

Vision

People living with genetic, undiagnosed and rare conditions flourish and live their best lives.

Mission

- Champion the long-term sustainability and value of support strategies and systems including genetic, undiagnosed and rare disease patient support groups.
- Build stakeholder capacity to improve engagement and collaborative outcomes.
- Be an enabler of a collaborative and connected support sector voice to explore issues/opportunities and co-design strategies and solutions.
- Listen and learn from people living with GUaRD and their families and support groups to represent, lead and advocate for positive change.

Advocacy Principles

- Access to testing, treatment, devices, support, information and services must be fair, inclusive and equitable.
- All Australians must have access to reliable and current information, services and supports so they can have better health outcomes.
- Patient care must be patient led and developed through a collaborative approach.
- Change requires a collaborative and united effort and appetite across health and service sectors.
- Representation comes from consultation and collaboration.

Operating Principles

- Inclusion is imbedded across all areas of operation.
- We communicate clearly and transparently.
- We engage strategically.
- We represent equitably.
- We support each other.
- We actively eliminate duplication of resources.
- Our work aligns with the National Strategic Action Plan for Rare Diseases and is consistent with national and state policies.
- We collaborate purposefully.
- We listen to our community.
- We stay informed and are current.
- We maintain our organizational identities and priorities.
- We are connected locally, nationally and internationally.

Key Strategic Goals

Patient and Community Led Agendas and Advocacy



Connected Community and Stakeholders



Increased capacity to optimise relationships for community and stakeholders



A strong, agile GSNV and support sector.



What critical actions are we taking to deliver the goals

- Establish an annual priority plan with community
- Drive awareness and education on community agendas
- Horizon scanning to bring issues to the community

- Strategically Improve Engagement, Membership & Partnerships
- Create and implement networking and communication opportunities between community and stakeholders
- Prioritise opportunities to come together around issues

- Develop working with community partnering opportunities with stakeholders to establish guidelines and principles.
- Establish GSNV as a house of resource for community and stakeholders

- Strong communications strategy increasing brand recognition, community and social media visibility and engagement
- Diversify stakeholder engagement and model inclusivity.
- Partner with, collaborate with and showcase the work of community and support groups

How we will know if we are successful

- A plan is developed and delivered.
- Community feels more empowered and influential.
- Community is ready to be engaged and active in consultation and issues arising.

- Community feels involved.
- GSNV has broader and deeper community relationships.
- Partnership is valued and evidenced through submissions, discussions and involvement.

- Stakeholder engagement is more impactful.
- Stakeholders and community are engaged in more equitable and valued dialogue that leads to agreed outcomes.
- Community and Stakeholders increasingly use GSNV and our resources.

- GSNV communications are purposeful and consistent.
- Community is directly involved in Communications and builds profile through GSNV.
- GSNV stakeholders and community are diverse.
- Our community feels represented by GSNV