Acknowledgements
The Genetic and Rare Disease Network appreciates the significant support from many individuals, agencies and organisations who have aided our efforts to deliver an effective, professional and successful service to the Western Australian community. We would like to thank the Department of Health Western Australia who have provided our core funding. We also acknowledge the support and assistance of the individual support groups and support organisations and the many non government agencies that collaborate with our organisation.

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COMMITTEE AND STAFF

Genetic and Rare Disease Network (GaRDN) Board

The GaRDN Board is responsible for the governance of GaRDN and establishes the key strategic priorities and outcomes to be achieved in line with our funding contract and rules of Association. The Board delegates the task of achieving these outcomes to the Executive Director and staff.

The members of the Executive and Board who held positions at any time since the previous AGM are:

- Melissa Devlin: Chair
- Sinead Glennon: Treasurer
- Shoma Mittra: Committee
- Hayley Lajcszcak: Committee
- Dorota Fretwell: Committee

Staff as at 30 June 2020

- Amanda Samanek: Executive Director (0.8 FTE)
- Regan Leen: Senior Project Officer (0.4 FTE)
- Lesley Stedman: Senior Project Officer (0.5 FTE)

Governance

Recognising that GaRDN provides services to WA families living with a genetic or rare disease and to meet all relevant legal, best practice and compliance issues.

GaRDN has maintained governance by:

- Ensuring compliance with the Australian Charities and Not-for-Profit Commission requirements.
- Identifying and mitigating organisational risk through reviewing financial and administrative practices.
- Developing sound project planning and reporting, with a focus on outcomes based reporting to support our contractual requirements.
ABOUT GaRDN

VISION

This year the organisation has continued to work toward achieving the outcomes of the strategic plan that reflects the changing nature of the environment in which GaRDN operates and meets the needs of Western Australians living with rare disease.

To fulfil our mission we:

CONNECT

- Establishing local partnerships and active engagement with all key stakeholders to address issues concerning genetic and rare disease, including:
  - Individuals diagnosed with a genetic or rare condition
  - Their families
  - Carers
  - Community service organisations
  - Researchers
  - Government
  - Health professionals.

- Providing a mechanism to link people living with genetic and rare diseases, their families and carers to genetic and rare disease support groups and existing health care and other services.

INFORM

- Providing information to key stakeholders on the perspectives, common needs, health care experiences and challenges across the diversity of people living with a genetic or rare disease.
- Developing and disseminating information to key stakeholders about rare diseases and genetic conditions relevant to the WA context.
- Providing educational opportunities such as workshops, seminars, patient information sessions and peer support training.
SUPPORT

- Being a point of contact for individuals and families seeking information and support about genetic and rare disease by:
  - Referring to support groups and other relevant community services
  - Facilitating peer support
  - Assistance in finding appropriate clinical services
  - Assisting with the establishment of new and the development of existing groups.
- Supporting clinical services and the delivery of quality health care relevant to genetic and rare diseases.

EMPOWER

- Empowering individuals and their families to reach positive health and life outcomes by connecting and supporting stakeholders.
- Representing the interests and views of individuals affected by genetic and rare diseases to the community as well as the State and Federal Governments.
- Promoting consumer participation and feedback.
- Advocating on behalf of patients with genetic and rare disease, their families and carers.
- Encouraging effective and efficient management and service delivery practices within member groups.

Genetic and Rare Disease Network
Strategic Plan 2018 - 2020

Vision: Improving the lives of people with genetic and rare conditions
Mission: To provide, information, advocacy and advice to support people living with genetic and/or rare disease to have the best possible outcomes

STRATEGIC PRIORITIES

- STRATEGIC GOALS
  - Deliver services that enable people living with genetic and rare disease to attain the best possible outcomes
  - Increase awareness of genetic and rare disease and facilitate access to available support and services
  - Deliver informed advice and communication that support people living with genetic and rare disease to be active participants in their rare disease journey
  - Influence decision makers at all levels to improve services, policy, frameworks and other activities that impact people living with genetic and/or rare diseases

- STRATEGIC GOALS
  - Elaborate the profile of genetic and rare disease to enable improved outcomes
  - Support health professional awareness of GaRDN services to ensure people with genetic and rare disease are actively supported to participate in their care
  - Facilitate opportunities for members and the community to contribute to awareness raising
  - Advocate broadly for the inclusion of genetic and rare disease as a state, national and global health issue

- STRATEGIC GOALS
  - Lead an informed, collaborative and sustainable rare disease support sector
  - Seek active and cross sector engagement to ensure we reflect the diversity of our genetic and rare disease community
  - Ensure the sustainability, viability and leadership of the organisation to achieve its mission and goals
  - Actively seek opportunities to contribute to research and innovation on rare disease issues
CHAIR'S REPORT

The past year has been unprecedented for GaRDN in both highs and lows with respect to the evolving global landscape amidst the COVID-19 pandemic, and importantly the Western Australian genetic and rare disease community and how life has changed significantly for us all. As an individual living with a rare disease, the exacerbation of my health insecurity, including anxiety around accessing critical health care during this time and the toll that has taken emotionally, I believe would not be dissimilar to many of our member groups, and the individuals and their families and carers of our sector. I’m doing the best I can to nurture my health and wellbeing, whilst taking care of my family, and am thankful every day for the positives and learnings in my health and care experience that empower me to attend to my needs in this way. If you are in need of personal support/assistance, reach out to your key health practitioners or contact key wellbeing service lines.

In a time of pandemic where the world has felt so physically disconnected, the GaRDN organisation grows developing virtual communities for those living in WA with a genetic, rare or undiagnosed disease and our members, and we continue to trial new methods of engagement.

We continue to research, listen for and understand where the need for access to equitable health care, clear information and services is growing or not being met across the diversity of people living with a genetic or rare disease. The GaRDN team has supported email and or phone enquiries for information, advice or support from the community and our members, reaching 230 new individuals this calendar year. Through new and greater collaboration nationally and locally with relevant stakeholders this year, GaRDN was privileged to represent our member and community voice in pursuit of the best possible outcomes for people living with a genetic, rare or undiagnosed disease. We were key in representing our member and broader community perspectives; to advocate for improved care, services and equipment and research opportunities to meet the unique needs of patients, families and their carers at all stages of their health journey.

