ANNUAL REPORT 2018-19
### 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
Gareth Baynam        Committee
Shoma Mittra         Committee
Leticia Grant        Committee (retired June 2019)
Hayley Lajcszcak    Committee
Dorota Fretwell      Committee (June 2019)

Staff as at 30 June 2019

Amanda Samanek        Executive Director (0.8 FTE)
Brooke Baxter        Senior Project Officer (0.6 FTE)
Regan Leen           Senior Project Officer (0.25 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.
It has been a positive and productive year for GaRDN and our members in 2018/19. We’ve been effective at influencing policy, frameworks and activities at both a state and national level throughout the year. This has included finishing the calendar year with some television coverage of the challenges in accessing support and disability funding faced by people living with rare disease; attending a Parliamentary event in Canberra to speak about rare disease and disability, including some options for addressing this with the proposed creation of a rare disease advisory group; and supporting Rare Voices Australia in undertaking consultation with stakeholders of the rare disease community in Western Australia to ensure the issues our members are dealing with are well represented.

This year our organisation has helped over 200 individuals and groups with information, advice and support in relation to a genetic, rare or undiagnosed disease. It’s been a great year of engagement for myself and the GaRDN Board Members with the WA genetic and rare disease community, hearing your feedback and experiences through WA regional consultation and Rare Disease Day events. As someone who lives with a rare condition, I know only too well how critical having somewhere to go for information is. This is what drives my commitment to GaRDN and the WA community.

An appreciative thank you to our strong, supportive Board who volunteer their time to provide governance and strategic direction for GaRDN. This financial year has seen the departure of the inimitable Leticia Grant whose experience, thoughtful input and good humour will be sorely missed by the Board. We have been fortunate to retain many Board members and with a number of Board positions becoming available at the AGM in December we look forward to welcoming new ideas to continue to grow GaRDN and ensure we can provide more support to Western Australians living with genetic, undiagnosed and rare diseases.

It’s been exciting to finalise the development and start implementation of our strategic plan. There are so many possibilities to enhance the way we deliver services and the new financial year, with all the staff available, including two coming back from parental leave, herald’s tremendous potential to achieve even more.
I'd also like to warm-heartedly thank the GaRDN team who, under the guidance of our incredibly dedicated Executive Director Amanda Samanek, work so hard to respond to the needs of the many individuals that contact them to seek support. Without the dedication and professionalism of the staff, people living with genetic and rare diseases would take longer to find the services, support and people they need to make their journey that little bit easier.

I look forward to more great things in 2019-20 as we continue to acknowledge and applaud the work of Western Australians in the rare disease arena and increase awareness of genetic and rare diseases and the unique needs of the people living with them.

Melissa Devlin
Chair
EXECUTIVE DIRECTOR’S REPORT

It has been a privilege to serve GaRDN members and the broader Western Australian community this year. We’ve had so many opportunities in 2018/19 to represent the WA perspective at a national level, including input to the National Action Plan, input to state and national policy activities and multiple submissions on a range of things that impact people living with rare disease. The team at GaRDN is extraordinary in listening to the issues that Western Australians face in dealing with their rare disease; from diagnosis to support, and everything in between, and we endeavour to reflect what we hear at every opportunity; striving to improve the way in which rare disease is considered and responded to, at every level of government and across sectors.

This report details just the highlights of what we have done this year and no amount of writing can give the reader a full understanding of what the team hears and deals with on a week to week basis. Two of the team undertook training in Applied Suicide Intervention Skills Training this year in an effort to better respond to people who ring our 1300 number. It has never been so apparent as this year, that rare disease has the potential to impact every aspect of someone’s life.

On New Years Eve, GaRDN featured in a television interview detailing the difficulty of obtaining support services when living with a rare disease. The impact of rare disease on this family went well beyond what was covered in the interview and their bravery and fortitude cannot be understated and, sadly, they are not alone. Throughout the year the team talks with and attempts to assist over 200 individuals, families, carers and others to navigate rare disease.

I am humbled by the professionalism, dedication and care exhibited by our staff and the feedback we recieve consistently indicates our role is extremely valued and critical in supporting so many people. This organisation would not be what it is without them and I am truly grateful to know them and have the opportunity to work with them.

