



ReNU Syndrome UK

Equality, Diversity and Inclusion Policy

1. Policy Statement

ReNU Syndrome UK (“the Charity”) is committed to creating and maintaining an organisation and community in which every individual is treated with dignity, kindness, fairness and respect.

The Charity believes that every person has inherent value and should feel welcomed, heard, supported and included regardless of background, identity, disability, personal circumstances or lived experience.

As a rare disease charity, ReNU Syndrome UK recognises that many families already face significant challenges in everyday life.

Families affected by rare diseases may experience:

- social isolation;
- misunderstanding;
- barriers within healthcare or education systems;
- financial pressures;
- emotional strain;
- communication difficulties;
- disability-related discrimination;
- reduced access to opportunities; or
- feelings of exclusion from wider society.

The Charity understands that these experiences can have a profound impact not only on affected children and vulnerable individuals, but also on parents, siblings, carers and extended family networks.

For this reason, equality, diversity and inclusion are not viewed by the Charity simply as legal or regulatory requirements.

They are fundamental to the Charity’s values, culture and charitable mission.

We believe that inclusion is about more than avoiding discrimination.

It is about creating a compassionate and respectful environment where individuals feel able to participate safely, contribute meaningfully, ask for support without judgement and feel valued as part of the Charity's wider community.

The Charity also recognises that people experience the world differently.

Individuals may have different:

- communication styles;
- cultural backgrounds;
- educational experiences;
- financial circumstances;
- disabilities or health conditions;
- emotional needs;
- religious beliefs;
- caring responsibilities;
- family structures; or
- experiences of trauma or exclusion.

The Charity therefore recognises the importance of listening carefully, avoiding assumptions and approaching situations with empathy, openness and respect.

ReNU Syndrome UK is committed to creating an environment in which:

- individuals feel emotionally and physically safe;
- diversity is welcomed and respected;
- discriminatory behaviour is challenged appropriately;
- barriers to participation are identified and reduced where possible;
- children and vulnerable individuals are treated with dignity and compassion;
- safeguarding and inclusion operate together;
- people are encouraged to contribute their perspectives and experiences; and
- fairness and respect form part of everyday organisational culture.

The Charity also recognises that inclusion is an ongoing process.

No organisation is perfect, and there may be occasions where language, assumptions, systems or practices unintentionally create exclusion or discomfort.

The Charity is therefore committed to remaining open to feedback, reflection and continuous learning.

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

- trustees;
- volunteers;
- beneficiaries and families;
- supporters and donors;
- healthcare professionals and researchers engaging with the Charity;
- contractors and consultants; and
- anyone acting on behalf of the Charity.

2. Understanding Equality, Diversity and Inclusion

2.1 Equality

Equality means ensuring that individuals are treated fairly and have equal opportunity to participate, contribute and access support.

Equality does not necessarily mean treating everybody in exactly the same way.

Different individuals and families may have different needs, communication requirements, disabilities, caring responsibilities, financial circumstances or cultural backgrounds.

In some situations, achieving fairness may require adjustments, flexibility or additional support.

2.2 Diversity

Diversity means recognising, respecting and valuing difference.

People may differ in many ways, including:

- disability;
- race or ethnicity;
- nationality;
- language;

- religion or belief;
- age;
- sex or gender;
- sexual orientation;
- socioeconomic background;
- caring responsibilities;
- neurodiversity;
- lived experiences;
- communication needs; and
- family circumstances.

The Charity believes that diversity strengthens communities, improves understanding and enriches decision-making.

2.3 Inclusion

Inclusion means creating an environment where people feel welcomed, heard, respected and able to participate meaningfully.

The Charity recognises that individuals may sometimes feel excluded unintentionally due to language, assumptions, accessibility barriers, communication methods, social dynamics or organisational culture.

The Charity is committed to identifying and reducing such barriers wherever reasonably possible.

3. Legal and Regulatory Framework

This policy is informed by:

- Equality Act 2010;
- Human Rights Act 1998;
- Children Act 1989 and 2004;
- Care Act 2014;
- Data Protection Act 2018;
- UK GDPR;

- Charity Commission guidance; and
- safeguarding legislation and guidance.

The Charity recognises the protected characteristics under the Equality Act 2010, including:

- age;
- disability;
- gender reassignment;
- marriage and civil partnership;
- pregnancy and maternity;
- race;
- religion or belief;
- sex; and
- sexual orientation.

