

PTENUKI Privacy and Data Policy - Last Updated 30/11/2023, Ian Stock

This privacy policy sets out how the PTENUKI uses and protects any information that you give the PTENUKI.

Who We Are

1. PTENUKI are a charity-based patient support group based in the UK which was started and still run by patients and families affected by the rare genetic condition PTEN Hamartoma Tumour Syndrome (PHTS).
2. Our charitable aims are to help and improve the lives of anyone impacted by PHTS through better patient support, more accurate and accessible information, greater awareness and education, and support of research and improved care.

Information we collect and how we use it

3. PTENUKI only collects unique/identifiable information about you when you specifically and knowingly provide such information (for example, when signing up for an event, our newsletter, or submitting a 'contact us' form). We will never pass on your details to anyone else without your explicit consent. We will only use your personal data when absolutely needed, with due justification and where law permits.
4. Website: We use cookies and website analytics to analyse and understand the performance of our website and most viewed / useful content.
5. Patient Days & Events: We explicitly collect personal information for event attendees to plan and deliver our events, and to make sure we can address health and safety needs. We may ask for e.g. medical needs or dietary information related to the event, attendee age, or financial information of attendees if requesting travel expenses.
6. Newsletters: We collect your email address and marketing consent if you sign up for our newsletter. You can unsubscribe at any time through the original email or by mailing info@ptenuki.org and requesting to be unsubscribed.
7. Videos or Promotional Material: We will always explicitly request your consent if we take video recordings or photographs of you during our events. We will always explicitly request your consent before publishing blog posts, social posts and any general messages that contain personally identifiable information about you.

Data Privacy and Security

8. We ensure all personal data is stored securely and retained only as long as necessary, in accordance with GDPR principles.
9. We only use your personal data when there is consent to do so and in the interest of meeting our charitable objectives.
10. Apart from as mentioned above for event organisation and health & safety, we do not collect any sensitive personal data such as race, ethnic background, health data, financial data, genetic data, biometric data, sexual orientation, political opinions, religious or philosophical beliefs, trade union memberships, credit worthiness, student data or government identifiers.
11. Our website contains links to other useful websites. Once you click on these links to leave our site, we are not responsible for and do not have any control over that other website and such sites are not governed by the privacy policy.
12. You may request a copy of your personal data or your personal data to be deleted by emailing info@ptenuki.org.

Who can I ask if I have additional questions?

13. If you have any questions about this privacy policy, please contact: info@ptenuki.org.