ReNU Syndrome UK

Data Protection, Privacy and Cookies Policy

1. Policy Statement

1.1 Commitment to Protecting Personal Information

ReNU Syndrome UK ("the Charity") is committed to protecting the privacy, dignity, confidentiality and security of everyone who engages with the Charity.

We recognise that families affected by rare disease often share deeply personal information with us, including medical information, family circumstances, emotional experiences, photographs, stories and sensitive personal details connected to the care and wellbeing of children and vulnerable individuals.

We understand that families place significant trust in us when sharing this information.

Protecting that trust is extremely important to the Charity.

We are therefore committed to handling personal information carefully, respectfully, transparently and securely.

This policy explains:

- what information we may collect;
- why we collect it;
- how we use it;
- how we keep it safe;
- when information may be shared;
- how long information may be retained; and
- the rights individuals have regarding their personal information.

We appreciate that privacy policies can often feel overly legal or difficult to understand. We have therefore tried to write this document in a way that is both clear and informative so that families, supporters and volunteers understand how and why their information may be used.

The Charity is committed to ensuring that personal information is always handled in accordance with:

- the UK General Data Protection Regulation (UK GDPR);

- the Data Protection Act 2018;
- safeguarding responsibilities;
- Charity Commission expectations; and
- broader principles of confidentiality, dignity and respect.

Because ReNU Syndrome UK works closely with children, families and vulnerable individuals, we apply particularly high standards when handling:

- medical or health-related information;
- photographs and videos;
- safeguarding information;
- information relating to children;
- disability-related information;
- personal family circumstances; and
- private communications shared in confidence.

The Charity also recognises that privacy and safeguarding are closely connected.

In many situations, protecting personal information is an important part of protecting people from harm.

At the same time, there may occasionally be situations where safeguarding responsibilities require information to be shared appropriately in order to protect a child or vulnerable individual from harm.

Where this occurs, the Charity will always seek to act proportionately, responsibly and in the best interests of the individual concerned.

This policy applies to all individuals who engage with ReNU Syndrome UK, including:

- beneficiaries and families;
- donors and supporters;
- volunteers and trustees;
- event participants;
- healthcare professionals and researchers;
- contractors and consultants; and

- users of the Charity's website, social media pages or online support platforms.

2. Data Controller

ReNU Syndrome UK is the data controller for the purposes of UK GDPR.

The Charity determines how and why personal information is processed.

Questions relating to this policy or to the handling of personal data should be directed to:

Data Protection Lead

ReNU Syndrome UK

24 Petrel Way, Leeds, LS27 8GB

Email: renusyndromeuk@outlook.com

The Board of Trustees retains overall accountability for ensuring compliance with data protection obligations.

3. Legal and Regulatory Framework

This policy has been developed with reference to:

- UK GDPR;
- Data Protection Act 2018;
- Privacy and Electronic Communications Regulations (PECR);
- Human Rights Act 1998;
- Children Act 1989 and 2004;
- Care Act 2014;
- Charity Commission safeguarding guidance;
- Information Commissioner's Office (ICO) guidance; and
- other applicable safeguarding and charity law obligations.

The Charity recognises that data protection and safeguarding obligations often operate together.

Where safeguarding concerns arise, the Charity may need to share information appropriately in order to protect children or vulnerable individuals from harm.

4. Principles of Data Protection

ReNU Syndrome UK is committed to processing personal data in accordance with the core principles established under UK GDPR.

Personal information shall be:

- processed lawfully, fairly and transparently;
- collected only for specified and legitimate purposes;
- limited to what is necessary;
- accurate and kept up to date where possible;
- retained only for as long as necessary;
- processed securely and confidentially; and
- protected against unauthorised access, misuse, loss or disclosure.

The Charity recognises that trust is central to its relationship with families and supporters. Personal information must therefore never be handled casually or without appropriate consideration.

5. How We Collect Information

The Charity may collect information directly from individuals whenever they engage with ReNU Syndrome UK.

In many cases, information is provided voluntarily by families, supporters or volunteers who contact the Charity seeking support, information, connection with other families, involvement in events or participation in the Charity's activities.

Information may be collected when individuals:

- contact the Charity by email, telephone, social media or online forms;
- register for events or conferences;
- participate in support groups or online communities;
- make donations or fundraising contributions;
- volunteer with the Charity;
- subscribe to newsletters or updates;
- share personal stories, experiences or photographs;
- complete surveys or feedback forms; or
- engage with trustees or volunteers.

Because the Charity works within a rare disease community, families may sometimes share highly sensitive information in the course of ordinary conversations.

For example, families may discuss:

- diagnoses;
- medical procedures;
- treatment journeys;
- educational needs;
- emotional wellbeing;
- hospital experiences;
- safeguarding concerns; or
- financial and caring pressures.

The Charity understands that this information is deeply personal.

Trustees and volunteers are therefore expected to handle such information with sensitivity, discretion and respect.