Events like our Rare Together Expo for Rare Disease Day in February enable connection into information, networks and service providers that help individuals to self-serve and navigate through the WA health system and support services available that assist with the day to day living with a rare or genetic disease. A major success this year was the development of the National Rare Disease Action Plan by Rare Voices Australia with key partners and stakeholders; an amazing outcome of which we are thankful to WA stakeholders who contributed their experience, knowledge and time, and a big thank you to Amanda Samanek for her extensive involvement as member of the Steering Committee. We look forward to the emergent pathways, partnerships and shifts made possible through national and state collaboration on key opportunities.
On behalf of the Board, I would like to extend our deepest thanks to the staff, Amanda, Brooke (resigned from GaRDN January 2020), Lesley and Regan for providing unwavering support to our local community in a particularly complex year, and for continuing to strive for greater outcomes nationally and locally.

I would like to take this opportunity to extend a huge thank you to Gareth Baynam, who completed his last term with GaRDN's Board prior to last year’s AGM in December. Gareth is an outstanding champion for positive change in the genetic and rare disease sector, and we thank him for his ongoing valuable contribution as a key stakeholder for GaRDN, he is sorely missed in Board engagements. As a Board of such diverse experience and backgrounds, we collectively exceed individual efforts, and I’d also like to acknowledge the expertise and leadership of Hayley Lajszczak who became Deputy Chair this year, and the valuable contribution of our Treasurer Sinead Glennon and Board Members Shoma Mittra and the newly welcomed Dorota Fretwell. The Board is implementing a proactive recruitment program for new Board Members, expecting to appoint several new members at the Annual General Meeting.

After four years on the Board, I have announced I will be resigning from the Board to attend to personal health matters and spend time with my young family. I would like to wish the Board and committed staff of GaRDN my very best wishes for a growing future delivering outstanding services to improve the lives of people living with genetic and rare conditions.

Melissa Devlin
Chair
EXECUTIVE DIRECTOR’S REPORT

Twenty-twenty has certainly been a year that has brought a mixed bag of incredible achievements and opportunities to assess our resilience. Throughout the latter half of 2019 the rare disease community was focused on supporting the work of Rare Voices who were coordinating the National Strategic Action Plan for Rare Disease. GaRDN was a member of the Steering Committee for this work and provided the venue and support for the Perth consultation as well as ongoing input to the final documents. It was a watershed moment to see the bipartisan support for the Action Plan at the launch in Canberra in February 2020. We are committed to ensuring our work supports the achievement of the goals of the action plan and look forward to a collaborative and consultative approach to implementation that leverages the remarkable skills and abilities of the individuals throughout Western Australia and Australia that run genetic and rare disease support organisations.

GaRDN also held an exceptionally well attended event for Rare Disease Day 2020 that enabled both individuals and support groups to create connections that we are sure will enable more collaborative work that will improve outcomes for Western Australians living with genetic and rare conditions.

During the latter half of 2019, prior to the COVID outbreak, the number of contacts from people living with rare conditions continued to increase steadily. This reflects the obvious need for the service that we provide. This need was assessed when I first joined GaRDN in 2015 where we asked the top five issues people were dealing with in the sector.

The first key issue was lack of understanding and information about rare disease – in response to this we redeveloped our website and the usefulness and credibility of our website was recognised and GaRDN became a partner with Healthdirect Australia the national public health information service. Our website performance regularly outperforms other like organisations and we are very proud that we provide people with well researched and easy to understand information about rare disease.

The register of health professionals with an interest in rare disease is another response to a key issue. Over 130 health professionals have generously provided their details for our searchable database so that people with rare conditions can access care from health professionals who have an interest in their condition. These health professionals have also demonstrated an incredible level of responsiveness when we have contacted them about individuals living with specific conditions and frequently been able to advise specialists for other conditions. The register saves people time, money and stress when trying to access appropriate care.

Another of the top five key issues was the uncertainty about NDIS and the level of competitiveness that was creating in the not for profit genetic and rare disease sector. We’ve been in contact with NDIS many times throughout this year and have high hopes that the genetic and rare disease support sector will have the opportunity to input to collaborative efforts to assist people with disability achieve the best possible support through more formal meetings in the near future.
GaRDN also responded to this by trying to communicate more frequently with other state and national organisations and this eventually lead to the creation of the Genetic Undiagnosed and Rare Disease Collaborative to demonstrate our commitment to and advantages of collaboration in the sector. This group included Syndromes Without A Name (Australia), Genetic Alliance Australia, Genetic Support Network Victoria and Rare Voices Australia. The organisations were all focused on the Action Plan in the first year but in 2020 (Rare Voices Australia advised they no longer wanted to be part of the collaborative in March 2020) we had other activities to focus on. GUARD consulted the rare disease community about their statement in relation to COVID 19 and we were impressed to have many groups add their logos to support the statement and we included their thoughtful input into the submission.

The other key issues were addressed during the last five years. GaRDN has also been working to support the Centre for Community Driven Research in expanding the rare disease telehealth project that will provide a service to the Australian rare disease community for the next two years. As I reflect on my time with GaRDN over the last five years I am confident we have achieved positive outcomes for Western Australians living with genetic and rare conditions.

The next five years will have a new set of challenges. Not least of these will be obtaining funds to continue our support of people living with genetic and rare disease and the groups that represent those people. The Department of Health, after a lengthy and prolonged approach to assessing our performance by increasing our reporting requirements by 300%, commissioning a report into the sector that was never released or discussed and taking every opportunity to diminish our efforts and demonstrate professional and personal discourtesy decided, in the midst of COVID 19 to provide us with less than 3 months’ notice that they were withdrawing our funding. Sadly, this was not unexpected but on the positive side COVID 19 has enabled the organisation to plan to continue for some time as a result of the Federal government support of charities.

I will be finishing my contract on 20 September 2020 but feel confident that the staff remaining at GaRDN will be able to navigate the next phase for GaRDN and continue to provide the exemplary service to the rare disease community that we always have. I wish each and every one of our support organisations the very best as they continue their work supporting the amazing people who live with and care for those with genetic and rare conditions.

Amanda Samanek
Executive Director
2019-20 IN REVIEW

CONNECT

GaRDN works to connect people across the genetic and rare disease spectrum to ensure that collaborative efforts are fostered to limit duplication and create efficient and effective opportunities to improve outcomes for people with rare conditions. Some of the ways in which we connect people are:

- Providing advice and information about available health, allied health and support services to help people navigate their genetic, rare or undiagnosed disease journey
- Fostering collaboration through research, registries and other initiatives that seek to improve patient outcomes
- Identifying opportunities for patients to connect, locally, nationally and internationally to enhance the potential for psycho-social support.

