

Privacy Policy

Online Privacy Policy

Any person accessing, browsing, or otherwise using the International Rett Syndrome Foundation ("IRSF") Web site <http://www.rettsyndrome.org> ("Site") either manually or via an automated device or program, to the extent permitted hereunder, shall be considered a "User" under this privacy policy. All Users are bound by the terms of this privacy policy. IRSF is committed to protecting the privacy of our Users. This privacy policy discloses the privacy practices governing the use of information submitted to IRSF through this Site. Capitalized terms shall have the meaning designated in this privacy policy.

The Information We Collect

Anonymous Browsing Information

You can browse the Site without revealing personal information that can be used to identify you. IRSF may collect non-personal information such as your Internet Protocol ("IP") address, the name of the domain you used to access the Internet, the Web site you came from and the site you visit next (see "How We Use It," below). However, IRSF does not associate any non-personal information with records containing any personal information submitted to us, so you remain anonymous when you browse the Site.

Personal Information

IRSF may collect personal information such as names, company names, titles, addresses, telephone numbers, fax numbers, e-mail addresses, and payment information (such as credit card numbers) from Users. For example, IRSF may collect personal information submitted through online application and event registration and donation forms. By submitting personal information to this Site, the User acknowledges that he or she has read this privacy policy, understands it, agrees to its terms and authorizes IRSF to collect, use and disclose personal information pursuant to the terms of this privacy policy.

Cookies

This Site may use cookies. A cookie is a small file that your Web browser places on your computer's hard drive. It functions as an identification card, recording your passwords, purchases and preferences. Most browsers are initially set to accept cookies. You can set your browser to notify you when you receive a cookie, giving you a chance to decide whether or not to accept it. While IRSF may use cookies to track your visit to the Site and our servers automatically log the IP address of your computer, this information does not identify you personally and you remain anonymous, even if you have previously submitted personal information to IRSF through the Site or otherwise.

Third parties whose Web sites are accessible through links on the Site may also use their own cookies when you link to their site or service. IRSF does not control these third parties' use of cookies and cannot guarantee that they will uphold the same privacy standards as IRSF. IRSF expressly disclaims any and all liability related to the collection, use or disclosure of information by third parties. You should review the privacy policies of any third party sites that you visit through a link from the IRSF Site to understand how they use cookies and the information they collect through cookies.

Children

The Site is not intended for the use of unsupervised children under the age of 13. IRSF does not collect personally identifiable information from any person IRSF actually knows is under the age of 13.

How We Use It

Anonymous browsing information, including your IP address, may be used to gather broad demographic information. This information may be aggregated to measure the number of visits, average time spent, page views and other statistics about users of the Site. We also may use this data to monitor Site performance and to make the Site easier and more convenient to use.

IRSF uses personal information collected from Users, such as names and e-mail addresses, to respond to User inquiries, to process User applications for grants or participation in IRSF programs, to process User donations, to help organize fund-raising events and to inform Users of new programs and services.

Who We Share It With

Unless we have your consent or except as required by law, IRSF will not share your personal information with any person or entity other than those affiliated with IRSF, entities acting on behalf of IRSF and relevant third parties such as IRSF partnership program participants and sponsors. By submitting personal information through the Site, you authorize IRSF to share this personal information for the purposes identified, such as determining qualifications for grants, organizing fund-raising events, responding to User inquiries, processing donations, or determining eligibility for ISRF programs. If you do not want IRSF to disclose your personal information to third parties, you may opt-out by submitting a written request to IRSF at International Rett Syndrome Foundation, 4600 Devitt Drive, Cincinnati, OH 45246 Attn: Website Administrator. If you opt-out, you may not be able to participate in or qualify for IRSF grants, or fund-raising events or programs, you may not receive the information you requested, and IRF may not be able to inform you of new programs, events, developments, products and services. IRSF may share non-personal, non-individual information in aggregate form with third parties.

Notwithstanding other provisions of this privacy policy, we may disclose personal information in special cases when we have found it necessary to identify, contact or bring legal action against someone

who may be violating any user agreement or may be causing injury to or interference with IRSF, its Users, or anyone else that could be harmed by such activities. IRSF reserves the right to disclose your personal information as explicitly set forth in this privacy policy or any user agreement agreed to by you, or as otherwise required by government or law enforcement officials. IRSF can, and you hereby authorize us to, disclose any information to law enforcement or other parties that IRSF in its sole discretion, believes is required or appropriate in order to comply with the law.

