

Privacy Statement of the Global Foundation for Peroxisomal Disorders

Adopted: February 23, 2017. Updated: June 2, 2018

Our Commitment to Your Privacy

Your privacy is important to us. To protect your privacy, The Global Foundation for Peroxisomal Disorders (referred to throughout as “us,” “we,” “our,” or “GFPD,” etc.) provides this notice explaining our information practices and the choices you can make about the way your information is collected and used.

The European Union’s new data privacy law, the [General Data Protection Regulation](#), went into effect on May 25, 2018 and applies not only to EU-based organizations, but also to anyone who has customers or contacts in the EU. As a global organization serving families affected by peroxisomal disorders as well as researchers around the world, the GFPD strives to be GDPR compliant.

Collection and Use of Personal Information

When you request information, enter your child into our registry, order a product or service, register using one of our forms, donate, or contact us offline, we may need your specific information to process your registration/request and reply promptly.

We may ask you for contact information (such as your name, email, and address) and demographic information (such as your zip code, gender, or age). We also collect demographic and profile data in our databases. We ask for health-related data about your child (such as diagnosis) to help us help you through our information, our programs, and our services. We use data you provide to tailor your experience at www.thegfpd.org, develop and distribute content that we think you might be interested in, and respond to your request for information or support.

In general, we use identifiable information to complete a transaction, as indicated in this statement. We do not provide your name and address or email to outside parties, except as described here. Please keep in mind that while we take reasonable precautions to safeguard your personal information no amount of protection can guarantee its security.

Links to Other Sites

The GFPD website, printed materials, and social media resources offer links to the websites of other organizations or resources. You acknowledge and agree that The GFPD:

- has no control over such sites and resources,
- is not responsible for the availability of such external sites or resources,
- does not endorse and is not responsible or liable for any materials, advertising, products, or other items on or available from such sites or resources, and
- will not be responsible or liable, directly or indirectly, for any damage or loss caused or alleged to be caused by or in connection with use of or reliance on any such materials or goods available on or through any such site or resource.

Monitoring of Information

The GFPD monitors customer traffic patterns and site usage to help us develop the design and layout of the GFPD website and social media resources. We may also use the information we collect to occasionally notify you about important changes to the website, social media resources, new programs or resources offered by The GFPD, and special announcements and information we think you will find valuable. If you would rather not receive this information, please contact us through one of the channels identified in "How to Correct or Update Information" (below).

Google Analytics is used to analyze traffic to this website. Google Analytics does not maintain individual profiles for visitors, nor does Google Analytics collect data that might identify the individual visitor. Google Analytics only collects aggregate data. Click here for more information about the Google Analytics [privacy](#) policy.

Protecting Personal Information

When you request information, enter your child into our registry, order a product or service, register using one of our forms, or contact us offline, we use a secure server. Donations and event registrations use the secure servers of our merchant providers (. Their secure server software, SSL (Secure Sockets Layer), encrypts all information you input before it is sent to us. Furthermore, all the customer transactional data we collect is protected against unauthorized access with the use of digital certificates. The digital certificates for www.thegfpd.org is issued by Let's Encrypt Authority X3.

Collection of Personally Identifiable Information and Cookies

We collect standard information, by way of a cookie, to help us evaluate how our sites are being used. A cookie is a small uniquely identifiable text file that is stored on your machine. A cookie collects information that is used for statistical purposes and does not identify you in any way.

Most web browsers automatically accept cookies, but you can change your browser settings to prevent that. Even without accepting cookies, you can still use most of the features throughout The GFPD website.

In accordance with the GDPR, site visitors have the right to access their data or "be forgotten" (to be permanently deleted from your databases). Our webhosting platform, Wix has developed two tools to assist all users in becoming GDPR compliant:

- Right to access data: <https://support.wix.com/en/article/getting-a-copy-of-your-customers-data>
- Right to have data forgotten: <https://support.wix.com/en/article/permanently-deleting-your-customers-data>

The GFPD does not share, sell, or exchange your information for third party fundraising, marketing, or research purposes.

Our Commitment to Children's Privacy

Protecting the privacy of the very young is especially important. We adhere to the 1998 Children's Online Privacy Protection Act (COPPA). (For more information, visit the Federal Trade Commission's [COPPA site](#).)

Special Considerations for Parents and Legal Guardians

Protecting the privacy of the very young is especially important. Children under age 18 are prohibited from entering GFPD's online support group area(s). Parents and legal guardians are encouraged to contact The GFPD at any time regarding privacy questions or concern. We will take steps to ensure that any person contacting us for a child's information is that child's parent or guardian.

The GFPD
PO Box 33238
Tulsa, OK 74135
Phone: 918-998-5798
Email: contactus@thegfpd.org

Notification Guidelines

The GFPD does not send unsolicited commercial communications to individuals with whom they do not have consent/permission or a pre-existing or current business relationship.

The GFPD provides all notified recipients with a clear, easy, and effective method to unsubscribe to all online communications.

How to Correct or Update Information

Here are the options for changing and modifying information previously provided.
Email or send a letter to:

The GFPD
PO Box 33238
Tulsa, OK 74135
Phone: 918-998-5798
Email: contactus@thegfpd.org

If you have any questions about this Privacy Policy or the practices of The Global Foundation for Peroxisomal Disorders, please contact us in writing at PO Box 33238, Tulsa, OK 74153, ATTENTION: Executive Director.

We do our best to ensure that all information posted on this website is accurate, respects copyright laws, and is non-defamatory. If you wish to bring our attention to content that you believe does not meet these standards, please contact us at contactus@thegfpd.org with the subject line: Web Content. Please include a link to the questionable webpage content along with your specific concerns. We will respond promptly.

We may update this Privacy Policy from time to time. If we do so, we will notify you by posting the date of the last change or amendment at the top of this page. You agree that this method of notice is sufficient and that you will regularly check this Privacy Policy to see if updates or changes have been made.

(The above will be placed on the contact and registry pages of thegfpd.org. The box must be checked before form can be filled out and submitted.)



I am voluntarily submitting contact information to the Global Foundation for Peroxisomal Disorders.