

Trustees' Annual Report for the period						
	Period start date				Period end date	
From	19	April	2024	To	31	03 2025

Section A Reference and administration details

Charity name	GRI-UK		
Other names charity is known by			
Registered charity number (if any)	1207930		
Charity's principal address	Durham House, 10 Pony Chase		
	Cobham		
	Surrey		
	Postcode	KT11 2PF	

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Alison Koopman	Chair of Board of Trustees	19.4.24	GRI-UK Board of Trustees
2	Toni Clarke	Deputy Chair of Board of Trustees	19.4.24	GRI-UK Board of Trustees
3	Kristina McKean	Treasurer	19.4.24	GRI-UK Board of Trustees
4	Sue Banks	Secretary	19.4.24	GRI-UK Board of Trustees
5	Jillian Hasting Ward	Research Lead	19.4.24	GRI-UK Board of Trustees
6	Shilpa Kaluti	Trustee	19.4.24	GRI-UK Board of Trustees
7	Colette Dufficey	Trustee	12.3.25	GRI-UK Board of Trustees
8				

Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

--

Section B Structure, governance and management

Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	Constitution
How the charity is constituted (eg. trust, association, company)	Charitable Incorporated Organisation
Trustee selection methods (eg. appointed by, elected by)	Elected by trustee majority

Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

GRI-UK works independently but is part of several rare disease networks and partners who we would closely work with. These are namely:

- The Genetic Alliance
- Global genes
- UK Rare Epilepsies Together
- The European GRI Alliance led by GRIN Europe

We have developed and finalised the following policies and procedures:

- Grant giving policy

We are in the process of finalising the following policies and procedures:

- Finance policy
- Privacy policy
- Social media policy
- Fundraising policy

Our trustees have attended a number of training opportunities provided by BEACON for Rare Diseases, which have included:

- Financial management for charities
- Fundraising
- Strategy
- Genomic research

We are working closely with other GRI organisations around the world including Cure GRIN and GRIN Europe. We are also developing working relationships with scientists and GRI Researchers across the UK including in University College London, Oxford University and Edinburgh University.

In our first year the major risks we have identified are

- Securing sustainable funding from a variety of income sources so in the future we are not building a funding model reliant on our small community of the families of GRI patients in the UK.
- Building a community of families affected by GRI conditions across the UK who want to participate in our activities.
- As entirely volunteer trustees who implement every aspect of the charity - the time commitment needed to build an active and impactful organisation versus the time commitment trustees actually have given their main work and family and caring commitments.

Section C Objectives and activities

Summary of the objects of the charity set out in its governing document

GRI-UK's objectives as set out in our CIO are: 1. Aiming to advance cures and treatments of GRI disorders 2. Supporting families so that those diagnosed with these disorders can lead the best life possible. 3. Raising awareness, including within the UK Health Service, and medical centres of the symptoms, needs and medical conditions of those living with GRI disorders to help enable better and faster access to diagnosis and treatments. 4. Making the UK a centre of excellence for the public benefit of finding treatments and cures for GRI disorders. 5. Bringing together patients, parents, family members, medical professionals, researchers, scientists, pharmaceutical, bioscience and academic communities across the UK.
--

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

GRI-UK has been busy in this first year of operation. Between team members we have attended several rare disease and genetic focused events to raise awareness of GRI gene disorders, the profile of GRI-UK and understand the landscape of rare disease support and research and how best we can develop as a charity to meet our aims. These have included: • Beacon Patient Group Mentoring Programme 2024-25 • Beacon Cambridge Rare Disease Showcase 2024 • Beacon: The fundamentals of fundraising without a fundraiser webinar. • Beacon: New Models of Drug Development meeting. • Beacon: Empowering patient groups in rare disease research funding webinar. • Beacon: Unlocking research opportunities: Partnering with academics' webinar. • A speaking session at the 2024 GenPAN conference (A sub-committee of the Association of Genetic Nurses and Counsellors). • The Festival of Genomics • EURORDIS Summer School on Rare Disease medicine development. Networks joined include the Genetic Alliance, UK RET (Rare Epilepsies Together) and Global Genes Alliance, attending Genetic Alliance Monthly Members Meetings and UK RET quarterly meetings. We have developed a 'This is Me Rare Disease Passport' for GRI patients in conjunction with CAMRare, which is available for all patients affected by GRI gene disorders. Through public social media, email and family connect sessions we have promoted opportunities to participate in GRI research amongst our community including GRIN Patient Registries, GRIA patient registries, The GRI faces project. We have registered as a patient group with NICE (National Institute for health and Care Excellence) to help facilitate our involvement in the drug licencing process in coming years and advocate for the best possible treatments to reach patients through the NHS. We have collaborated with other GRI organisations across the globe to strengthen the position of patients in the UK to understand and participate in GRI research and benefit from treatments for GRI symptoms. • Bi-monthly meetings with counterparts in USA, • We partnered with Cure GRIN on promoting the Global GRI

Census.