The Charity also recognises that discrimination and exclusion may arise in relation to additional factors including:

- caring responsibilities;
- socioeconomic disadvantage;
- neurodiversity;
- health conditions;
- communication needs;
- offending background;
- educational background;
- mental health;
- employment status; or
- other personal circumstances.

4. Commitment to Non-Discrimination



ReNU Syndrome UK is committed to ensuring that no individual is treated unfairly, excluded, disadvantaged, humiliated or made to feel unwelcome because of personal characteristics, background or circumstances.

The Charity will not tolerate unlawful discrimination, harassment, bullying, victimisation or exclusionary behaviour.

This applies across all areas of the Charity's work, including:

- governance;
- volunteering;
- recruitment;
- support activities;
- online communities;
- social media interactions;
- events and conferences;
- fundraising activities;
- partnerships and collaborations;
- communications;
- decision-making processes; and
- interactions between families, trustees and volunteers.

The Charity recognises that discrimination is not always obvious or intentional.

Sometimes exclusion or distress may arise through assumptions, language, attitudes, unconscious bias, lack of awareness or systems that unintentionally create barriers.

For example, individuals may unintentionally:

- make assumptions about a family's financial circumstances;
- use language that excludes or stereotypes;
- overlook communication needs;
- fail to consider accessibility barriers;
- dismiss the experiences of disabled individuals;
- minimise emotional pressures experienced by carers; or

- unintentionally create environments where some people feel less able to participate.

The Charity therefore believes that promoting equality and inclusion requires ongoing awareness, reflection and willingness to learn.

The Charity also recognises that individuals affected by rare disease may experience multiple and overlapping forms of disadvantage simultaneously.

For example, a child may experience barriers connected not only to disability, but also to language differences, educational inequality, financial hardship, neurodiversity, ethnicity or social isolation.

The Charity therefore seeks to adopt a person-centred and compassionate approach which considers the wider circumstances affecting individuals and families.

ReNU Syndrome UK expects trustees and volunteers to contribute towards a culture where:

- people are treated respectfully;
- concerns can be raised safely;
- different perspectives are listened to;
- vulnerable individuals feel protected;
- families are treated compassionately;
- discriminatory behaviour is challenged appropriately; and
- inclusion is considered in both everyday interactions and strategic decision-making.

The Charity also recognises that discussions relating to equality, identity, disability or inclusion can sometimes be sensitive or emotionally complex.

Individuals may hold different experiences, beliefs or perspectives.

The Charity therefore encourages respectful dialogue, empathy and constructive communication.

Disagreement should never result in hostility, intimidation or exclusion.

5. Accessibility and Inclusion

The Charity is committed to improving accessibility wherever reasonably possible.

The Charity recognises that accessibility is not limited to physical access.

Accessibility may also involve:

- communication methods;
- digital accessibility;
- language;
- sensory considerations;
- emotional accessibility;
- financial barriers;
- transport considerations;
- timing of events;
- caring responsibilities; and
- cultural awareness.

The Charity will seek, where reasonably practicable, to:

- provide accessible communications;
- consider disability-related needs;
- support participation in events;
- use inclusive language;
- avoid unnecessary barriers;
- listen to feedback from families and supporters; and
- consider safeguarding and wellbeing needs when planning activities.

The Charity recognises that small charities may have financial and operational limitations. However, trustees remain committed to making reasonable and proportionate efforts towards inclusion and accessibility.

6. Respectful Behaviour and Organisational Culture

ReNU Syndrome UK believes that organisational culture plays a central role in whether people feel safe, valued and included.

Policies alone cannot create inclusion.

The way people communicate, listen, support one another and respond to differences has a significant impact on whether individuals feel welcomed and respected.

The Charity therefore seeks to foster a culture that is compassionate, respectful, collaborative and emotionally safe.

All individuals involved with the Charity are expected to conduct themselves in a manner that promotes dignity, kindness and mutual respect.

This includes interactions:

- during meetings;
- within online groups;
- through social media;
- at conferences and family events;
- within private messaging;
- during fundraising activities; and
- in informal conversations connected to the Charity.

The Charity recognises that rare disease communities can sometimes involve high levels of emotional stress.

Families may be coping with:

- medical uncertainty;
- hospitalisation;
- exhaustion;
- grief;
- financial pressure;
- caring responsibilities;
- fear for the future;
- frustration with services; or
- emotional burnout.

The Charity therefore understands that individuals may occasionally experience heightened emotions.

However, emotional stress does not justify behaviour that is abusive, discriminatory, intimidating, hostile or harmful to others.

Bullying, harassment, exclusionary behaviour, personal attacks, intimidation, discriminatory comments or aggressive conduct are not acceptable.