Some of the ways we have done this in the last year included at least the following activities:

**Advice and information**

GaRDN continues to provide advice about services to assist people navigate their rare disease journey - there is an overview of our work in this area in the support section of the report. We’re continuing to identify new resources and services and wherever possible these are on our website to enable people to self service where they’d like to.

GaRDN has maintained a focus on assisting people to navigate the health system in Western Australia throughout this year. A large proportion of calls relate to finding health professionals and support for rare conditions, where other health providers have been unable to assist. Through responding to these inquiries we are able to identify and share new resources and services with our rare disease community via our website and social media pages.
Collaboration

The GUARD Collaborative

The GUARD Collaborative is a coalition of peak body organisations, Genetic Support Network Victoria, Genetic Alliance Australia (NSW), Syndromes Without A Name (SWAN Australia) and Genetic and Rare Disease Network (WA) that came together to:

- Increase awareness of genetic, rare and undiagnosed diseases in Australia
- Develop agreed position statements on matters that impact people living with genetic, rare and undiagnosed diseases in Australia to represent their views and for use in advocacy
- Collaborate to reduce duplication and ensure consistency of messages on matters of importance to the genetic, rare and undiagnosed disease communities in Australia
- Develop and deliver activities in the relevant national documents, including the National Genomic Health Framework and the soon to be developed National Rare Disease Framework.

GaRDN, GSNV, GAA, and SWAN Australia are committed to maintaining a positive and cooperative working relationship and where practicable to work collaboratively to deliver outcomes related to the goals and objectives detailed above. Each organisation has its own goals to achieve but seeks to ensure that work is undertaken using the best available information shared between organisations across Australia. The GUARD collaborative meet monthly.

GUARD developed a position statement developing a statement to encourage policy makers in the health and disability sector to consider the needs of people living with genetic, undiagnosed and rare disease during the COVID-19 outbreak.
Collaborative launch of National Strategic Action Plan for Rare Diseases

The National Strategic Action Plan for Rare Diseases (the Action Plan) was launched in February 2020 after Australian academics first called for a national plan for rare diseases in 2010. Rare Voices Australia led the collaborative development of the Action Plan. After extensive consultation with GaRDN and other stakeholders around the country, the Action Plan has been developed by the rare disease sector, for the rare disease sector.

GaRDN developed the Plan on a Page insert for the Action Plan and provided input throughout the document.

The Action Plan works towards the best possible health and wellbeing outcomes for Australians living with a rare disease and can be read at www.rarevoices.org.au/actionplan

As a member of the Steering Committee, the Executive Director of GaRDN attended the launch of the National Strategic Action Plan for Rare Disease and parliamentary event in Canberra in February 2020.

Raising awareness of the benefits exercise has on rare diseases, chronic pain and mental health

GaRDN has begun a partnership with local mountain biker Matt Williams who has Elhers Danlos Syndrome. Planning was underway to apply for grants to help fund Matt doing a mountain bike along the Munda Biddi Trail from Perth to Albany to raise awareness of the benefits exercise has on rare diseases, chronic pain and mental health. – this unfortunately had been delayed due to COVID-19 until 2021 but planning is underway to raise awareness, beginning with a social ride for Bike Week in October 2020.
Health professional register
Our health professionals register continues to be one of our most frequently accessed resources. The register is a valuable tool to enable staff to support people in identifying clinicians with knowledge, interest and experience in their condition. Clinicians listed in the registry have also been a valuable resource in providing information assisting us to link people with specialists and services in different jurisdictions. The registry also assists links with clinicians, researchers and other health professionals.

We have over 150 health professionals on the register and the disciplines represented are illustrated below:

Many people have reported that they have been able to obtain treatment and have had an improvement in health outcomes as a result of our support in helping them navigate the system. Some of the comments we’ve received include:
Research

GaRDN has been requested to be involved in several research projects in this period:

- Two papers have been submitted for publication, one of which ‘HGSA Position Statement for Online DNA Testing’ has been accepted and will shortly be published in Twin Research and Genetics. A further paper relating to the UNCRC series is currently in draft awaiting submission.
- A literature review on rare disease and its links to mental health has been conducted. The review will be utilised for future funding applications.
- A comprehensive information document for individuals interested in Genetic Testing has been developed and is currently in final draft for inclusion on the GaRDN website.
- GaRDN has provided input on the NHMRC Grant Review Panel
- GaRDN sits on the Mackenzies Mission consumer reference group. Mackenzies Mission is a research study which offers genetic carrier screen to 10 000 couples either planning to have children or in early pregnancy. The information and support provided through this program gives couples access to informed choices regarding potential severely debilitating or life limiting genetic conditions.
- GaRDN in collaboration with the other GUARD organisations undertook research in to the impact of COVID-19 on people living with rare and genetics disease and their carers and families. The results of this research as detailed in an infographic in the Empower section of this report
- Promotion of C19 journals project
2019-20 IN REVIEW - CONNECT CONTINUED

Patient and Clinical Registries

This search tool on our website continues to be a valuable resource for patients and clinicians to link with registries for their condition if one exists.
Oppportunities to connect

Rare Disease Day Event

To mark Rare Disease Day 2020, GaRDN hosted a very successful ‘Rare Together Expo’ at Heathcote Cultural Precinct, Applecross on a very hot and humid February 29, 2020. GaRDN's goal was to facilitate a community event which provided an opportunity for adults and children living with rare disease, their families and carers to obtain information, meet health service providers and network with other members of the rare disease community. The Expo also encouraged GaRDN members and service providers to promote their organisation, while networking with other industry experts in rare and genetic disease support.

The stallholders provided information sheets and brochures about the services their organisation offers and gave people the opportunity speak with them about how these services may assist them. Attendance at the event far exceeded expectations, with well over 100 attendees on the day, allowing GaRDN to provide timely, relevant and up to date information to support their health and wellbeing. GaRDN was pleased to note the networking among service providers and members facilitated commitment to future collaboration.

The Expo had 10 stallholders:

- NDIS
- Genetic Services WA
- Harry Perkins Institute People with Disabilities WA
- Be Inspired Foundation
- Tèa Lake and the Rare Disease Association
- Matt and Stacie for Ehlers Danlos Syndrome (incl Break the Boundary pamphlets)
- Developmental Disability WA
- Handmade Disability Products
- Australian Sickle Cell Advisory Group

As well as brochures made available from Kalparrin and My Health Record and a face painter to keep the children entertained.
Opportunities to connect

GaRDN conducted two satisfaction surveys, one for individual attendees and one for stall holders, both with outstanding feedback.