- Attending the GRIN Europe Conference in Barcelona (funded independently of the charity). Presenting a poster on our community and work. We fed back to families in the UK on the different sessions and presentations at the conference through a family connect zoom meeting.
- Feeding into the Epicare Leaflets for GRIN patients (arranged through GRIN Europe).
- Joined and attended meetings of the Informal European GRI Alliance – which brings together patient originations across Europe to network and build areas of work together.

By the end of the reporting year, we have held 10 trustee meetings covering regular updates on all aspects of the charities function and growth.

We have developed a website for families affected by GRI conditions, clinicians, researchers, and the general public, which launched in October 2024 and holds a wealth of information in GRI disorders and their treatment.

We have grown a stronger online presence and social media following. Over the course of the year through Facebook we had 246 net follows, bringing our total number of followers to 417, with 2,905 interactions, 260 comments and 303 shares.

We have identified and registered 60 families over the course of the reporting year who represent 65 patients with GRIN and GRIA disorders. Over the year we developed onboarding procedures for families so that they receive relevant and available information on GRI disorders and a welcome to the organisation.

We have supported the first ever clinical trial specifically for GRI patients, by meeting with GRIN Therapeutics in London and Glasgow to visit the sites and discuss the roll out of Radiprodil Clinical Trials across the 2 sites. We have continued to support this work throughout the year.

We have updated families and supporters through different forms of communication including primarily through social media but also a Newsletter which was sent to all our families and others on Rare Disease Day.

We initiated Family Connect Sessions, which are promoted publicly and amongst families – a monthly drop-in online meeting held with parents/caregivers caring for children and adults affected by GRI conditions. We held 3 'Family Connect' Meetings across the end part of the year. One on the Barcelona GRIN Europe Conference one with Dr. Al Freedman psychologist, who talked about mental health of rare disease patients, families and Communities. One was an informal general 'getting to know you' session.

We have supported 3 individual families find further information on their genetic variant, or access research clinicians to improve health outcomes for their children.

March 2025 was GRI Awareness Month and Light up for GRI, and we were active in promoting a lot of social media content and information

about GRI Disorders.

We have also started the process of planning a number of activities in future reporting periods including:

- Two face to face meetups with GRI families across the UK in September and October 2025.
- Drafting and developing the GRI-UK Family Survey – which aims to give us a broader understanding of our community across the UK.
- The GRI Conference for families and other scientists in May 2026 jointly with researchers in Edinburgh University.
- Drafting and finalising policy and procedures across a range of issues.

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

Our policies are still in draft stages of development.

The involvement of volunteers beyond the Board of Trustees - which is entirely voluntary and currently only made up of family members with children or grandchildren affected by GRI disorders – has been absent in the reporting period. We plan that in 25/26, we will have these elements further developed.

Section D

Achievements and performance

Summary of the main achievements of the charity during the year

- We have started regular dialogue with our community and now 60 families affected by GRI conditions have been identified and registered with the charity.
- A total of £37,965.58 has been raised by the charity. This has set us up well to be able to fund our first piece of research in 2025 as we plan towards our first family scientific conference in 2026.
- The relationships we have built have given us a strong foundation in the GRI community, GRI research field and the UK genomics arena to be able to grow in 2025/2026 and raise further funding for projects which support families and seek to find treatments and cures for GRI disorders.
- We launched the www.gri-uk.org website.
- We have grown a stronger online presence and social media following.

Section E

Financial review

Brief statement of the charity's policy on reserves

The Board are aware of their responsibilities surrounding the going concern status of The Charity and will monitor this on a regular basis. The reserves policy of The Charity is reserves policy aims to retain reserves equivalent to 2 months unrestricted operating costs in order to offset costs that would be incurred if it was necessary to wind The Charity. These costs at all times are to be held in general unrestricted funds.

Details of any funds materially in deficit

N/A

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

Our principal sources of funds are from community level fundraising efforts amongst families who are affected by GRI disorders.

Expenditures have been limited in this operating year as the entire team is voluntary, and the activities we have done have been focused on setting up the charity and identifying and getting to know families. Any expenditure we have had has been used operationally to facilitate the website set up or elements of banking to facilitate online donations.

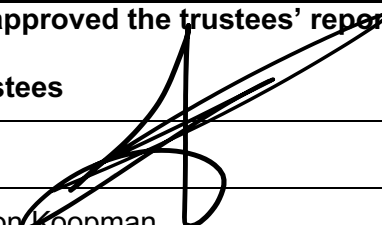
We don't have an investment policy and have no plans to invest in coming years.

Section F Other optional information

Section G Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		<i>KM</i>
Full name(s)	Alyson Koopman	Kristina McKean
Position (eg Secretary, Chair, etc)	Chair of the Board of Trustees	Treasurer and Trustee
Date	1.10.2026	