We’ve taken every opportunity this year to engage with our member organisations who do an incredible job in their own right. GaRDN is committed to understanding the rare disease environment and representing this whenever the opportunity arises. Our new initiatives for the next year hope to build on this and create a more networked rare disease sector....rare diseases are rare but together we can be powerful...the power of our shared understanding is critical to improving policy and outcomes for everyone living with rare disease. I look forward to working with you all in 2019/20.

Amanda Samanek
Executive Director
2018-19 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.

Collaboration

Our most significant achievement this year has been the establishment of the GUARD (Genetic Undiagnosed and Rare Disease) collaborative, a partnership between the peak state and national genetic, undiagnosed and rare disease organisations. The Collaborative consists of GaRDN, SWAN, RVA, GSNV (Victoria) and GAA (NSW). We are looking to establish a work plan over the course of this calendar year.

To date we have corresponded with the Health Technology Assessment section in the Department of Health (Federal) to advise them of our existence and that we are happy to be involved as consumer representatives on committees and support them in accessing our member organisations to provide feedback on Pharmaceutical Benefits Advisory Committee (PBAC) and Medical Services Advisory Committee (MSAC) applications to ensure adequate consumer input.
Collaboration continued

GUARD has also developed a position statement in response to the Financial Services Commission moratorium on genetic testing and life insurance.

In June GUARD agreed to involvement in the Australian Genomic Health Alliance review of the impact of the moratorium.

These activities are intended to ensure the needs of people living with rare disease are adequately reflected in the development of policy positions.

Research and Registries

Health professional register
In this financial year our health professional register has been one of our most frequently accessed resources and has enabled staff to support people in identifying clinicians who have knowledge of their condition and link clinicians, researchers and other health professionals with each other.

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

![Disciplines chart](chart.png)
Research
GaRDN has been requested to be involved in several research projects in this period:

- WACRF rare disease project grant as a co-investigator
- NHMRC Ideas grant – Identifying disease-associated rare genetic variants to facilitate diagnosis in paediatric patients - associate investigator
- NDIS ILC grant application – plain English resources for rare disease – co-investigator
- MRFF ELSI application – genetic ethics applications how to guides – deferred submission
- GaRDN is represented on the Facing Clinical Trials project that has been successful in obtaining 2 years funding as part of the Perth Children’s Hospital Research Fund. The project is investigating the use of 3D photography to create tools to support diagnosis of diseases. https://ww2.health.wa.gov.au/Articles/S_T/Telethon-Perth-Childrens-Hospital-Research-Fund-recipients/2017-Telethon-Perth-Childrens-Hospital-Research-Fund-Awards-Round-6-recipients

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

"It has been amazing to be able to get all this information as I had no idea where to go or how to get this information. This has offered me hope. Your assistance means very much to me."

"Thank you for the information and support. Much appreciated"

"Thank you, thank you, thank you"

"Thanks so much. You have been very helpful."

"You've been an absolute blessing; I can look forward to moving forward with a diagnosis now"
Patient and Clinical Registries

This search tool on our website allows patients and clinicians to find registries for their disease if one exists.
Opportunities to connect

Rare Disease Day Event
The GaRDN Rare Disease Day event ‘Meet the Rare’ was held at Perth Zoo on Sunday 24 February. Participants were given the opportunity to interact with other rare disease families, as well as with one of the zoo’s rare creatures, through an Eye to Eye encounter with the giraffes.

The theme for Rare Disease Day 2019 ‘Bridging health and social care’ paired with the board commitment to provide more member focussed activity in 2019, provided an opportunity to bring people living with genetic and rare disease, as well as their families, together with the goal of encouraging networking and establishing a community connection.

The event was well attended with 22 adults and 15 children at the zoo on the day. Due to the discounted entry for children (as a result of the zoos annual Teddy Bear Picnic being on the same day), we were able to provide extra adult tickets. 15 people were fortunate enough to experience the giraffe encounter, mostly the children supervised by a few adults.
Opportunities to connect

My Health Record Event
In partnership with WA Primary Health Alliance, GaRDN hosted a My Health Record information and connection morning on June 22, 2019.

The event goal was to educate our members about My Health Record, as a tool for medical record keeping and assisting with management of their rare condition. Networking was encouraged before the presentation, allowing attendees to establish connections in the local rare disease community and children’s entertainment was organised to assist family attendance.