Attendee feedback:
- ‘Well organised - thank you for accepting my registration on behalf of my son.’
- ‘I feel that it was well organised and had a nice warm vibe’
- ‘It was my first time to attend and I'm happy that I did. Although the venue provided some challenges I could see it was a well planned and executed event and congratulate the organisers and all stall holders.’
- ‘I received a wealth of relevant information and all stall holders were extremely helpful!’
- ‘I appreciate all the effort that you put into organising such a helpful and wonderful event!’
- ‘Enthusiastic and knowledgeable stallholders’
- ‘The people organising the event were very kind’.

Stallholder feedback:
- ‘It was important to interact with other similar organisations’
- ‘There were quite a lot more attendees than expected overall and certainly more people attended our stall than expected. This was a well put together event’.
- ‘Great networking opportunity among people and organisations that Be Inspired Foundation would like to be more known and engaged among.’
Providing information

GaRDN continues to provide information to key stakeholders on the perspectives of people living with rare disease. We do this by undertaking surveys or targeted consultations to inform the submissions we have provided in our advocacy efforts.

Promotion - Google Ad Grant activation

At the end of October 2019, GaRDN was approved to participate in the ‘Google Ad Grants’ program for not for profit organisations. An extensive criterion of eligibility is required in relation to the GaRDN brand and website standard in order to be initially approved and to remain in the program. The program entitles GaRDN $10,000 USD of in-kind Google Ads advertising each month as well as support.

This opportunity provides GaRDN with increased exposure to people with genetic and rare conditions to find our website and contact GaRDN. As well as provide additional marketing support and assists to upskill GaRDN staff in online marketing.

Analytics from this program are monitored to determine ongoing participation.

Review of the regulation of certain self-testing in vitro diagnostic medical devices (IVDs) in Australia

GaRDN, representing the WA genetic and rare disease community, provided a submission to the public consultation by the Therapeutic Goods Association (TGA) in regards to whether Direct to Consumer Genetic Tests and self-tests for serious diseases be permitted in Australia, with consideration to risks, ethical frameworks and overall evaluation guidelines.
Public consultation on mitochondrial donation

GaRDN consulted with the National Health and Medical Research Council on the social and ethical issues associated with mitochondrial donation. Information was distributed to the genetic and rare disease community via GaRDN’s eNewsletter, website and social media platforms.

As a result of public consultation, GaRDN, representing the WA genetic and rare disease community, provided a submission to the public consultation by the National Health and Medical Research Council (NMHRC) about the ethical and social issues for Mitochondrial donation.

GaRDN Website

Our online presence is critical to our visibility, and our website is often the first thing people see of our organisation.

Our website is GaRDN’s primary portal, with the majority of email inquiries coming through the contact form on the website.

We had almost ninety thousand webpage views, which was up by 30% on the previous year.

Members can log on and update their own information, sign up online and add events to the GaRDN events section (with GaRDN approval).
GaRDN Website

The types of information to support the healthcare experience that we currently provide to support people living with rare conditions includes:

- A directory of over 140 support organisations and services
- A directory of over 150 health professionals with an interest in rare and genetic conditions
- Genetic and Rare Disease Knowledge Base
- Information about respite and home care services
- Information about clinical trials available in Australia and available to Australians but conducted overseas
- Over fifty information packs for people newly diagnosed with rare and/or genetic conditions
- Over fifty registries that are related to rare and/or genetic conditions that enable people with those conditions to become involved in research
- A resource guide that provides information about services and how they can be accessed
- A list of online portals for sourcing reputable information about conditions
- Information about genetic and clinical services
- An overview of the Life Saving Drugs Program and the drugs available
- Information on how to participate in and review research to support better understanding of the research and the conditions
- Information for those people with undiagnosed conditions who face greater uncertainty and a lack of access to services without a diagnosis.

These resources are all available to support people living with rare diseases to support them in self-management of their care.

As part of our commitment to supporting our members and their events, GaRDN continues to add member events to the GaRDN events calendar and share them to the GaRDN Facebook page.

The website has two interactive maps for support groups and support organisations and services creating a ‘one-stop’ shop for people seeking this information.
Social Media

Social media is playing an increasing role in peoples lives both as a way of connecting with friends and their communities and as a way of finding information about things that matter to them.

Social Media has become a big part of how we connect with and inform the rare disease community about events, announcements, opportunities for input into research. We share events and news posts of our members, interesting posts related to rare disease and post weekly motivational quotes and images.

We currently have Facebook, Twitter, Instagram and LinkedIn. Facebook being the most popular with 2613 followers and growing every week.
Patient Pathways Program - Telehealth Nurse

GaRDN, as part of the GUARD collaborative with Genetic Alliance, Genetic Support Network of Australia and Syndromes without a Name, completed documentation to support CCDR. As a result GaRDN is now part of the Patient Pathways Program.

The program, federally funded through the Centre for Community-Driven Research aims to increase the capacity of patient organisations such as GaRDN to assist patients in navigating the health system and help them to access all of the services available to them. The telehealth nurse will commence in the 20-21 period.

The United Nation Convention on the Rights of the Child Series

The UNCRC series culminated on Rare Disease Day, 29 February 2020 with our final of 35 posts summarising UNCRC article 42 in relation to rare disease and providing a summary of the series. The posts have contributed to an increase in interactions with our social media, with 9 posts uploaded during the reporting period, there has been an average reach of 908 people per post and an average of 56 engagements.

Work is currently underway to analyse the responses and impact of the series.
New information developed

Information sheets created

- Darier Disease
- Dercum’s Disease
- Ehlers-Danlos Syndrome (Draft for Comment)

The information sheets provide easy to read summarised information on rare conditions, living with a diagnosed/undiagnosed genetic and rare condition, treatment options that are currently available, support for individuals and their families living with a diagnosed or undiagnosed genetic and rare condition, care co-ordination and information on research. However, based of Department of Health advice, information sheets were removed from our website in 2020.

People/organisations consulted during their development

- Orphanet https://www.orpha.net
- Genetic and Rare Diseases Information Center https://rarediseases.info.nih.gov/
- National Organisation for Rare Disorders (NORD) https://rarediseases.org/
Facebook Closed Groups

During the reporting period GaRDN developed two closed Facebook groups via the GaRDN Facebook page:

**Genetic and Rare Disease Network Member Organisation Group**

This group was created to further the support we give members, allowing us to provide support group specific information. The aim was to inform members of the services available to them as a support group, and enable members to contribute to the collective voice of the genetic and rare disease community for submissions and have input on rare and genetic disease matters, as well as giving members the opportunity to share information and advice while networking between groups.

