



PURA Syndrome Foundation

Data Protection & Privacy Policy

This policy document sets out how the PURA Syndrome Foundation collects, stores and uses the personal data you share with us, for example when you send us contact information, fundraise for us, make donations or provide images for our website. It describes the information we collect, how long we will retain it for, who will have access to it and your rights, such as your right to access the information we hold about you.

Policy Summary

Please read our policy describing how the PURA Syndrome Foundation collects, stores and uses the personal information you share with us. It describes what information we collect, how long we will retain, who will have access to it and your rights. This is a summary of the policy:

We collect personal information allowing us to contact you, including your name, child's name, address and email. We may use this contact information to send you:

- Updates for research projects being conducted by the PURA Syndrome Foundation and PURA Syndrome Global Research Network
- Opportunities to be included in new research involving the PURA Syndrome Foundation
- PURA Syndrome Foundation periodic newsletters and reports
- Information about fundraising activities
- Other PURA syndrome-related news

We collect information about our supporters, fundraisers and volunteers to enable us to contact you about your fundraising, donations, volunteering and buying merchandise and to meet our legal requirements to maintain accurate financial records. We only collect the information we need to provide the best possible service to the PURA syndrome community.

Data provided when you first contact the PURA Syndrome Foundation is stored for as long as necessary. Other data, such as financial records of donations, are retained as long as is necessary to meet our legal requirements. For purposes other than our support services (e.g. fundraising, volunteering) we will seek to check your consent (to contact you) every three years.

We protect the security of the data you provide us, including using the latest encryption technologies and secure backups. The data storage company has robust policies in place and we would be happy to share these with you on request.

We will never sell or otherwise share your personal data with third parties for marketing purposes. Personal (i.e. identifiable), data would only be shared for other purposes if we were required by law to do so or we had your explicit, express consent.

You have a number of rights, including the right to access the data we hold about you and the right to ask us to delete all data we hold about you at any time.

We may change this policy from time to time, e.g. to react to changes in the law or guidelines from appropriate regulators. Please check our website (purasyndrome.org) regularly for details of any changes.



Full Data Protection & Privacy Policy

Who we are

We are the PURA Syndrome Foundation.

The PURA Syndrome Foundation is a globally focused charitable organisation, registered in the USA as a 501(c)(3) tax-exempt non-profit corporation. The Foundation supports and educates patients and their families, providing a global community. Governed by volunteer international board members, the Foundation provides the global PURA community with a place to belong. For those isolated by rare disease, the Foundation provides access to medical research being completed and educates people about the condition. We keep our families informed by organizing a yearly global conference, developing educational materials and sending out quarterly newsletters.

In this policy,

'we', 'us', 'our' or 'Foundation' refers to the PURA Syndrome Foundation;

'you' or 'your' means any person(s) from or about whom we collect personal information/data;

'Our website' refers to www.purasynndrome.org;

'Personal information/data' is information that can be used to identify a living individual, for example name, address, telephone number or email address.

Your privacy

Protecting your privacy is one of our top priorities. Please take a few minutes to read the following carefully to understand our views and practices regarding your personal data and how we will treat it.

We take your privacy seriously and adhere to the Principles of the General Data Protection Regulation (GDPR) and relevant European Union Data Protection Directives such as the Privacy and Electronic Communication Regulations (PECR). For help and guidance about any aspect of the law relating to privacy and data protection, visit the EU GDPR information portal at <https://www.eugdpr.org/>

Our privacy commitment

This document sets out the basis on which the PURA Syndrome Foundation will process any personal data we collect from you. We will make every effort to protect your privacy by adopting strict company policies on the storage and use of personal information. This privacy policy has been developed in accordance with our legal support and may be updated from time to time. We will post revisions on our website.

Language of Terms

Where this Privacy Policy has been translated into a language which is not English, that has been done for your convenience only to aid your interpretation of our policy. The English language version shall prevail in the event of any conflict between the English language version and a version in any other language.