The event was promoted through our social media pages, website and eNewsLetter. Interaction with our social media was good. There were several ‘shares’ to other organisations and networks, promoting GaRDN as a peak organisation for genetic and rare disease support groups to a wider audience. This possibly contributed to a peak in the number of people liking our Facebook page through that time.

WAPHA have provided a copy of the presentation that is on our website.
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.

Respite care for people living with rare disease

In 2017 GaRDN provided a proposal to Curtin University to have a student undertake some research into respite care for people living with a rare disease. Some of the key themes that were identified from interviews were:

- "Respite was available but was not family-centred"
- A need for respite because caring for a child with rare and genetic diseases is different from caring for most other children
- A need for respite because the demands of caring impact on the mothers’ health and occupations
- Respite carers need to be a good fit with the child and mother
- Negotiating respite is too complex"

Respite experiences and perspectives of primary carers of children with rare and genetic diseases.
Suat Kee Tieh
A Report Submitted in Partial Fulfilment of the Requirements for the Award of Bachelor of Science, Occupational Therapy (Honours), Faculty of Health Sciences, Curtin University.

These findings have implications for public policy and the National Disability Insurance Scheme which no longer has a focus on providing respite to people caring for those with disability but on the needs of the individual. This change in language has increased the challenges faced by carers of those living with rare disease.
GaRDN Website

Our online presence is critical to our visibility, and our website is often the first thing people see of our organisation. In early August 2017 GaRDN launched a new website with significantly more content and opportunities for member input. The changes to the website were in response to feedback and have focused on increasing the amount of information available on conditions, support and support groups.

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

The new modern website has enabled GaRDN to:

- Improve communications and online services to our audiences
- Increase the number of visits to the site, reduce the bounce rate and increase time on the site
- Promote GaRDN to new audiences and supporters
- Use modern design techniques to make it easier for our website visitors to find relevant content, and to give a better impression to potential members and supporters
- Ensure the website adheres to best practice with respect to privacy and security and accessibility for people with special needs.

The new website has become GaRDN’s primary portal, with the majority of email inquiries coming through the contact form on the website.

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

- 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 directory of over 140 support organisations and services
- 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 an interactive map for support organisations and services https://gardn.org.au/support-organisations/#!directory/map and we are developing a similar map that will focus specifically on healthcare, allied health, disability and other support services. This will assist in creating a ‘one-stop’ shop for people seeking this information.
Health Direct

In 2019, in recognition of the quality of the information provided on our web page we were asked to apply to become a HealthDirect partner organisation and were successful in being accepted. This has resulted in our site being linked as a place to go for further information for genetic conditions listed on their site.

UNCRC series – Rights of the Child

A postgraduate medical student, auspiced under GaRDN and supervised by Dr Gareth Baynam has developed with the support of a local lawyer, a series of posts linking rare disease with the United Nations Charter for the Rights of the Child. We started posting this series on Facebook in May and are progressively adding them to the news section of the website. This series has performed well, with people connecting with the posts and sharing the information provided on a regular basis, starting important conversations about the importance of children's rights in the rare disease community. These are now being shared by GaRDN, RVA, Academy of Child and Adolescent Health and the Commissioner for Children and Young People (WA).
Example of a UNCRC series post:

New information developed

Information sheets created

- Coffin Lowry
- Angelman syndrome
- CUL-4B
- Atypical hemolytic uremic syndrome (aHUS)

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.

GaRDN have finalised the questionnaires to be sent out early 2018 to receive feedback from individuals, families, support groups and networks, to help us develop and improve the information packs. The purpose of the engagement is to ensure the Information Packs are designed and based around the unanswered questions and needs of patients and their families living with a diagnosed or undiagnosed genetic and/or rare condition.
Western Australian Primary Health Alliance Pathways

GaRDN continues to provide information and networking opportunities to increase awareness of rare disease amongst health professionals. Work in relation to this outcome is important to influence a reduction in the time to diagnosis. One of the key issues for people living with rare disease is the difficulty they face in obtaining an accurate and timely diagnosis, with many people waiting up to twenty years or more to be definitively diagnosed and receive appropriate treatment. The flow on effects of increasing awareness of rare disease amongst health professionals is the potential to reduce costs to the health system related to admissions, investigations and unrelated treatments.