All of our members were encouraged to join, however due to our funding arrangements there is a West Australian focus on the information shared and requested.

**WA Adult Rare and Undiagnosed Conditions Support Group (WA ARUCS)**

This group was created as a safe place for adults with rare and undiagnosed conditions to link with others who may have shared experiences and be a support to each other.

Adults who join WA ARUCS will have a rare or undiagnosed condition where there are no existing support groups available for their condition.

Our hope is this group will fill that void for those adults with rare and undiagnosed conditions where they do not have an online support network available to them.

Both Facebook groups are in their early stages of development, with membership in the Member Organisation Group at 37 members and the WA ARUCS group with 12 members (this is deliberately conservative to ensure quality and reliability of the group and member privacy). Members are starting to initiate their own posts and interact through the groups. There have been 27 posts to the Member Organisation Group in this reporting period, with members beginning to initiate their own posts.

These groups will provide a valuable insight into the views and opinions of people living genetic and/or rare diseases. The GaRDN team are developing a strategy to ensure both groups are engaged and provided with relevant information.
Consumer Input

GaRDN makes continued efforts to understand and reflect the views of Western Australians living with genetic and rare conditions through networking, discussion and other means as below. In this quarter GaRDN has been requested to provide consumer input via:

- The National Congenital Anomalies Advisory Group (as a consumer representative member)
- An invitation to attend the Primary HealthCare Roundtable (RVA were unable to attend and agreed we could speak on their behalf)
- As a consumer representative panel member for the National Health and Medical Research Futures Fund Rare Cancer, Rare Disease and Unmet Need grant round.
- Two documents developed as part of the Medical Device Action Plan Consumer Working Group - Australian Government Department of Health, Therapeutic Goods Administration (TGA).
- GaRDN also participated in a teleconference on genetic tests component of the regulation of certain self-testing in vitro diagnostic medical devices (IVDs) in Australia.
- Provided input to the Rare Diseases International focus group meeting
SUPPORT

GaRDN offers support to individuals, families and groups in a number of ways:

- Support, information and assistance to the general community
- Linking patients with rare conditions
- Referring people to specialised services/organisations
- Health professional enquiries
- Service enquiries
- Network enquiries.

Phone and email support

We’ve had over 230 phone calls and emails from individuals requesting assistance – ranging from support group information to requests to research complex information. As in previous years the largest number of inquiries were about health professionals who know about a specific condition.

GaRDN is careful not to ‘recommend’ a health professional but we will provide information about health professionals who have self-registered as having an interest in a rare disease via our register or we will research for a health professional who has a publication record or is identified via someone with a publication record about a specific rare condition.

In many instances we have been able to provide specific details and the health professionals we have contacted have offered to see people at their clinics or recommended someone else.

The types of information we have provided this year by email and phone have included:

- RESEARCH TRIALS
- FINANCIAL SOLUTIONS
- SUPPORT GROUPS
- SPECIALISTS/GP’S
- CONDITION SPECIFIC EDUCATION
- GENETIC TESTING/COUNSELLING
- EDUCATION – PRESENTATIONS
- ADVOCACY SUPPORT
- EDUCATION INFORMATION
- DISABILITY INFORMATION
- MENTAL HEALTH INFORMATION
Support groups refers to peer support organisations or sites that provide people with an opportunity to make linkages with other people with the same or similar diagnosis. Support organisations refers to organisations that offer services that can support people e.g. NDIS, advocacy services, etc.

We have been able to source information from reputable sources for everyone that has contacted us and provided them with information about items such as those below:

### Types of Information Requested

<table>
<thead>
<tr>
<th>Information Type</th>
<th>Requested Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Professionals</td>
<td>25%</td>
</tr>
<tr>
<td>Support Group</td>
<td>24%</td>
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<tr>
<td>Condition Information</td>
<td>8%</td>
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<tr>
<td>Advocacy</td>
<td>6%</td>
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<tr>
<td>Patient Linkages</td>
<td>6%</td>
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<tr>
<td>Service Information</td>
<td>5%</td>
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<tr>
<td>Genetic Testing</td>
<td>5%</td>
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<tr>
<td>Research Information</td>
<td>4%</td>
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<tr>
<td>NDIS Information</td>
<td>2%</td>
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<tr>
<td>Clinical Trials/Patient registries</td>
<td>2%</td>
</tr>
<tr>
<td>Other</td>
<td>13%</td>
</tr>
</tbody>
</table>
Most of our requests come from patients and parents but we also assist other support organisations and other state-based organisations in responding to queries.

The provision of this varied information supports individuals in managing their care which is in line with the WA Health Strategic Framework for Rare Diseases. Ultimately this advice has the potential to reduce the impact to patients and the health system from inappropriate referrals and treatments.

Our ongoing satisfaction survey indicates that contacts come from a variety of people, ranging from those that are newly diagnosed to carers. All respondents have reported the service to be excellent and that they appreciated follow up contact.

We have also had an increasing number of calls from other services seeking information about rare conditions to support their interaction with patients and clients. These have ranged from advocacy services representing people with rare diseases seeking support via the National Disability Insurance Scheme (NDIS) or community services, general practitioners seeking sources for specific condition information and advice about support and allied health services.
GaRDN works with...

109 Support Groups
38 Support Organisations

Assisted over 230 people navigate the health system

Types of info requested
- Health Professional: 25%
- Condition Info: 8%
- Support Groups: 24%
- Linking Patients: 6%
- Genetic Testing: 5%
- Advocacy: 6%
- Clinical Trials: 2%
- Research Info: 4%
- Service Info: 5%
- Other: 13%

Assisted people with 109 different rare conditions

2805 Facebook followers
102 Twitter followers
144 Instagram followers

OVER 2000 CALLS AND EMAILS
88,268 WEB PAGE VIEWS
GaRDN continues to refine and record data from incoming requests to ensure that information obtained through each inquiry is available to contribute to continuous improvement and reduction of duplication in dealing with future inquiries.

GaRDN's commitment to continuous improvement in service delivery to the genetic and/or rare disease community is also evident in the recent implementation of the GaRDN member satisfaction and planning survey. The results of this survey is included in the infographic below:
EMPOWER

GaRDN actively seeks opportunities to provide a voice for and provide representation on behalf of individuals and families affected by genetic conditions.

In providing consumer feedback GaRDN has provided comment on a wide range of issues including access, equity, health reform, management, support and systemic reform.

