



PURA Syndrome Foundation data consent form

In this document:

- 'we' means the PURA Syndrome Foundation;
- 'you' means any person(s) about whom we collect non-personal and/or personal information (parent of child with PURA Syndrome).
- 'Media' means photos, video and/or sound files

Contact information / personal data

Purpose

The purpose of collecting this information is to allow us to contact you and provide you with information concerning the PURA Syndrome Foundation, updates for research being completed by the PURA Syndrome Global Research Network or other PURA related news.

Providing information is voluntary and is not mandatory for involvement with the PURA Syndrome Foundation.

Parent's full name: _____
Email: _____
Address: _____
Country: _____
Telephone No: _____

Would you like to help?

Every now and then, The PURA Syndrome Foundation can use your help. If you are willing to help us and have any skills or experience that you think could be of use to us, please let us know by stating them below. We reserve the right to keep this information on file and to contact you directly if and when the need arises. Thank you.

Usefull skills/experience: _____

Consent for use of your personal media

Purpose

The purpose of asking your consent to use your media, is for us to be able to use the images or video to promote PURA syndrome and the PURA Syndrome Foundation. This includes use on our website, social media, in promotional and fundraising materials and publications, both online and printed. By consenting, you waive any rights of compensation or ownership thereto.

By checking the yes-box, you consent to having media be used for purposes of the PURA Syndrome Foundation. If you don't want to give us such consent, please select "no".

- Yes, I give the PURA Syndrome Foundation consent to use media containing me and/or my child.
 No, I DO NOT give the PURA Syndrome Foundation consent to use media containing me and/or my child

I, _____ (full name parent), parent of _____ (full name child), have read the contents of this data consent form and the privacy policy of the PURA Syndrome Foundation (see other side). I agree to my contact information being stored by the PURA Syndrome Foundation, as per their data policy documentation. If I checked the yes-box, I also consent to the use of media containing me and/or my child.

Parent's name (printed): _____

Signature of parent: _____

Date: _____



PURA Syndrome Foundation privacy policy and consent to use of data

Our use of your information

As the information you provide is of a personal nature, we use your information only for its intended purpose. We do not sell or trade your information to other organizations or individuals. 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 medical research teams.

We will endeavor to contact you at least once a year with a complete copy of the information we hold on your family in the database. You can amend, update and add to your information, or have your records deleted as you choose.

We respect your confidentiality

The PURA Syndrome Foundation will hold your personal information in confidence. The PURA Syndrome Foundation will take all reasonable measures to insure 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. Our drives and office-space 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 U.S. Federal law, these transmissions are not secured.

Can you access the information we hold about you, amend, update or add to it or cease involvement?

We keep your information for only as long as is necessary. If you choose to be involved in providing personal details to the PURA Syndrome Foundation, you can at any time decide to stop providing additional information and ask to cease involvement.

You have the right to access information stored about you by the PURA Syndrome Foundation. We can then provide you what personal data is stored and who has access to your data.

If you wish to access the information we have stored, want to amend, update or add to it, or cease involvement in the registry, please send us a written request at d.spadafore@pura-syndrome.org

Applicable Law/Global Users

Because we are committed to protecting your privacy, personal information that is submitted 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, 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 have any questions about our website or our privacy policy, please contact us at d.spadafore@pura-syndrome.org

Full details of our data policy can be located at www.purasyndrome.org/foundation