What information do we collect?

We collect various different types of personal information:

1. When we collect your Personal Contact Information

Family Information

Your contact details, including your full name, address, email address, telephone number, country you are living in and the name and date of birth of your PURA family member, will be collected and stored. This information only occurs with your consent, gained when you first provide the data. The information you provide to us, will be stored in our electronic database.

We only collect this information from you if you choose to provide it to us. You can ask us to delete or change your data at any time by emailing us at info@pura-syndrome.org.

Our basis for collecting and storing your name, address, email address, telephone number and country you are living in, enables us to:

- Answer your question(s)
- Communicate with you about new research opportunities
- Provide you with PURA Syndrome research updates
- Send you periodical newsletters, fundraising updates and other PURA related news
- Help connect families who live near each other, speak the same language or have children of the same age
- Determine countries / areas where we need to expand our services
- Provide you with country / area / age specific PURA information

Professional Information

We collect contact information from clinicians and researchers in order to provide global contacts for PURA families and their treating doctors. You can choose to terminate this contact information and/or have your data altered or deleted at any time by emailing us at info@pura-syndrome.org.

2. When you make a financial transaction, such as a donation.

We collect information about our sources of income in order to produce accurate financial statements and to comply with the law relating to the retention of financial data.

The Foundation uses Network for Good to process our donations. When you make a donation via Network for Good we collect certain information to enable us to process the transaction. This information includes your name, address, email address and credit/debit card details, reason for donation (if provided) and amount of donations made. When making a donation, each donor has the option of anonymity. We recommend that you consult Network for Good's data protection policy on their website <https://www.networkforgood.com/about/privacy-eu/>

If you make a payment or a donation by any other method, e.g. post, cheque/check, direct debit, we retain a paper record of financial transaction. This is shared with our chosen auditors and if we are legally required to disclose it, to the relevant authorities. By voluntarily submitting your personal information to us, you are consenting to the use of your personal information for effecting a payment or donation.



3. When you fundraise or volunteer for Foundation:

We collect and store your contact details, including your name, address, telephone number and email address, plus any other information you provide voluntarily, such as your reason for fundraising/volunteering. We also store details of your online fundraising page(s) and the event(s) you are taking part in or the fundraising/volunteering/awareness-raising you are undertaking.

Our bases for collecting and storing this data are that this meets our legitimate interests, to raise the funds we need to meet our mission of to serve, educate and fund research for families coping with the effects of PURA syndrome. We also need to maintain accurate financial statements and taxation records.

When contacting us about fundraising, we will store emails you send us. We collect this information to enable us to send administrative messages, to thank and support you, send you fundraising materials and contact you in case of query. This information also enables us to meet our legal requirements to accurately produce accounts/ financial statements.

4. When you agree to be contacted by the PURA Syndrome Foundation about other topics and updates:

We also ask PURA syndrome families for their consent for us to:

- Communicate with them about new research opportunities
- Provide PURA syndrome research updates
- Send out periodical newsletters, fundraising updates and
- Other PURA related news

You can choose not to be contacted about these topics at any time by emailing us at info@pura-syndrome.org.

5. When you agree to provide images and/or your personal story to the PURA Syndrome Foundation:

PURA syndrome families have the option to provide us with a personal story and/or images of their child. This includes use of the personal story and/or images on:

- The purasyndrome.org website
- In social media pages specifically operated by the Foundation
- In promotional and fundraising materials both online and printed
- In educational materials, both online and printed.

By agreeing to this, you waive any rights of financial compensation or ownership of what you provide us. You can choose to remove your personal story or image at any time by emailing us at info@pura-syndrome.org.



6. When you consent to us for making recordings of your presentations during our annual conferences:

Presenters at the annual PURA Syndrome Foundation Conference will be asked to allow us to record and use their full presentation for informational/educational purposes. The presentations will be recorded in whole as an mp4 media file and after consent will be shared on our website and on the PURA Syndrome Foundation social media sites (youtube, facebook, twitter).

