



The Genetic and Rare Disease Network (GaRDN) is a not for profit organisation that acts as a peak body for genetic and rare disease support groups in Western Australia, working to empower individuals and their families to reach positive health outcomes. We inform health professionals and the wider community on the perspectives and experiences of those affected by genetic and rare diseases. We connect key stakeholders and service providers with people affected by genetic and rare diseases.

GaRDN works to ensure that people with genetic and rare diseases have timely access to relevant, up-to-date information about their condition and the healthcare and other services available to them in WA. GaRDN represents the collective voices of people with genetic and rare diseases, their families and carers, to ensure that they are included in health policy and strategic decision making. GaRDN aims to make health professionals more aware of genetic and rare diseases. GaRDN works to develop integrated, coordinated health care and support by stakeholders involved in the support and health care of people with genetic and rare diseases, their families and carers.







A world where genetics is an integral component of health and health care, where human genetic variation is celebrated and where all people benefit from advances in genetic science and technology.

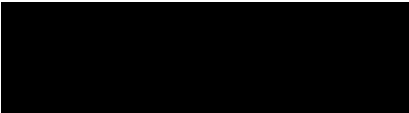

The GaRDN is committed to the promotion of fulfilled lives through:

- Promoting Best Possible Outcomes- GaRDN is committed to assisting individuals and families in achieving positive outcomes in all life stages
- Building Relationships- GaRDN is committed to fostering productive and strategic relationships with all stakeholders including health professionals, the health system and the community
- Capacity Building- GaRDN is committed to achieving the best possible outcomes for individuals, families, support groups and health professionals with the available resources.

To promote and develop awareness of genetic conditions and their impact on families and community, foster research, encourage and support service delivery by genetic support groups and facilitate their development by linking and empowering individuals, families and communities.

The four pillars of GaRDN's services are

- provide referral services
 - publish a quarterly newsletter and a fortnightly electronic E-News
 - develop an understanding of views of members by consultation, research and surveys and further represent these views across all sectors and levels of government
 - offer a link line to connect people with rare conditions
 - publish a Directory of Genetic & Rare Disease Support Groups and Community Support Organisations
 - foster an effective working relationship with health professionals and key stakeholders
 - develop, participate in and collaborate with relevant organisations and networks at local, national and international levels
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- facilitate issue-based focus groups
 - organise and host information forums
 - act as an information hub
 - conduct disease specific seminars
 - promote existing services to the genetic and rare disease networks and other sectors
 - provide advice, comment and/or recommendations on government policy and strategic issues that are relevant to the genetic and rare disease community
 - participate in committees of external stakeholders to inform, influence and secure change
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- provide members and the broader genetic and rare disease community sector with a united, credible, effective, authoritative and inclusive voice
 - develop an understanding of the views of members via consultation, research and surveys and represent these across all sectors and levels of government
 - undertake research to identify common issues across the spectrum of genetic and rare diseases
 - provide operational assistance to support groups
 - provide one on one advocacy and assistance to families
 - provide advice towards the development of public policy and procedures

- provide members and the broader genetic and rare disease community sector with a united, credible, effective, authoritative and inclusive voice
- develop an understanding of the views of members via consultation, research and surveys and represent these across all sectors and levels of government
- undertake systematic advocacy to secure change in government systems, including but not limited to health and disability policy programs and services
- provide leadership and lobby WA politicians at state and national levels to achieve bipartisan support for genetic and rare diseases and related issues
- submit submissions to government and others in the fields of genetics
- participate in committees of external stakeholders to inform, influence and secure change