

# **The United Mitochondrial Disease Foundation (UMDF)**

## **Donor Privacy Policy**

UMDF maintains the highest level of respect for the privacy of its donors. In furtherance of our commitment to honor your rights, we have developed this Donor Privacy Policy to guide our staff and volunteers on how they may and may not use your personal information.

### **What information we collect**

We use personal information collected from donors for the purposes of processing payments and communicating with donors about UMDF as well as conducting the fundraising and other operations of UMDF. This information may include name, amount donated, address, telephone number, donor comments, e-mail address, and any other personal information provided to us (“Donor Data”). For donations by check, Donor Data also includes the data visible on the check.

### **How we use that information**

Donor Data may be used for these kinds of purposes:

- Distributing receipts and thanking donors for donations
- Informing donors about upcoming fundraising and other activities of UMDF
- Internal analysis, such as research and analytics
- Record keeping
- Reporting to applicable government agencies as required by law
- Surveys, metrics, and other analytical purposes
- Other purposes related to the fundraising operations

We do not publish, sell, trade, or rent Donor Data and never send out mailings on behalf of other organizations.

### **Financial information**

It is our internal policy to limit access to financial information to professional staff and volunteers who need to process that information for the purposes described above. Personal financial information is not sold to or traded with other parties.

We use partners to provide online payment processing services. If you pay by credit card, we do not store your credit card information, bank account numbers, or other financial account data sent directly to those processing services.

### **Contact us**

If you have questions about this Donor Privacy Policy or requests about the status and correctness of your donor data, please email [info@umdf.org](mailto:info@umdf.org) or write to:

United Mitochondrial Disease Foundation  
8085 Saltsburg Rd, Suite 201  
Pittsburgh, PA 15239  
USA

## **Security**

We are committed to protecting donor personal information from unauthorized access, alteration, disclosure, or destruction. Among other things, we undertake a range of security practices, including measures to help secure web access to sensitive data and undertake efforts to address security vulnerabilities for various tools and databases.

## **Updates**

We may change the Donor Privacy Policy from time to time. Any and all changes will be reflected on this page. Substantive changes may also be announced through the standard mechanisms by which we communicate with our users and community. You should periodically check this page for any changes to the current policy.

## **Data Retention**

We seek to retain donor-related information only as needed to fulfill the purposes described in this policy unless a longer retention period is required by law or regulations. For example, tax laws in the United States may require the Foundation to keep contact information and contribution level of donors on file.

## **Rights**

You have certain rights with respect to the information we collect about you. Upon request, we will tell you what information we hold about you and correct any incorrect information. We will also make reasonable efforts to delete your information if you ask us to do so, unless we are otherwise required to keep it.

UMDF subscribes to the Donor Bill of Rights that was created by the American Association of Fund Raising Counsel (AAFRC), Association for Healthcare Philanthropy (AHP), the Association of Fundraising Professionals (AFP), and the Council for Advancement and Support of Education (CASE). It has been endorsed by numerous organizations.

## **The Donor Bill of Rights**

Philanthropy is based on voluntary action for the common good. It is a tradition of giving

Philanthropy is based on voluntary action for the common good. It is a tradition of giving and sharing that is primary to the quality of life. To assure that philanthropy merits the respect and trust of the general public, and that donors and prospective donors can have full confidence in the not-for-profit organizations and causes they are asked to support, we declare that all donors have these rights:

1. To be informed of the organization's mission, of the way the organization intends to use donated resources, and of its capacity to use donations effectively for their intended purposes.
2. To be informed of the identity of those serving on the organization's governing board, and to expect the board to exercise prudent judgment in its stewardship responsibilities.
3. To have access to the organization's most recent financial statements.
4. To be assured their gifts will be used for the purposes for which they were given.
5. To receive appropriate acknowledgment and recognition.

6. To be assured that information about their donations is handled with respect and with confidentiality to the extent provided by law.
7. To expect that all relationships with individuals representing organizations of interest to the donor will be professional in nature.
8. To be informed whether those seeking donations are volunteers, employees of the organization or hired solicitors.
9. To have the opportunity for their names to be deleted from mailing lists that an organization may intend to share.
10. To feel free to ask questions when making a donation and to receive prompt, truthful and forthright answers.

The text of this statement in its entirety was developed by the Association of Fundraising Professionals (AFP), Association for Healthcare Philanthropy (AHP), Council for Advancement and Support of Education (CASE), and the Giving Institute: Leading Consultants to Non-Profits.