By agreeing to this, you waive any rights of financial compensation or ownership of what you provide us. You can choose to revoke your consent at any time by emailing us at info@pura-syndrome.org.

7. When you register to attend our annual PURA Syndrome Foundation Conference

When you register to attend our annual conference, we will collect your personal contact information to allow us to organise the conference and provide you with regular updates. This contact information includes your name, address, email, telephone number, country you live in and the name of your PURA family member. Any other personal information, like dietary wishes, need for assistance or preferred language will only be used to organise the conference. This information will be shared with the venue of the conference, caterers or co-organisers, relevant suppliers and contractors of the conference (where applicable).

8. PURA Syndrome Foundation committees and Global Research Network.

When contacting members of the PURA Syndrome Foundation board or committees, we may store any emails you send us. This information you provide us with will be kept confidential and will not be shared with any other party. Unless we have your consent or except as required by law, we will not share your personal information with any person or entity other than those affiliated with PURA Syndrome Foundation, entities acting on behalf of PURA Syndrome Foundation and relevant third parties such as PURA Syndrome Foundation committees and PURA Syndrome Global Research Network.

9. Each time we process your data, we must have a 'Legal Basis' for doing so.

GDPR (EU Regulation 2016/679) states that in order to collect, store or process different categories of data, organisations who are 'data controllers' need to meet one or more of a number of 'legal bases for processing' data. This includes Specific, Informed Consent (i.e. where you have given your consent, such as when you join us as a member or agree to us contacting you about other relevant topics), Meeting our Legitimate Interests as a charity (except where this would override your individual rights or interests), Meeting our Legal Requirements (e.g. to maintain accurate financial statements under the Companies Act, 2006) and Carrying out the requirements of a Contract.

For further information about these legal bases for processing data, please see the EU GDPR information portal at <https://www.eugdpr.org/>



10. Data Security and Access

Keeping your data safe

The PURA Syndrome Foundation will hold your personal information in confidence. The PURA Syndrome Foundation will take all reasonable measures ensuring that your information is not compromised in any way. As the information you provide us is of a personal nature, we safeguard your privacy by storing this information on password-protected drives. 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 U.S. Federal law, these transmissions are not secured.

We have a contractual relationship with a provider of bulk email and storage services and store limited data on their secure servers to enable us to communicate with you cost effectively. While we cannot absolutely guarantee that loss, misuse or alteration of data will not occur, we use our very best efforts to prevent this.

Google

Google Analytics uses cookies and usually stores them outside of the EU/EFTA area. Google uses this information in order to evaluate the use of the website for PURA Foundation and to compile reports on website activities and the use of the Internet. In addition, Google states that it transmits this information to third parties, if this is required by law or if third parties process the data on behalf of Google. The IP address transmitted by the browser in the context of the use of Google Analytics is not combined by Google with other data. Users can prevent the storage of cookies (cf. "cookies" above). Users can also prevent the transmission of the data generated by the cookie concerning their use of the website (incl. IP address) to Google, and also the processing of such data by Google, by downloading and installing the browser plugin which is available under the following link:

<https://tools.google.com/dlpage/gaoptout?hl=de>

<https://cloud.google.com/security/gdpr/>

Facebook

On the basis of statutory requirements, the PURA Syndrome Foundation website and social media pages contain information which permit rapid electronic contact with our Foundation and also direct communication with us, which also includes a general address by electronic mail (email address). If a data subject contacts the controller by email or via a contact form, the personal data transmitted by the data subject will be automatically stored. The personal data which have been voluntarily transmitted to the controller by a data subject will be stored for the purposes of dealing with enquiries or contacting with the data subject. The personal data will not be passed on to third parties.

Other Social Media

Social media platforms generally collect personal data in performing their services to platform users. The purpose and scope of such data collection and the further processing and use of the data by the social networks, as well as the user's rights in this regard and the setting options for the protection of the user's private sphere, are set out in the data protection provisions of the social platforms. The user can prevent the social networks collecting data about the websites he has visited by logging off before visiting the websites.



