# ReNU Syndrome UK

# Safeguarding, Protection from Harm and Welfare Policy

## 1. Introduction

ReNU Syndrome UK ("the Charity") is committed to creating and maintaining a safe, respectful, inclusive and supportive environment for all children, young people, adults at risk, families, trustees, volunteers, staff, contractors and individuals who engage with the Charity.

The Charity recognises that safeguarding is a fundamental governance responsibility and forms an essential part of good charity management, risk management and public trust.

The Charity understands that children and vulnerable individuals affected by rare diseases may face increased vulnerability due to medical complexity, disability, communication difficulties, social isolation, emotional pressures, dependence on carers, financial stress, online exposure, or reliance upon specialist support networks.

Safeguarding is therefore not viewed solely as a reactive process relating to abuse disclosures. It is a proactive organisational commitment to:

- protecting people from harm;
- promoting welfare and dignity;
- creating safe organisational cultures;
- preventing abuse, neglect and exploitation;
- managing risk appropriately;
- ensuring safe recruitment and supervision;
- responding appropriately to concerns; and
- complying with legal and regulatory duties.

This policy establishes the safeguarding framework for ReNU Syndrome UK and provides practical guidance for trustees, volunteers and anyone acting on behalf of the Charity.

This policy should also be read alongside the Charity's:

- Photography, Video and Media Consent Policy;

- Data Protection and Confidentiality Policy;
- Social Media Policy;
- Code of Conduct;
- Conflict of Interest Policy;
- Online Safety Guidance;
- Volunteer Policy; and
- Equality, Diversity and Inclusion Policy.

These policies operate together to ensure that children, adults at risk and families are protected appropriately across all Charity activities, communications and media engagement.

## 2. Purpose of this Policy

The purpose of this policy is to:

- protect children, young people and adults at risk who engage with the Charity;
- protect trustees, volunteers and representatives from unsafe practices or allegations;
- establish clear safeguarding responsibilities;
- ensure concerns are identified and escalated appropriately;
- support compliance with legal and regulatory obligations;
- create a culture of safeguarding awareness and accountability; and
- provide practical procedures for responding to safeguarding concerns.

This policy is intended to operate as both a governance policy and an operational safeguarding procedure.

## 3. Scope of this Policy

This policy applies to:

- trustees;
- volunteers;
- committee members;
- ambassadors and representatives;

- contractors and consultants acting on behalf of the Charity;
- event volunteers;
- fundraisers;
- advisory board members; and
- any individual representing the Charity formally or informally.

The policy applies to all Charity activities including:

- online support groups;
- social media engagement;
- fundraising events;
- conferences and family events;
- advocacy work;
- welfare support;
- communications and messaging;
- photography and media activity;
- research participation support;
- home visits where applicable;
- virtual meetings and webinars; and
- interactions involving children or adults at risk.

## 4. Legal and Regulatory Framework

This policy is informed by:

- Children Act 1989 and 2004;
- Care Act 2014;
- Safeguarding Vulnerable Groups Act 2006;
- Working Together to Safeguard Children guidance;
- Data Protection Act 2018;
- UK GDPR;

- Human Rights Act 1998;
- Equality Act 2010;
- Charity Commission guidance on safeguarding and protecting people for charities and trustees;
- Keeping Children Safe in Education guidance where relevant;
- Mental Capacity Act 2005; and
- relevant local safeguarding partnership procedures.

The Charity Commission expects trustees to take reasonable steps to protect people who come into contact with the charity from harm. Trustees are responsible for ensuring safeguarding is embedded into governance, culture, decision-making and operational practice.

## 5. Safeguarding Principles

ReNU Syndrome UK believes that safeguarding is not simply a compliance obligation or an isolated policy area. It is a fundamental part of the Charity's culture, governance, decision-making and day-to-day interactions with families and vulnerable individuals.

The Charity recognises that many families affected by rare disease live under considerable emotional, medical, financial and practical pressures. Children and vulnerable individuals may experience increased dependency upon adults, healthcare professionals, support groups and online communities. This can create additional safeguarding vulnerabilities which require careful, compassionate and professional handling.

The Charity therefore adopts a safeguarding approach that is preventative, person-centred, trauma-informed and rooted in dignity and respect.

The welfare and safety of children and adults at risk must always take priority over organisational convenience, fundraising objectives, reputational concerns, personal relationships or operational pressures.

