELATIONSHIPS WITH THE PHARMACEUTICAL INDUSTRY

POLICY STATEMENT

The Fabry International Network (FIN) recognises the importance of maintaining relationships with the pharmaceutical companies that have FDA or EMA approved therapies or devices or who are developing therapies or devices for individuals with Fabry disease. Ethical relationships with companies are critical to ensuring that FIN provides accurate and unbiased education to individuals and their families affected by Fabry disease about available and future therapies or devices.

The role of the pharmaceutical industry is to provide an educational role to FIN about the benefits and risks of therapies and devices and to provide scientific and educational information. The information received from the pharmaceutical industry must be managed and tempered due to its conflicted nature.

Through interaction with FIN the pharmaceutical companies may gain unique patient perspectives in living with Fabry disease, information about the needs and priorities of FIN members as well as insight into clinical trial designs. This interaction also provides the opportunities for project collaboration including but not limited to disease focus groups, HTA surveys, medical education about diseases and advocacy for product (therapy / device) approval and reimbursement.

PRACTICES

The Fabry International Network Board of Directors are the primary liaisons with the pharmaceutical industry.

FIN should only accept funds from the pharmaceutical industry that are consistent with its charitable registration.

FIN should only accept funds for core activities on an unconditional basis.

Project funding should not be subject to any conditions set by the pharmaceutical industry. Any ensuing publication will be the property of FIN and any findings may not be quoted by the funder without the explicit permission of FIN.

FIN may accept funds from one or more pharmaceutical companies to host specific events.

FIN should mention the names of the sponsors supporting their website or electronic materials. Sponsor logo size and the space dedicated to the mention of the pharmaceutical company on the website should be modest and appropriate in size.