Our aim is to represent the genetic and rare disease patient perspective in the overall approach to health, health care and service delivery and the quality of life of those living with genetic conditions.

Advocacy involves representing the interests and views of people and their families affected by a genetic condition to the community, State and Federal Government.

GaRDN works to empower members and the general community by raising issues and providing feedback on a range of topics.

In the year to date, advocacy and representation work has included:

Consumer workshop on the Action Plan for Medical Devices by Australian Government Department of Health, Therapeutic Goods Administration (TGA)

GaRDN was invited to attend the Workshop ‘An Action Plan for Medical Devices Co-Design Consumer Engagement’ 20 August 2019. The Action Plan for Medical Devices aims to strengthen Australia’s medical device regulatory framework. The Plan sets out a range of actions that continue to improve the safety, performance and quality of medical devices in Australia, as well as enhancing transparency and increasing public confidence in the regulatory system.

GaRDN attended the workshop representing a collective voice of the WA community of people living with genetic and/or rare disease to discuss how to best achieve good communication regarding new devices on the market and how to provide consumer friendly information on high risk devices. Awareness raising of the regulatory system, including clinical evidence, manufacturers’ inspection reports and searchable incident reports were also considered.
GaRDN encouraged any future consultation with the WA genetic and/or rare disease community about the medical devices plan be channeled through State peak organisations such as GaRDN. As no other representation from the genetic and/or rare disease community were present at the workshop, therefore GaRDN represented both WA and the Genetic, Undiagnosed and Rare Disease (GUARD) Collaborative.

GaRDN has undertaken consultation with the WA genetic and/or rare disease community to provide relevant feedback (as applicable) to any materials and processes undertaken by the TGA regarding the Medical Device regulatory framework.

Following GaRDN’s attendance at the Workshop. GaRDN was invited to become a member of the ‘Medical Device Action Plan Consumer Working Group’. A program of work over the next 12 months for the ‘Medical Device Action Plan Consumer Working Group’ is planned. GaRDN will have the opportunity to engage with our members to represent their views to the TGA.

Consumer Roundtable discussion on the best Privacy and Responsible Information Sharing arrangement for the WA public sector

GaRDN was invited to attend a Consumer Roundtable discussion regarding Privacy and Responsible Information Sharing in the WA public sector on 27 August 2019. The Consumer Roundtable discussion was run by Telethon Kids Institute, WA Health Translation Network and the WA Government’s Premier and Cabinet privacy project team.

A proposed legislative model for privacy and responsible information sharing in the public sector and with authorised third parties, and what this means to them was discussed with health consumers.

The WA health sector has a longstanding successful record of capitalising on the public value of safely linking WA Government data sets. By sharing information and integrating data sets, researchers and policy makers can gain new insights and develop solutions that are tailored and forward-looking.

However, the WA public sector is one of only two jurisdictions in Australia without overarching legislation that either protects people’s personal information or provides a framework for safely sharing information.
That is why the WA Government has announced its commitment to introducing new whole-of-government privacy and responsible information sharing legislation for the WA public sector.

GaRDN's attendance at the Consumer Roundtable discussion enabled us to contribute to the collective voice of the genetic and rare disease community within WA. GaRDN was able to ensure that any concerns, criticisms or comments pertinent to the genetic and rare disease community were heard and noted in feedback on the proposed legislation. People living with rare disease have much to gain from data sharing, however, are also easily identified due to the rare nature of their disorder, consideration of these special needs is essential in considering privacy and information sharing legislation. GaRDN was also able to hear the opinions and individuals within the community to ensure our understanding continues to align with community beliefs and expectations.

GaRDN encouraged and facilitated the WA genetic and rare disease community to provide feedback on the proposed legislation via online feedback and suggested attendance at further discussions.

43rd Human Genetics Society of Australasia (HGSA) Annual Scientific Meeting

GaRDN, along with a number of other peak support organisations, was successful in having a poster accepted for presentation at this meeting. The meeting is well attended by clinicians, genetic counsellors, researchers and laboratory staff and provides an ideal platform to raise awareness of the importance of support services for people newly diagnosed or living with rare conditions.

Attendance at the HGSA ASM is an ideal opportunity to remain up to date with current activities and projects in the genetics area. Attending this meeting ensures that GaRDN can provide contemporary and relevant advice to our member organisations as well as respond to health policy and strategic decision making in an informed manner. All peak support organisations in Australia and New Zealand made an effort to attend the ASM this year and took the opportunity to further build on the Genetic, Undiagnosed and Rare Disease collaborative to ensure that all organisations are aligned when responding to national policy and strategic issues. One of the key learnings from the conference was the approach to indigenous genomics in New Zealand and how this might be improved in Australia.
Australian Genomics Health Alliance – National Conference

This event was invitation only, GaRDN accepted an invitation and attended the meeting to understand current activities and provide input where possible. This meeting was an ideal opportunity to remain up to date with current activities and projects in the genetics area. The intended outcome was to ensure that GaRDN can provide contemporary and relevant advice to our member organisations as well as respond to health policy and strategic decision making in an informed manner. The conference provided a key networking opportunity and since the meeting we have been included in opportunities to provide feedback on learning materials for a key genomics project.

Consultations on a nationally consistent consent for genetic/ genomic testing

GaRDN, representing the WA genetic and rare disease community, participated in a teleconference with a consultancy engaged by NSW Health to provide feedback for the national model for clinical consent to genetic/ genomic testing. NSW Health is working on behalf of the Australian Health Ministers Advisory Council (AHMAC) Project Reference Group on Health Genomics to develop a national model for clinical consent to genetic/ genomic testing.

Medical Services Advisory Committee (MSAC) submission

In collaboration with other state peak body rare disease organisations, a submission was made to MSAC supporting an application for a Medicare item for reproductive carrier genetic screening for Fragile X syndrome, spinal muscular atrophy and cystic fibrosis. If granted, couples will have greater reproductive options, thus reducing the economic, physical and psychological impact of supporting families with these conditions.

Human Genetics Society of Australasia (HGSA) Education, Ethics and Social Issues Committee

GaRDN continues to provide input to this committee, ensuring consumer perspectives are represented on key ethical and social issues documentation.
Products used for and by people with disabilities: Therapeutic Goods (Excluded Goods) Determination 2018

Feedback was sought on options for amending the Therapeutic Goods (Excluded Goods) Determination 2018, to clarify which products intended for use for, or by, people with disabilities are excluded goods, and so regulated as consumer rather than therapeutic goods. Consultation with people living with genetic and/or rare disease in WA was done through direct email to GaRDN members and the closed GaRDN Facebook group for member organisations.