The Charity has zero tolerance for abuse, neglect, exploitation, bullying, harassment, discrimination or unsafe conduct.

Safeguarding is viewed as a shared responsibility. Every trustee, volunteer and representative of the Charity has a duty to remain alert to concerns, to behave appropriately, to maintain professional boundaries and to escalate concerns promptly.

The Charity recognises that safeguarding concerns are not always clear or obvious. Individuals may sometimes feel uncertain as to whether a situation constitutes a

safeguarding matter. In such circumstances, concerns should still be discussed with the Designated Safeguarding Lead rather than ignored or minimised.

Safeguarding also requires sensitivity and proportionality. Families affected by rare disease often rely heavily upon trusted support networks and may share highly personal information. Trustees and volunteers must therefore balance empathy and support with appropriate professional judgement, confidentiality and safeguarding boundaries.

The Charity is committed to creating an organisational culture where:

- concerns can be raised safely;
- safeguarding discussions are encouraged;
- individuals feel listened to;
- poor practice is challenged;
- mistakes are addressed openly and constructively; and
- safeguarding learning is continuous.

## 6. Definitions

### 6.1 Child

A child is any person under the age of 18.

### 6.2 Adult at Risk

An adult at risk is a person aged 18 or over who:

- has care and support needs;
- may be unable to protect themselves from abuse or neglect; or
- may be vulnerable due to disability, illness, mental health, communication difficulties or dependency.

### 6.3 Safeguarding

Safeguarding refers to the actions taken to protect people's health, wellbeing, rights and safety and to enable them to live free from abuse, harm and neglect.

### 6.4 Abuse

Abuse may include:

- physical abuse;
- emotional abuse;

- psychological abuse;
- sexual abuse;
- financial abuse;
- neglect;
- discriminatory abuse;
- coercive control;
- online abuse;
- bullying or cyberbullying;
- exploitation;
- domestic abuse; and
- organisational abuse.

## 7. Roles and Responsibilities

### 7.1 The Board of Trustees

The Board of Trustees holds ultimate accountability for safeguarding within ReNU Syndrome UK.

Safeguarding is not solely the responsibility of the Designated Safeguarding Lead. Trustees collectively remain responsible for ensuring that safeguarding is embedded into the Charity's governance, operations, culture and strategic decision-making.

Trustees must ensure that safeguarding considerations are integrated into:

- event planning;
- recruitment decisions;
- volunteer management;
- communications and social media activity;
- partnerships and collaborations;
- fundraising activities;
- online support environments;
- photography and media use;

- data handling; and
- risk management processes.

Trustees should actively consider whether Charity activities could expose children or vulnerable adults to harm, exploitation, emotional distress, unsafe situations or inappropriate influence.

The Board must ensure that safeguarding remains a standing governance issue and should periodically review:

- safeguarding risks;
- safeguarding incidents and trends;
- training needs;
- policy effectiveness;
- recruitment safeguards;
- online safeguarding arrangements; and
- whether appropriate resources and oversight exist.

Trustees must also ensure that safeguarding concerns are never dismissed solely because an individual is well known, trusted, professionally respected or closely connected to the Charity.

### 7.2 Designated Safeguarding Lead (DSL)

Given the current size and structure of ReNU Syndrome UK, the Chair of the Board of Trustees shall ordinarily act as the Charity's Designated Safeguarding Lead ("DSL").

The Board considers this arrangement appropriate at the present time in order to ensure safeguarding remains embedded at the highest level of governance and oversight.

The Board also recognises that, as the Charity develops, grows operationally, increases volunteer engagement or expands its activities, safeguarding responsibilities may require redistribution or greater operational separation.

For this reason, the Board shall review the appropriateness of the Chair acting as DSL at least annually as part of the Charity's governance and safeguarding review processes.

The Board may decide in future to appoint:

- a separate independent DSL;
- a Deputy DSL;

- an operational safeguarding officer; or
- an external safeguarding advisor,

where this is considered proportionate to the Charity's activities, risk profile or organisational growth.

The DSL acts as the principal safeguarding contact for the organisation and is responsible for providing safeguarding leadership, guidance and coordination.

The DSL is not expected to investigate abuse allegations independently unless specifically directed by statutory authorities. Rather, the DSL's role is to ensure concerns are handled appropriately, documented properly and escalated where necessary.

