

NATIONAL FABRY DISEASE FOUNDATION

PRIVACY POLICY

The National Fabry Disease Foundation (NFDF) is a nonprofit, tax-exempt organization dedicated to identifying people with Fabry disease, educating healthcare providers, patients and others about Fabry disease, providing assistance to Fabry patients as appropriate, and furthering research, information gathering, awareness, advocacy efforts and opportunities with respect to this disease. NFDF is not a health plan, health clearinghouse or health care provider and as a result is not subject to the HIPAA (Health Insurance Portability and Accountability Act) privacy rules. However, NFDF has adopted the following privacy rules to guide its operations.

Personal medical information. NFDF uses personal information, generally the identification of persons being treated, or at risk, for Fabry disease to provide information directly to these individuals and/or their family members about the disease and available resources. NFDF may disclose information if we believe that we are required to do so by law, or that by doing so is reasonably necessary to comply with legal process or respond to legal claims. If an individual with Fabry disease requests assistance from NFDF to facilitate healthcare, insurance or other services requiring disclosure of personal information, the NFDF will obtain a written consent from the individual prior to providing assistance.

Aggregate data. NFDF may, from time to time, provide aggregate data or information regarding persons being treated, or at risk, for Fabry disease to other organizations, health providers, government entities and others. Such aggregate data does not include personally identifying information about specific patients or individuals.

No sale or marketing. NFDF does not sell, rent, share or disclose information that identifies you personally to any other organization. NFDF does not release personal information to health plans or health care providers or others without your written consent.

Access to records. Individuals, by written request to NFDF's headquarters' office, may request a copy of information, if any, in NFDF's records regarding them. Individuals are asked to notify NFDF whenever contact or medical information should be updated.

Complaints. If an individual is ever concerned that information held by NFDF is inaccurate or has been used improperly they are encouraged to contact NFDF immediately. Every effort is made to resolve any problems or concerns.

Changes to this Policy. NFDF reserves the right to change any of its policies, including this policy, at any time. NFDF posts changes to its policy on its website. We encourage you to review our policies whenever you use our website.

Adopted 22 April 2006