Applicable Law/International Issues

Because we are committed to protecting your privacy, personal information that is submitted to this Site will be collected, processed, stored, disclosed and disposed of in accordance with applicable U.S. law. If you are a non-U.S. user, you acknowledge and agree that we may collect and use your personal data and disclose it to other entities, as discussed above in "Who We Share It With," outside your resident jurisdiction. In addition, such personal information may be stored on servers located outside your resident jurisdiction. U.S. law may not provide the degree of protection for personal information that is available in other countries. By providing us with your personal information, you acknowledge that you have read this privacy policy, understand it, agree to its terms and consent to the transfer of such information outside your resident jurisdiction. If you do not consent to the terms of this privacy policy, please do not use this Site, but if you have already provided us with personal information, please send us a written request IRSF at International Rett Syndrome Foundation, 4600 Devitt Drive, Cincinnati, OH 45246, Attn: Website Administrator, or send an e-mail to admin@rettsyndrome.org and let us know how you would like us to handle such information.

How to Access, Review and Update Your Information

Should your personal information need to be reviewed, updated, corrected or deleted, please submit your request in writing and send to IRSF at International Rett Syndrome Foundation, 4600 Devitt Drive, Cincinnati, OH 45246, Attn: Website Administrator, or send an e-mail to admin@rettsyndrome.org

Opt-Out Policy

You may request not to be contacted by the IRSF in connection with any new services, updates, programs or promotions. Requests not to be contacted by the IRSF should be sent in writing to IRSF at International Rett Syndrome Foundation, 4600 Devitt Drive, Cincinnati, OH 45246, Attn: Website Administrator, or send an e-mail to admin@rettsyndrome.org You also may make your request

verbally by calling (800) 818-RETT.

Security

This Site has security measures in place to protect against the loss, misuse and alteration of information under our control. However, we cannot guarantee that such security measures will be sufficient, will not be breached, and that your personal information may not be disclosed or otherwise accessed in an unauthorized manner. Certain information may be transmitted to you by electronic mail. Although it is illegal to intercept or disclose these messages under Federal law, these transmissions are not secured.

Online Policy Changes

This privacy policy may be modified. Any changes to the IRSF online privacy policy will be posted on the Site. All information submitted through this Site is subject to the terms and conditions of this privacy policy, as it may be amended from time to time.

How to Contact Us

If you have any questions about the Site, our privacy policy or the information we collect, please contact us at International Rett Syndrome Foundation, 4600 Devitt Drive, Cincinnati, OH, 45246, Attn: Website Administrator, or send an e-mail to admin@rettsyndrome.org.

Direct Mail Privacy Policy

Any person or organization that makes a financial contribution in response to a International Rett Syndrome Foundation ("IRSF") Direct Mail Program solicitation shall be considered, to the extent permitted hereunder, to be a "Donor" under this privacy policy. IRSF and all Donors are bound by the terms of this privacy policy. IRSF is committed to protecting the privacy of our Donors. This privacy policy discloses the privacy practices governing the use of information submitted to IRSF through its Direct Mail Program solicitations. Capitalized terms shall have the meaning designated in this privacy policy.

The Information We Collect

Personal Information

IRSF may collect

personal information such as names, company names, titles, addresses, telephone numbers, fax numbers, e-mail addresses, and payment information (such as credit card numbers) from Donors. For example, IRSF may collect personal information submitted from Donors via return mail or during telephone calls. IRSF may also collect such information by appending from "public records" such as, but not limited to, United States Postal Change of Address (COA) information and local and state government records. The IRSF may also append information to its Direct Mail files concerning the Donors' volunteer activities on behalf of the IRSF such as, but not limited to, participation in local chapter fund-raising events. By submitting personal information to the IRSF, Donors acknowledge that they have read this privacy policy, understand it, agree to its terms and authorize IRSF to collect, use and disclose personal information pursuant to the terms of this privacy policy.

Children

The IRSF does not knowingly solicit contributions from individuals under 18 years of age. Because IRSF obtains prospective new donor names from such lists as magazine subscribers, which do not append the age of subscribers, it is occasionally unavoidable.

How We Use It

The IRSF uses personal information collected from Donors, such as names and e-mail addresses, to respond to Donor inquiries, to process Donor requests for information, for issuing donation receipts, to help in deciding who receives future Direct Mail Program solicitations, to process User donations, to help organize fund-raising events, and to inform Donors of new programs and services.