The DSL should maintain appropriate safeguarding knowledge and remain familiar with current safeguarding expectations and reporting pathways.

The DSL is responsible for:

- receiving safeguarding concerns and disclosures;
- maintaining safeguarding records securely;
- advising trustees and volunteers on safeguarding matters;
- supporting safeguarding risk assessments;
- liaising with statutory agencies where appropriate;
- ensuring concerns are escalated promptly;
- monitoring patterns or recurring concerns;
- supporting safeguarding awareness and training; and
- reporting safeguarding matters to the Board where appropriate.

Where a safeguarding concern involves the Chair acting in their capacity as DSL, the matter must immediately be escalated to another trustee designated by the Board, and external safeguarding advice should be sought where appropriate.

The Charity should appoint a Deputy DSL where feasible in order to provide continuity and resilience as the organisation grows.

### 7.3 Trustees, Volunteers and Representatives

All individuals acting on behalf of the Charity have safeguarding responsibilities.

Trustees and volunteers are expected to conduct themselves in a manner that promotes safety, dignity and trust.

They should understand that safeguarding risks do not arise only during formal activities. Risks may also arise through:

- informal support conversations;
- online messaging;
- social media interactions;
- fundraising activities;
- family events;
- travel arrangements;
- photography;
- emotional dependency;
- sharing of medical information; or
- relationships developed within support networks.

Individuals must therefore maintain appropriate professional boundaries at all times.

Trustees and volunteers are expected to:

- read and understand this policy;
- comply with safeguarding procedures;
- behave appropriately and professionally;
- report concerns promptly;
- challenge unsafe behaviour where appropriate;
- cooperate with safeguarding processes;
- maintain confidentiality appropriately; and
- prioritise the welfare of vulnerable individuals.

Individuals should never assume that somebody else has already reported a concern.

## 8. Safer Recruitment

The Charity recognises that safe recruitment is an essential safeguarding measure.

Depending upon the nature of the role, recruitment measures may include:

- application forms;

- interviews;
- references;
- identity verification;
- DBS checks where legally eligible and appropriate;
- safeguarding declarations;
- probationary periods; and
- role descriptions outlining safeguarding expectations.

No individual may begin regulated or unsupervised activities involving children or adults at risk without appropriate checks being completed where legally required.

The Charity will comply with DBS eligibility rules and will not request inappropriate checks.

## 9. Training and Awareness

Safeguarding awareness must form part of induction for trustees and volunteers.

Training should be proportionate to the level of contact individuals have with children and adults at risk.

Training may include:

- recognising abuse;
- responding to disclosures;
- online safeguarding;
- professional boundaries;
- disability awareness;
- trauma-informed communication;
- confidentiality;
- reporting procedures; and
- whistleblowing.

Trustees should periodically review safeguarding learning needs.

## 10. Recognising Safeguarding Concerns

Safeguarding concerns may arise through:

- direct disclosures;
- observed injuries or behaviours;
- changes in emotional wellbeing;
- online interactions;
- inappropriate communications;
- concerns raised by third parties;
- patterns of behaviour;
- breaches of boundaries;
- unsafe practices; or
- allegations against trustees or volunteers.

Indicators of abuse are not always obvious.

Individuals should not ignore concerns simply because they are uncertain.

It is not the role of trustees or volunteers to investigate abuse allegations themselves.

## 11. Responding to a Disclosure

Children, young people and adults at risk may disclose abuse, neglect, exploitation or distress in different ways.

Some disclosures are direct and explicit. Others may be indirect, hesitant, fragmented or communicated through behaviour, emotional distress, online activity or changes in presentation.

Individuals responding to disclosures should remain calm, patient and supportive.

It is important that the individual feels listened to and taken seriously.

Trustees and volunteers should avoid reacting with shock, disbelief, anger or excessive questioning.

The role of the individual receiving the disclosure is not to investigate or determine whether abuse has occurred. Their responsibility is to listen appropriately, reassure the individual and ensure the concern is escalated promptly.

Where a disclosure occurs, the individual should:

- listen carefully and allow the person to speak freely;

- avoid interrupting unnecessarily;
- avoid asking leading or investigative questions;
- avoid making promises of secrecy or confidentiality;
- explain that information may need to be shared in order to keep people safe;
- reassure the person that they have done the right thing by speaking up;
- avoid making judgements or assumptions;
- record the information factually as soon as possible; and
- report the concern immediately to the DSL.