Who can access your data?

Our Foundation Board members have access to your basic personal information. Unless we have your consent or except as required by law, we will not share your personal information with any person or entity other than those affiliated with PURA Syndrome Foundation, entities acting on behalf of PURA Syndrome Foundation and relevant third parties such as PURA Syndrome Foundation committees and PURA Syndrome Global Research Network.

We may also use third party companies to provide services on our behalf. This could include services such as bulk email services, in order that we can communicate with you in the most cost-effective way. In these cases, data will be stored on the third parties' servers and we will ensure that we have undertaken appropriate due diligence and have agreements in place which commit them to high levels of data security and confidentiality. However we cannot guarantee your email or any attachments will be encrypted.

We may disclose personal information if required to do so by law or if we have reasonable grounds to believe that such action is necessary to protect and defend the rights, property or personal safety of the Foundation.

11. Translation

Information you provide for our website may be translated by a third-party on request. PURA Syndrome Foundation will take all reasonable measures to insure that your information is not compromised in any way.

12. How long do we keep your information?

We keep your information for only as long as is necessary to provide you with the services and information needed to service you, unless and to the extent that a longer time is necessary, required by law, or until you ask us to erase it. We will contact families every 3 years to ask you to update us about the data we hold in our database about you and/or your family. You will receive a copy of the data we hold (using a 'database form') and you will be asked to update this. We will erase any data on request.

13. Your Rights

Under the GDPR, individuals have a number of rights concerning their personal information and we will adhere to these:

You have the right to be **informed** about how and why we collect, store and use your information. We will do this when we collect your information, or when you sign up to receive emails through our website. This Privacy Policy is available on the PURA Syndrome Foundation.

You have the right to **access** the personal information we hold about you. You can request this verbally or in writing and when we receive such a request we will endeavor to respond quickly but within a maximum of one month. This is called a Subject Access Request (SAR) and there is no charge.



Following this you have a right to request that any data held about you that you feel is inaccurate is **rectified** or completed if incomplete.

You also have the '**right to be forgotten**', i.e. for all data we hold about you to be erased and also to require us to restrict or 'suppress' how we use your data (you might for example be happy for us to store it but not process it for certain purposes). Again, we will respond as quickly as we can to such requests but within a maximum of one month.

To make a request, for example to access the information we hold about you, email us at info@pura-syndrome.org.

For help and guidance about any aspect of the law relating to privacy and data protection, visit the EU GDPR information portal at <https://www.eugdpr.org/>

14. Websites

The Foundation's website purasyndrome.org may contain links to selected websites which we feel may be of interest. Please note that once you use one of these links to leave our website, we do not have any control over that other website. Please exercise caution and refer to their privacy policy and/or terms & conditions of use before providing any personal information as we cannot be held responsible for the protection or privacy of any information you provide to a third party.

The PURA Syndrome Foundation website may be used for personal, non-commercial informational or entertainment purposes only. You may not copy, reproduce, reuse, retransmit, adapt, publish, frame, post, upload, modify, broadcast or distribute any website content in any way, including for any public or commercial purpose whatsoever, without our prior written permission. You may not use any third parties' likenesses, names, images and/or properties without their express permission. Please email us at info@pura-syndrome.org with any questions regarding this.

Any questions?

If you have any questions or concerns about how we protect your personal information, please contact us info@pura-syndrome.org.

If you have a complaint and we can't come to a solution together, you have the right to file a complaint at the Office for Civil Rights (OCR) – <https://www.hhs.gov> and/or Federal Communications Commission (FCC) – <https://www.fcc.gov>.

Changes to this Policy

We may make changes to this policy from time to time, for example to update it to reflect changes in the law or guidelines from appropriate regulators such as the EU GDPR information portal at <https://www.eugdpr.org/>

Please check our website purasyndrome.org regularly for details of any such changes.



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