The Charity may also occasionally receive information indirectly through:

- healthcare professionals where consent exists;
- safeguarding referrals;
- fundraising platforms;
- partner organisations;
- publicly available sources;
- event booking systems; or
- social media interactions.

We aim to ensure that individuals understand why information is being collected and how it may be used.

Where possible, we seek to collect only the information that is reasonably necessary for the relevant purpose.

6. Types of Information We May Collect

The Charity may process personal information including:

- names;
- addresses;
- telephone numbers;
- email addresses;
- emergency contact information;
- donation records;
- volunteer records;
- event participation details;
- photographs and videos;
- communication preferences;
- correspondence;
- safeguarding information;
- DBS-related information where appropriate; and
- information relating to health, disability or support needs where voluntarily provided.

Some information processed by the Charity may constitute “special category data” under UK GDPR.

This includes information relating to health conditions, disability, genetic conditions or safeguarding matters.

Such information shall only be processed where there is an appropriate lawful basis and where additional safeguards are applied.

7. How We Use Personal Information

ReNU Syndrome UK uses personal information in order to carry out its charitable purposes and support the families and individuals who engage with us.

We aim to use personal information responsibly, proportionately and in ways that individuals would reasonably expect.

Depending upon the nature of the relationship with the Charity, personal information may be used to:

- provide support, guidance or signposting;
- communicate with families and supporters;
- organise events, meetings or conferences;
- administer volunteering activities;
- process donations and fundraising activities;
- manage safeguarding concerns;
- maintain governance and financial records;
- improve our services and activities;
- share newsletters, updates or awareness campaigns;
- respond to enquiries;
- comply with legal obligations; or
- protect the Charity and individuals from harm or risk.

In some situations, families may choose to share personal stories, photographs or experiences to support awareness raising, fundraising or advocacy work.

We recognise that these stories are often shared with considerable trust and emotional openness.

The Charity will therefore seek to ensure that such information is handled sensitively, respectfully and in accordance with any permissions or consent arrangements provided.

We will never knowingly exploit personal stories, medical information or photographs in a manner that undermines dignity or creates unnecessary safeguarding or privacy risks.

The Charity will only process personal information where there is an appropriate lawful basis for doing so.

Depending upon the circumstances, lawful bases may include:

- consent;
- legitimate interests;
- safeguarding responsibilities;
- legal obligations;
- contractual necessity; or

- protection of vital interests.

Where consent is relied upon, individuals may withdraw consent at any time.

However, there may occasionally be circumstances where the Charity is legally or ethically required to retain or share information despite withdrawal requests, particularly where safeguarding obligations arise.

Any such decisions would be carefully considered and handled proportionately.

8. Communications and Marketing

The Charity may contact individuals regarding:

- events;
- support opportunities;
- fundraising activities;
- campaigns;
- awareness initiatives;
- newsletters; or
- updates relating to the Charity's work.

Marketing communications by email or text message will only be sent where appropriate consent exists or another lawful basis applies.

Individuals may opt out of communications at any time.

Requests to unsubscribe or amend communication preferences will be respected promptly.

The Charity does not sell personal data or share supporter data with external marketing organisations.

9. Photography, Video and Media Content

The Charity recognises that photographs, videos and personal stories may involve particularly sensitive safeguarding and privacy considerations.

The use of images and personal stories is governed by the Charity's Photography, Video and Media Consent Policy.

Photographs or videos involving children or vulnerable individuals will only be used where appropriate informed consent exists and where use of the material does not create safeguarding, privacy or dignity concerns.

The Charity reserves the right not to publish material even where consent exists if publication could:

- expose individuals to harm;
- compromise dignity;
- reveal sensitive medical information;
- create safeguarding risks; or
- adversely affect the welfare of a child or vulnerable individual.

10. Safeguarding and Information Sharing

The Charity recognises that safeguarding responsibilities may sometimes require information to be shared appropriately with statutory authorities or safeguarding professionals.

Where safeguarding concerns arise, information may be shared with:

- police;
- local authority safeguarding teams;
- NHS safeguarding professionals;
- regulatory bodies; or
- other agencies involved in protecting individuals from harm.

Information sharing decisions will be made carefully, proportionately and in accordance with safeguarding obligations and data protection law.

Confidentiality will be respected wherever possible, but confidentiality must never prevent appropriate safeguarding action.

11. How We Protect Personal Information

The Charity understands that families and supporters trust us with highly personal and sensitive information.

We therefore take the security and confidentiality of personal information seriously.

The Charity takes reasonable organisational, administrative and technical measures to help protect information from:

- unauthorised access;
- accidental disclosure;

- misuse;
- inappropriate sharing;
- loss;
- destruction; or
- cyber-related risks.

Safeguards may include:

- password-protected systems;
- restricted access controls;
- secure storage systems;
- role-based access permissions;
- trustee confidentiality obligations;
- secure disposal procedures;
- safeguarding restrictions on access to sensitive records; and
- use of secure cloud-based platforms where appropriate.

Access to particularly sensitive information, such as safeguarding records or medical information, will normally be restricted to individuals who genuinely require access in order to carry out their role.