The written record should clearly distinguish between:

- what was directly observed;
- what the individual said;
- what actions were taken; and
- any professional opinions or concerns.

Where immediate danger exists or urgent medical assistance is required, emergency services must be contacted without delay.

In situations involving online harm, harmful communications, inappropriate imagery or digital exploitation, screenshots or evidence should be preserved where appropriate without unnecessarily circulating sensitive material.

## 12. Reporting Safeguarding Concerns

All safeguarding concerns must be reported promptly.

Concerns should normally be reported to the DSL.

Where the concern involves the DSL, the concern must be reported directly to the Chair of Trustees.

Where the concern involves the Chair, the concern should be escalated to another trustee or directly to statutory authorities where appropriate.

Safeguarding concerns may require referral to:

- local authority children's services;
- adult safeguarding teams;

- police;
- NHS safeguarding teams;
- DBS;
- Charity Commission; or
- other regulatory bodies.

The Charity must not prioritise reputation management over safeguarding.

## 13. Record Keeping

Safeguarding records must be:

- factual;
- accurate;
- dated;
- signed where appropriate;
- confidential;
- securely stored; and
- retained in accordance with data protection requirements.

Records should distinguish clearly between observed facts, disclosures and opinions.

Access to safeguarding records must be restricted appropriately.

## 14. Online Safety and Digital Safeguarding

Because ReNU Syndrome UK operates significantly through online communities and support networks, digital safeguarding is particularly important.

Trustees and volunteers must:

- behave professionally online;
- avoid inappropriate private communications;
- use approved communication channels where possible;
- avoid sharing confidential information online;
- maintain appropriate boundaries;
- monitor online groups appropriately;

- escalate harmful content or concerning behaviour;
- protect photographs and personal information; and
- ensure consent is obtained before sharing images or stories.

Private messaging involving children should generally be avoided unless authorised and appropriately safeguarded.

At least two adults should ideally have oversight of online groups involving minors.

## 15. Photography, Media and Consent

The Charity recognises that photographs, videos and personal stories can play an important role in awareness raising, advocacy, fundraising, community engagement and celebrating the experiences of families affected by ReNU Syndrome.

However, the Charity also recognises that the use of images and personal information involving children and vulnerable individuals carries important safeguarding, privacy and dignity considerations.

Children affected by rare diseases may be particularly vulnerable to unwanted exposure, misuse of personal information, inappropriate online circulation of images or breaches of privacy.

Trustees and volunteers must therefore ensure that photographs, videos and personal stories are always handled respectfully, lawfully and sensitively.

All photography, filming and media activity undertaken on behalf of the Charity must comply with the Charity's Photography, Video and Media Consent Policy.

That policy sets out:

- consent requirements;
- parental responsibilities;
- image storage expectations;
- social media controls;
- retention and deletion arrangements;
- online publication safeguards;
- restrictions relating to vulnerable individuals;
- withdrawal of consent procedures; and
- guidance regarding professional and personal use of images.

No image, video, recording or identifiable personal story involving a child or vulnerable individual should be used without appropriate informed consent.

Trustees and volunteers must also remain mindful that consent alone does not automatically eliminate safeguarding risk.

The Charity reserves the right not to publish or share material where doing so may place an individual at risk, compromise dignity, expose sensitive medical information, or create safeguarding concerns.

Particular care must be exercised in relation to:

- hospital environments;
- medical procedures;
- children lacking capacity to understand publication implications;
- emotionally distressing situations;
- online support groups;
- public fundraising campaigns;
- geolocation information;
- school or home locations; and
- social media sharing by third parties.

Images and stories should never be used in a manner that is exploitative, sensationalised, intrusive or likely to undermine the dignity of the individual concerned.

## 16. Professional Boundaries

Trustees and volunteers must maintain appropriate professional boundaries.

This includes:

- avoiding favouritism;
- avoiding dependency relationships;
- not engaging in inappropriate emotional involvement;
- not sharing inappropriate personal information;
- avoiding unsafe lone working situations where possible;
- not giving personal financial assistance without Board approval; and

- ensuring relationships remain appropriate.

Boundary concerns should be discussed early with the DSL or Chair.

## 17. Managing Allegations Against Trustees or Volunteers

Any allegation involving a trustee, volunteer or representative must be taken seriously.