MacKenzies Mission

GaRDN attended the Consumer Reference Group of Mackenzies Mission and has supported document development and provided input to the Mackenzies Mission support group activities via the Engagement Reference Group.

WA Ambulance Service Opportunity to Input

GaRDN, on behalf of Health Consumers' Council (WA) and the Behaviour Change Collaborative utilised our social media channels to give the rare disease community an opportunity to comment on their experience with using an ambulance in the past five years. Participants in the survey were asked about their experience with wait times, the friendliness and efficiency of ambulance staff and how their experience could be improved. Our community was also invited to attend a consumer forum discussion about WA ambulance services.

COVID-19 survey for people living with genetic, undiagnosed and rare disease

With permission from NORD, the peak state and national support organisations, under the banner of GUARD, modified and distributed a COVID 19 survey. The survey was distributed to member organisations and individuals to assess the impact of COVID on people living with genetic, undiagnosed and rare conditions. Survey results were compiled and the results are summarised below.
## COVID-19 Survey

83 Respondents - April-May 2020

**59%** believe they are at increased risk of COVID-19

**87%** have been impacted by COVID-19

**Why?**
- Genetic and Rare Disease
- **Vulnerable**
- Worried great risk
- Respiratory weakness
- Complications
- **Increased risk of dying**
- Compromised Immune System
- Immune Deficiencies
- Breathing Issues
- Sick
- Low Immune System
- Infections
- Risk of seizures with any fever

### Medical Supplies

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>29%</strong></td>
<td>Experienced challenges getting medicine as a result of COVID-19</td>
</tr>
<tr>
<td><strong>34%</strong></td>
<td>Have had challenges getting medical supplies</td>
</tr>
<tr>
<td><strong>41%</strong></td>
<td>Are concerned with future medication and medical supply shortages</td>
</tr>
</tbody>
</table>

### Challenges getting medication included:
- 59% Pharmacy unable to fill prescription due to a shortage
- 30% Unable to or are afraid to travel to the pharmacy
- 12% Not able to get a medical appointment with doctor for prescription

### There were challenges getting:
- 40% Personal protective equipment
- 7% Medical foods, supplements
- 5% Medication infusion services
- 5% Feeding tube supplies
- 5% Durable medical equipment

### GP and specialists

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>19%</strong></td>
<td>Have been contacted by their GP or specialist about COVID 19 and their genetic, rare or undiagnosed condition</td>
</tr>
<tr>
<td><strong>60%</strong></td>
<td>Have had a medical appointment cancelled due to COVID-19</td>
</tr>
<tr>
<td><strong>80%</strong></td>
<td>Have been offered a phone or video call as an alternative to an in-office appointment with a doctor</td>
</tr>
<tr>
<td><strong>25%</strong></td>
<td>Would continue with telehealth appointments whenever possible in the future</td>
</tr>
<tr>
<td><strong>62%</strong></td>
<td>Would continue with telehealth for some appointments</td>
</tr>
</tbody>
</table>

### Other

- **40%** have experienced challenges with accessing medical care or treatment
- **67%** of allied health appointments are being offered through telehealth and **70%** found the telehealth experience adequate or very good
- **42%** have had to limit or stop support workers coming to their home due to COVID 19
- **22%** have accessed mental health services as a result of distress related to COVID 19
- **16%** needed to seek urgent care or visit the emergency department during the COVID-19 outbreak, but **9%** didn’t seek treatment due to the COVID risk
- **37%** of households have been impacted by a loss of income due to coronavirus, resulting in **5%** losing health insurance
- **47%** are overwhelmed by the information they are receiving

### COVID-19 concerns and experiences

- Experience has been awful
- **Really overwhelming!!!**
- Emotionally and physically abandoned by the system
- Enormous strain
- Second wave
- Mental breakdown
- Treatment delayed
- Inability to access essential therapies
- SO HARD
- Increased cost of living
- Deterioration of condition
- Lack of funding
- PPE hard to find
- Trial treatment cancelled
- Stress and anxiety
- Just give up
- Constant struggle
## GENETIC SUPPORT COUNCIL WA INC.
### ABN: 63 614 315 270

**STATEMENT OF FINANCIAL POSITION AS AT 30 JUNE 2020**

<table>
<thead>
<tr>
<th></th>
<th>NOTE</th>
<th>2020</th>
<th>2019</th>
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<tbody>
<tr>
<td><strong>CURRENT ASSETS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cash &amp; cash equivalents</td>
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<td>167,693</td>
<td>175,030</td>
</tr>
<tr>
<td>Total Current Assets</td>
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<td>167,693</td>
<td>175,030</td>
</tr>
<tr>
<td><strong>NON-CURRENT ASSETS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Property, Plant &amp; Equipment</td>
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<td>7,518</td>
<td>5,448</td>
</tr>
<tr>
<td>Total Non-Current Assets</td>
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<td>7,518</td>
<td>5,448</td>
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<tr>
<td><strong>TOTAL ASSETS</strong></td>
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<td>175,210</td>
<td>160,478</td>
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<tr>
<td><strong>CURRENT LIABILITIES</strong></td>
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<tr>
<td>Payables and Accruals</td>
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<tr>
<td>Employee Provisions</td>
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<tr>
<td>Total Current Liabilities</td>
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<td>3,438</td>
<td>31,082</td>
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<tr>
<td><strong>NON-CURRENT LIABILITIES</strong></td>
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<td>12,863</td>
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<tr>
<td>Employee Provisions</td>
<td></td>
<td>-</td>
<td>12,863</td>
</tr>
<tr>
<td>Total Non-Current Liabilities</td>
<td></td>
<td>-</td>
<td>12,863</td>
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<tr>
<td><strong>TOTAL LIABILITIES</strong></td>
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<td>3,438</td>
<td>43,945</td>
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<tr>
<td><strong>NET ASSETS</strong></td>
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<td>171,772</td>
<td>136,533</td>
</tr>
<tr>
<td><strong>ACCUMULATED FUNDS</strong></td>
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<tr>
<td>Accumulated Surplus</td>
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<td>136,533</td>
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<tr>
<td>Net Surplus for the year</td>
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<td>35,239</td>
<td>31,602</td>
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<tr>
<td></td>
<td></td>
<td>171,772</td>
<td>136,533</td>
</tr>
</tbody>
</table>
OUR MEMBERS
FULL MEMBERS
Acoustic Neuroma Association of WA
ADHD WA
Albinism Fellowship of Australia
Alpha-1 Association of Australia
Androgen Insensitivity Support Group Australia Inc
Angelman Syndrome Association of WA
Arthritis & Osteoporosis WA
Arthrogryposis Group (TAAG) Inc, The Australian
AusDOCC Inc (Australian Disorders of the Corpus Callosum)
AusEE
Australia Alopecia Areata Foundation
Australian Sickle Cell Advocacy Inc
ARCAN (Australian Rare Chromosome Awareness Network)
Batten Disease Support and Research Association (Australian Chapter)
Bertolotti’s Syndrome Support
Bowel Group for Kids (BGK)
Cardio-Facio-Cutaneous (CFC) Syndrome Support Group
CDH (Congenital Diaphragmatic Hernia) Australia
Charcot-Marie-Tooth Association Australia- WA Division
CHARGE Syndrome Association of Australasia
Chiari & Syringomyelia Australia
Children’s Tumour Foundation of Australia (NF Australia)
Chromosome 18 Registry & Research Society
CJD (Creutzfeldt-Jakob Disease) Support Group
CleftPALS WA
Clinikids - Telethon Kids Institute
Coeliac Western Australia
ConnecTeD Foundation Inc
Cornelia de Lange Syndrome Support Group of Australia
Cri du Chat Syndrome Support Group of Australia
Cushing's Disease Support Group
Cystic Fibrosis WA Inc
Cystinosis Support Group, Australian
DEBRA Australia
Dementia Australia
Diabetes WA
OUR MEMBERS CONTINUED