Trustees and volunteers are expected to exercise professional judgement when handling personal information.

For example, individuals should avoid:

- discussing confidential matters in public places;
- forwarding emails unnecessarily;
- sharing photographs casually;
- storing sensitive information on personal devices without appropriate safeguards; or
- using personal messaging platforms inappropriately.

The Charity also recognises that modern communication methods inevitably carry some level of residual risk.

While we take reasonable precautions, no online platform, website or electronic transmission system can ever be guaranteed to be entirely secure.

Individuals who choose to communicate electronically with the Charity should therefore understand that some degree of risk remains despite appropriate safeguards being implemented.

Where particularly sensitive matters are involved, the Charity may sometimes recommend alternative communication methods.

12. International Data Transfers

The Charity may occasionally use service providers or digital platforms based outside the United Kingdom.

Where personal data is transferred internationally, the Charity will take reasonable steps to ensure that appropriate safeguards are in place.

This may include:

- adequacy regulations;
- standard contractual clauses;
- secure platform arrangements; or
- additional organisational safeguards.

The Charity recognises that some online communication platforms and social media providers may store information outside the UK.

13. Data Retention

Personal information will only be retained for as long as reasonably necessary.

Retention periods may vary depending on:

- safeguarding considerations;
- legal obligations;
- financial record requirements;
- insurance obligations;
- governance needs;
- consent arrangements; or
- operational necessity.

The Charity will securely delete, anonymise or dispose of information once it is no longer required.

Safeguarding records may require longer retention periods depending upon risk and legal guidance.

14. Volunteers, Trustees and Recruitment

Where individuals apply to volunteer or work with the Charity, personal information may be collected for recruitment, safeguarding and governance purposes.

This may include:

- references;
- DBS-related information where appropriate;
- suitability assessments;
- role-related records; and
- safeguarding declarations.

The Charity will only retain recruitment-related information for as long as reasonably necessary.

Trustees and volunteers are expected to comply with confidentiality and data protection obligations.

15. Children's Data

The Charity recognises that information relating to children requires particular care and protection.

Where appropriate, parental or guardian consent will be sought before collecting or using information relating to children.

The Charity will always consider:

- safeguarding risks;
- age and understanding;
- best interests of the child;
- dignity and privacy; and
- whether use of information is proportionate and appropriate.

The Charity does not knowingly collect unnecessary personal information relating to children.

16. Individual Rights

Under UK GDPR, individuals may have rights relating to their personal information.

These rights may include:

- the right to access personal data;
- the right to request correction of inaccurate data;
- the right to request deletion in certain circumstances;
- the right to restrict processing;
- the right to object to processing;
- the right to withdraw consent; and
- the right to complain to the Information Commissioner's Office.

Requests relating to personal information should be submitted in writing to the Charity.

The Charity may need to verify identity before responding to requests.

17. Confidentiality

Trustees, volunteers and representatives of the Charity may have access to highly personal and sensitive information.

Such information must be treated confidentially and only shared where necessary and appropriate.

Confidentiality obligations continue even after an individual ceases involvement with the Charity.

Information must not be discussed casually, shared on social media, circulated unnecessarily or disclosed for personal reasons.

18. Cookies Policy

18.1 Use of Cookies

The Charity's website may use cookies and similar technologies to improve website functionality, user experience and website performance.

Cookies are small text files placed on a user's device when visiting a website.

Some cookies are necessary for website operation, while others help analyse website usage or improve functionality.

18.2 Types of Cookies

The Charity may use:

- strictly necessary cookies;
- performance and analytics cookies;
- functionality cookies; and
- preference cookies.

The Charity does not use cookies to collect sensitive personal information without consent.

18.3 Analytics

Website analytics may be used to understand:

- website usage patterns;
- visitor numbers;
- pages viewed;
- device types;
- navigation behaviour; and
- overall website performance.

Analytics information is generally anonymised.

18.4 Managing Cookies

Users may manage or disable cookies through browser settings.

However, disabling cookies may affect website functionality.

Continued use of the Charity's website may be interpreted as consent to use cookies where legally permissible.

19. Third Party Websites and Social Media

The Charity's website and communications may contain links to third party websites or social media platforms.

The Charity is not responsible for the privacy practices or content of third party services.

Individuals should review the privacy policies of external websites separately.

20. Data Breaches

The Charity takes data breaches seriously.

Any actual or suspected data breach must be reported promptly to the Board or designated data protection lead.

The Charity will assess:

- the nature of the breach;
- risks to individuals;
- safeguarding implications;
- legal reporting obligations; and
- remedial actions required.

Where legally required, breaches may be reported to the Information Commissioner's Office and affected individuals.

21. Policy Review

The Board of Trustees is responsible for overseeing this policy.

The policy shall be reviewed annually or sooner where:

- legal or regulatory changes occur;
- safeguarding requirements evolve;
- operational activities change;
- new technologies are adopted; or
- governance reviews identify improvements.

Version Control

Version	Date	Approved By	Review Date
1.0	May 2026	Board of Trustees	May 2027