The Charity must:

- respond fairly;
- prioritise safety;
- avoid prejudging outcomes;
- maintain confidentiality appropriately;
- seek external advice where necessary;
- document actions carefully; and
- consider regulatory reporting obligations.

Suspension from duties may be considered as a neutral protective measure while concerns are assessed.

Where concerns potentially involve criminal behaviour, statutory agencies must be involved.

## 18. Whistleblowing

The Charity encourages individuals to raise concerns about unsafe, unethical or improper conduct.

No individual should suffer detriment for raising safeguarding concerns in good faith.

Concerns relating to misconduct, unsafe practices or safeguarding failures may be raised with:

- the DSL;
- the Chair;
- trustees;
- statutory agencies; or
- regulators where appropriate.

## 19. Risk Assessments

Safeguarding risk assessments should be undertaken for activities involving children or adults at risk.

Risk assessments should consider:

- supervision levels;
- venue safety;
- online risks;
- accessibility;
- medical needs;
- transport arrangements;
- emergency procedures;
- communication risks;
- photography and media; and
- staffing ratios where applicable.

Safeguarding should be embedded into event planning and operational decision-making.

## 20. Serious Incident Reporting

Certain safeguarding incidents may require reporting to the Charity Commission as serious incidents.

Trustees must consider reporting where incidents:

- result in significant harm;
- expose beneficiaries to serious risk;
- involve criminal allegations;
- involve serious governance failings; or
- may significantly damage the Charity's reputation.

The Charity should seek appropriate advice where uncertainty exists.

## 21. Confidentiality and Information Sharing

Safeguarding information must be handled sensitively.

However, confidentiality must never prevent appropriate safeguarding action.

Information may be shared where necessary to:

- protect individuals from harm;
- comply with legal duties;
- support safeguarding investigations; or
- engage statutory agencies.

Information sharing decisions should be proportionate, necessary and documented.

## 22. Equality, Diversity and Inclusion

Safeguarding practices must be inclusive and accessible.

The Charity recognises that disability, communication needs, cultural factors, language barriers and social circumstances may affect how abuse is experienced, recognised or disclosed.

Safeguarding responses should therefore be trauma-informed, person-centred and respectful.

## 23. Policy Monitoring and Review

The Board of Trustees is responsible for monitoring implementation of this policy.

This policy shall be reviewed annually or sooner if:

- legislation changes;
- Charity Commission guidance changes;
- safeguarding incidents occur;
- operational activities change significantly; or
- governance reviews identify improvements.

Safeguarding should remain a standing governance matter for the Board.

## Appendix 1 – Safeguarding Reporting Procedure

### Immediate Danger

If a child or adult is in immediate danger:

- contact emergency services immediately;

- ensure immediate safety where possible; and
- inform the DSL as soon as practicable.

**Non-Urgent Concern**

1. Record the concern factually.
2. Report the concern to the DSL.
3. DSL assesses risk.
4. DSL determines whether external referral is required.
5. Actions and decisions are documented.
6. Board informed where appropriate.

## Appendix 2 – Safeguarding Incident Record Template

### Safeguarding Concern Record

Date:

Time:

Name of person reporting concern:

Name of individual at risk:

Nature of concern:

What was seen/heard/disclosed:

Immediate action taken:

Who was informed:

External referrals made:

Outcome/follow-up:

Recorded by:

Date:

## Appendix 3 – Code of Safer Behaviour

Individuals representing ReNU Syndrome UK must:

- treat everyone with dignity and respect;
- maintain appropriate boundaries;
- avoid inappropriate private communications;
- avoid favouritism;
- avoid inappropriate physical contact;
- avoid sharing confidential information;
- challenge unsafe behaviour;
- report concerns promptly; and
- model safe and respectful behaviour.

Individuals must never:

- engage in abusive or exploitative behaviour;
- develop inappropriate relationships;
- share sexualised content;
- humiliate or intimidate others;
- ignore safeguarding concerns; or
- misuse their position of trust.

## Appendix 4 – Safeguarding Contacts

Designated Safeguarding Lead:

Deputy DSL:

Chair of Trustees:

Emergency Services: 999

NSPCC Helpline: 0808 800 5000

Childline: 0800 1111

Local Authority Safeguarding Team:

Charity Commission Serious Incident Reporting: https://www.gov.uk/guidance/how-to-report-a-serious-incident-in-your-charity

**Version Control**

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