This applies equally to behaviour occurring online and offline.

The Charity also recognises that harmful behaviour is not always intentional.

Sometimes language or conduct may unintentionally cause hurt or exclusion.

Where appropriate, the Charity encourages constructive conversations, reflection and learning.

However, repeated, serious or deliberate misconduct may require formal intervention.

Trustees and volunteers are expected to model respectful behaviour and to contribute positively to the Charity's culture.

Individuals should feel able to raise concerns, ask questions and participate without fear of ridicule, hostility or exclusion.

The Charity believes that respectful and inclusive environments ultimately strengthen safeguarding, wellbeing, governance and community trust.

7. Equality, Diversity and Safeguarding

The Charity recognises that equality, diversity and safeguarding are closely connected.

Children and vulnerable individuals who experience discrimination, exclusion or social isolation may also face increased safeguarding vulnerability.

Trustees and volunteers should therefore consider whether:

- communication barriers;
- disability-related needs;
- language differences;
- cultural issues;
- financial hardship;
- online exclusion; or
- social isolation

may affect a person's ability to access support, raise concerns or participate safely.

The Charity is committed to ensuring that safeguarding practices are inclusive, trauma-informed and respectful.

8. Trustee and Volunteer Responsibilities

All trustees and volunteers share responsibility for promoting equality, diversity and inclusion.

Individuals acting on behalf of the Charity are expected to:

- treat people fairly and respectfully;
- avoid discriminatory language or behaviour;
- challenge inappropriate conduct where appropriate;
- consider accessibility and inclusion;
- maintain professional boundaries;
- support safeguarding principles;
- listen respectfully to different perspectives;
- avoid assumptions or stereotypes; and
- comply with Charity policies and procedures.

Trustees are additionally responsible for ensuring that equality and inclusion considerations are integrated into governance and decision-making.

This includes considering equality implications when:

- planning events;
- approving policies;
- managing volunteers;
- producing communications;
- reviewing safeguarding arrangements; or
- developing partnerships.

9. Recruitment and Participation

The Charity is committed to encouraging participation from individuals with diverse experiences and backgrounds.

Trustee and volunteer recruitment processes should seek to be fair, transparent and inclusive.

The Charity recognises that talent, compassion, commitment and lived experience exist across all communities.

Selection decisions should therefore be based upon:

- suitability for the role;
- safeguarding considerations;
- skills and experience;
- values and conduct; and
- the needs of the Charity.

The Charity will not unfairly exclude individuals on discriminatory grounds.

However, safeguarding obligations, legal restrictions or operational requirements may occasionally require proportionate limitations in certain roles.

10. Communications and Representation

The Charity aims to communicate in ways that are respectful, inclusive and accessible.

Where possible, the Charity will seek to:

- use clear and inclusive language;
- avoid stigmatising terminology;
- respect preferred identities and names;
- consider accessibility of communications;
- represent diverse experiences appropriately; and
- avoid stereotypes or assumptions.

The Charity recognises that photographs, stories and awareness campaigns can shape perceptions and influence how families feel represented.

Care should therefore be taken to ensure that communications preserve dignity and avoid exploitation or tokenism.

11. Reporting Concerns

Any concerns relating to discrimination, bullying, harassment, exclusion or victimisation should be raised promptly.

Concerns may be raised with:

- the Chair of Trustees;
- another trustee;
- the Designated Safeguarding Lead where safeguarding concerns arise; or
- another designated individual within the Charity.

The Charity will seek to:

- listen carefully;
- respond fairly;
- maintain confidentiality appropriately;
- investigate proportionately;
- support affected individuals; and
- take reasonable corrective action where concerns are substantiated.

The Charity recognises that individuals may sometimes feel anxious about raising concerns.

Concerns raised in good faith will be taken seriously.

12. Monitoring and Review

The Charity is committed to ongoing learning and improvement in relation to equality, diversity and inclusion.

The Board of Trustees will periodically review:

- policies and procedures;
- accessibility considerations;
- safeguarding implications;
- complaints or concerns;
- participation and engagement patterns; and
- opportunities for improving inclusion.

The Charity recognises that equality and inclusion are ongoing responsibilities rather than one-off compliance exercises.

13. Related Policies

This policy should be read alongside the Charity's:

- Safeguarding Policy;
- Code of Conduct;
- Data Protection and Privacy Policy;
- Photography and Media Consent Policy;
- Conflict of Interest Policy;
- Volunteer Policy; and
- Social Media Policy.

Version Control

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