Who We Share It With

The IRSF does—;from time to time—;share the names and addresses of its donors with other worthwhile organizations. We do not, however, share telephone numbers, e-mail addresses, or any financial information about any person. This process enables us to introduce thousands of new volunteers to International Rett Syndrome Foundation's efforts and provides significant funds to help support our vital research and care programs. If you do not want us to share your name and address, please contact us by calling (800) 818-RETT or by sending an e-mail to: admin@rettsyndrome.org. You also may write to us at International Rett Syndrome Foundation, 4600 Devitt Drive, Cincinnati, OH 45246 ATTN: Direct Marketing.

Notwithstanding other provisions of this privacy policy, we may disclose personal information in special cases when we have found it necessary to identify, contact or bring legal action against someone who may be violating any agreement or may be causing injury to or interference with IRSF, its Donors, or anyone else that could be harmed by such activities. The IRSF reserves the right to disclose your personal information as explicitly set forth in this privacy policy or any agreement agreed to by you, or as otherwise required by government or law enforcement officials. The IRSF can, and you hereby authorize us to, disclose any information to law enforcement or other parties that the IRSF in its sole discretion, believes is required or appropriate in order to comply with the law.

IRSF Disclosure Policy

The IRSF does communicate directly to Donors (both new and continuing) to its Direct Mail Program, at least annually, a means for both new and continuing donors to inform IRSF that they do not want their names and addresses shared outside the IRSF.

Applicable Law/International Issues

Personal information that is submitted to the IRSSF will be collected, processed, stored, disclosed and disposed of in accordance with applicable U.S. law. If you are a non-U.S. donor, you acknowledge and agree that we may collect and use your personal data and disclose it to other entities, as discussed above in "Who We Share It With," outside your resident jurisdiction. In addition, such personal information may be stored on servers located outside your resident jurisdiction. U.S. law may not provide the degree of protection for personal information that is available in other countries. By providing us with your personal information, you acknowledge that you have read this privacy policy, understand it, agree to its terms and consent to the transfer of such information outside your resident jurisdiction.

How to Access, Review and Update Your Information

Should your personal information need to be reviewed, updated, corrected or deleted, please submit your changes to IRSF at International Rett Syndrome Foundation, 4600 Devitt Drive, Cincinnati, OH 45246 , Attn: Direct Marketing, or send an e-mail to admin@rettsyndrome.org, or call toll-free (866) 818-RETT.

Policy Regarding Removing Names from Mailing List

You may request not to be contacted by the IRSF in connection with any solicitations, new services, updates, programs or promotions. Requests not to be contacted by the IRSF may be made by writing the International Rett Syndrome Foundation, 4600 Devitt Drive, Cincinnati, OH 45246 , Attn: Direct Marketing, or send an e-mail to admin@rettsyndrome.org, or call toll-free (866) 818-RETT.

It is IRSF policy to remove (flag) names from our mailing list immediately upon request. It is important to point out that we legally cannot remove a name (record) from our database if that record contains information concerning donations. The record is marked to receive no other mailings (flagged).

It is IRSF policy not to remove names from our mailing list unless the request to take such action is communicated by Donors or their legal representatives. Requests to take such action by other third parties cannot be honored.

It is IRSF policy to inform Donors requesting that their names be removed from our mailing list that they may contact the Direct Marketing Association (DMA) at (212) 790-1488 or via the World Wide Web at www.dmaconsumers.org to request that their names be placed on the national Pander List. This list is used by most nonprofit and commercial mailers similar to IRSF to take reasonable care not to mail to those persons not wanting to receive any type of solicitation mail.

Security

IRSF data files have security measures in place to protect against the loss, misuse and alteration of information under our control. However, we cannot guarantee that such security measures will be sufficient, will not be breached, and that your personal information may not be disclosed or otherwise accessed in an unauthorized manner. Certain information may be transmitted to you by electronic mail. Although it is illegal to intercept or disclose these messages under Federal law, these transmissions are not secured.

Direct Mail Privacy Policy Changes>

This privacy policy may be modified. Any changes to the IRSF Direct Mail privacy policy will be posted on the IRSF Web Site (www.rettsyndrome.org) All information submitted through this Site is subject to the terms and conditions of this privacy policy, as it may be amended from time to time.

How to Contact Us

If you have any questions about our privacy policy or the information we collect, please write to the IRSF at International Rett Syndrome Foundation, 4600 Devitt Drive, Cincinnati, OH 45246 , Attn: Direct Marketing, or send an e-mail to admin@rettsyndrome.org, or call toll-free (866) 818-RETT.