Down Syndrome WA
Dyslexia SPELD Foundation WA Inc
Dysplasia Support Group Australia (ozED)
Epilepsy Association of WA Inc
Even Keel Bi-Polar Disorder Assoc. Inc
Fabry Australia
FaceUp
Familial Hypercholesterolaemia Support Group of WA
Fragile X Association of Australia Inc
Friedreich Ataxia Network (FAN)
GAPPS Support
Gelastic Seizure Support Hub
Genetic Alliance Australia
HAE Australasia (Hereditary Angioedema)
Haemochromatosis Australia
Haemophilia Foundation WA Inc
Heart Kids WA Inc
HHT Alliance
Homocystinuria (HCU) Network Australia
HSP Research Foundation Inc
Huntington’s WA (Inc)
Hypersomnolence Australia Inc
Immune Deficiencies Foundation Australia (IDFA)
Kawasaki Disease Foundation Australia
Klinefelter’s Support Group WA
Klippel Trenaunay Support Group
Leukodystrophy Support Group, Australian
Liver Foundation of Western Australia
Lupus Group of WA Inc
Lyme Disease Association of Australia
Machado Joseph Disease (MJD) Foundation Ltd
Meniere’s Australia WA Branch
Mental Illness Fellowship Australia
Mitochondrial Disease Foundation Australian (AMDF)
Motor Neurone Disease Association WA (MNDAWA)
Mucopolysaccharide & Related Diseases Society
Multiple Sclerosis Society of WA
OUR MEMBERS CONTINUED

Muscular Dystrophy Association of WA
Myasthenic Association (The Australia, in NSW Inc)
Neurofibromatosis Association of WA Inc
Noonan Syndrome Awareness Association
Osteogenesis Imperfecta (OI) Society of Australia
Our Faces Support
Pallister-Hall Syndrome (PHS) Support Hub
Pallister-Killian Syndrome Foundation of Australia
Parenteral Nutrition Down Under (PNDU)
Parkinson's Western Australia
PKD Australia
Pompe Association, Australia
Primary Orthostatic Tremor Group
Retina Australia (WA)
Rett Syndrome Association of WA
Sanfilippo Children’s Foundation
Senses Australia
Short Statured Peoples Association WA Branch
Red Nose WA (Formerly SIDS and Kids WA)
Sjogren’s Syndrome Association Australia Inc
SOFTWA (Support Organisation for Trisomy and Related Disorders of WA)
Sotos Syndrome Association of Australasia
Spina Bifida and Hydrocephalus Association of WA
Spinocerebellar Ataxia Australia Inc
Syndromes Without a Name (SWAN)
Tarlov Cyst Society of Australia & New Zealand
Thalassaemia Australia Inc
Thalassaemia Foundation Ghana
The PFIC Network
Tourette Syndrome Support Group, Perth
Tuberous Sclerosis Australia
Turner Syndrome Association of Australia (WA)
Deaf Blind West Australians (Formerly Usher Syndrome Support Group)
VCFS 22q11 Foundation
VHL Alliance WA
Williams Syndrome Association of WA
XYY Syndrome Association of Australia
OUR MEMBERS CONTINUED

ASSOCIATE MEMBERS

Activ Foundation
Association for the Wellbeing of Children in Healthcare
Asthma Foundation of WA
Be Inspired Foundation
Cancer Council Helpline
Carers Association of WA Inc
Children and Young People with Disability Australia
Connect Groups Support Groups Association WA
Deaf Society Inc, WA
Developmental Disability WA
Disability Services Commission
EDGE Employment Solutions
Ethnic Disability Advocacy Centre (EDAC)
Genetic Alliance Australia
Genetic Services of WA
Health Consumers’ Council (WA) Inc
Helping Minds - Mental Health Carers and Friends Association
Jack’s Butterflies
Immunodeficiency Research Centre
Independent Living Centre WA
Intelife
Ishar Multicultural Women’s Health Centre
Kalparrin Centre
Kidney Health Australia
Linkwest
Office of Population Health Genomics
People with Disabilities WA
Rare Disease Ghana Initiative
Rare Voices Australia
Rocky Bay (and Spina Bifida and Hydrocephalus Association of WA)
Self Help QLD
SHOUT (Self Help Organisations United Together)
Speak Easy Association of WA
OUR MEMBERS CONTINUED

Technology Assisting Disability WA (TADWA)
The Centre for Genetics Education
The Neurological Council of WA
Therapy Focus

INDIVIDUAL ASSOCIATE MEMBERS

Mitch Messer
Robyn Hendriks
Prof David Ravine
Prof Charles Watson
Anja Hermann
Dr Darren Webb

HONORARY LIFETIME MEMBERS

Dr Gareth Baynam
Address: PO BOX 1023 , Booragoon WA 6954
Phone: 1300 770 995
Email: hello@gardn.org.au
Web: www.gardn.org.au
Hours: Monday to Friday  8.30 am to 4.30 pm
ABN: 63 614 315 270