ReNU Syndrome UK

Medical Information Statement

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1. Our Commitment to Accurate and Evidence-Based Information

ReNU Syndrome UK is committed to providing reliable, balanced and evidence-informed information to individuals and families affected by ReNU syndrome associated with pathogenic variants in the RNU4-2 gene.

As a newly recognised rare genetic condition, scientific knowledge and clinical understanding of ReNU syndrome continue to evolve. New research is being published, clinical experience is increasing, and recommendations may change as further evidence becomes available. We are committed to ensuring that the information we provide reflects the best available knowledge at the time of publication.

2. Role of the Medical Advisory Panel

ReNU Syndrome UK is supported by an independent Medical Advisory Panel comprising clinicians, researchers and healthcare professionals with expertise relevant to ReNU syndrome and related fields.

The Panel provides strategic advice to the Trustees to help ensure that the charity:

- Publishes accurate, balanced and evidence-based information.
- Develops educational resources that reflect current clinical knowledge.
- Identifies emerging research and developments relevant to families.
- Supports awareness of ReNU syndrome among healthcare professionals.
- Promotes collaboration, research and opportunities to improve care.
- Helps identify priorities where the charity can have the greatest impact for patients and families.

The Medical Advisory Panel advises the charity as a whole rather than individual families.

3. Individual Medical Advice

ReNU Syndrome UK does not provide medical advice, diagnoses or treatment recommendations for individual patients.

Neither the charity, its Trustees nor members of the Medical Advisory Panel are able to provide personalised clinical opinions through the charity or review individual medical cases.

Questions relating to diagnosis, treatment, medication, investigations or ongoing clinical management should always be discussed with your own healthcare professionals, who are best placed to consider your individual circumstances.

4. Supporting Families

One of the charity's strengths is the close relationship we have with families across the United Kingdom. By listening to the experiences, questions and challenges shared by our community, we are able to identify common themes and areas where additional information or support may be beneficial.

These themes may be discussed with the Medical Advisory Panel to help the charity:

- Improve educational resources.
- Develop webinars and conferences.
- Produce information that addresses frequently asked questions.
- Identify unmet needs within the ReNU community.
- Inform future research priorities and advocacy initiatives.
- Explore opportunities to improve awareness and clinical pathways within the NHS.

Discussions are conducted at a general and strategic level and are not intended to replace consultations between families and their healthcare teams.

Our Scope

ReNU Syndrome UK has been established to support individuals and families affected by ReNU syndrome associated with pathogenic variants in the RNU4-2 gene.

As research into RNA-related neurodevelopmental disorders continues to evolve, the charity will keep its educational materials and public information under regular review, guided by emerging scientific evidence and advice from the Medical Advisory Panel.

5. Working Together

ReNU Syndrome UK believes that the greatest progress is achieved through collaboration between families, clinicians, researchers and healthcare professionals.

By combining lived experience with clinical expertise and scientific research, we aim to improve understanding of ReNU syndrome, support affected families, encourage research, and contribute to the development of better care for future generations.

This statement should be read alongside our Safeguarding Statement, Privacy Policy and the Terms of Reference for the ReNU Syndrome UK Medical Advisory Panel.