This year work was undertaken on pathways for Osteogenesis Imperfecta and Noonan Syndrome.
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 200 phone calls and emails from individuals requesting assistance – ranging from support group information to requests to research complex information. 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. There has only been one instance where we have not been able to provide information about a health professional who has knowledge of a specified rare disease.
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.

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:
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.
OUR IMPACT IN 2018-19

GaRDN works with...

104 Support Groups
36 Support Organisations

Assisted over 200 people navigate the health system

Types of info requested
- Health Professional: 27%
- Condition Info: 19%
- Support Groups: 19%
- Linking Patients: 11%
- Genetic Testing: 9%
- Advocacy: 5%
- Clinical Trials: 4%
- Family Support: 3%
- Other: 5%

Assisted people with 132 different rare conditions

2295 Facebook followers
64 Twitter followers

OVER 1800 CALLS AND EMAILS
68919 WEB PAGE VIEWS
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:

**Steering Committee for the National Rare Disease Strategy**

This has been the primary focus for advocacy in this reporting period. The first meeting of the committee was held in Sydney in February and established the approach for the following meetings. GaRDN assisted Rare Voices Australia (RVA) to produce a document summarising the initial discussion and suggesting some early pilot projects. The strategy will create the work plan for implementing activities over the next two to three years in Australia and is a critical activity for us to represent our members at. The strategy builds on the work undertaken by GaRDN in developing the first drafts of the Call for a National Rare Disease Framework with RVA.

The consultation meeting in Perth was supported by GaRDN at both an administrative (booking venues) and promotion level. We promoted the event to members via direct email and more broadly via Facebook and other social media. GaRDN also made some targeted calls to representatives of the disability community in an effort to ensure the rare disease community was broadly represented.
The Executive Director and Chair of GaRDN attended the Perth Strategic planning meeting and there was very considered, fruitful discussion at this meeting that certainly assisted in further refining issues of importance for the action plan.

The Executive Director had a further meeting with RVA staff on the day after the strategic planning meeting where we worked through some key concepts and GaRDN will provide some assistance with these based on already undertaken work.

Further input to the draft documents was made prior to them being submitted to the Federal Minister for Health.

The intended outcome of this activity is to input to a draft of the national action plan to ensure the needs of people living with rare disease are represented. This input was informed by our ongoing communication with people living with rare disease, particularly through our recent events such as the Rare Disease Day activity.

**Human Genetics Society of Australasia – Annual Scientific Meeting**

The Human Genetics Society of Australasia conference was held in early August and GaRDN co-chaired the community session on genetic testing and screening. The session was well attended, and the panel included, Rachel Callander, Yvonne Bombard, Julie McGaughran and Lucinda Freeman. The session was entirely interactive, and the questions and comments were thought provoking and useful. The over-riding theme of the session was that communication and relationships are critical when discussing testing screening and results. There was positive discussion about the use of more inclusive and non-judgmental language, and it was clear the community discussion and consent regarding these types of test need to be considered carefully.

There is considerable work to do in this area and community consultation is critical to ensuring the viability of programs such as this. Our involvement from an early stage is assisting us in developing a position statement that is likely to be used for consultation with consumers by the peak organisations.
Human Genetics Society of Australasia – Direct to Consumer testing position statement

The Direct to consumer testing position statement was finalised this period https://www.hgsa.org.au/documents/item/18 and the position of the HGSA focuses on the importance of consumers and health care professionals being supported to make informed choices. There are several more position statements currently being developed.

Joint statement on the Moratorium on genetic testing and life insurance

In November 2018, the Financial Services Commission released a statement detailing a moratorium on genetic testing information being used to limit life and other insurance. Several key organisations, including the Australian Genomic Health Alliance, have responded to this statement detailing that it is insufficient to protect people who have genetic tests for medical or research purposes.

GaRDN has supported the State and National peak genetic, undiagnosed and rare disease organisations by developing a draft position statement on this issue which is currently out for consultation with members and is likely to be released early in 2019. A copy of the draft is available upon request.

Medical Services Advisory Committee (MSAC)

The Medical Services Advisory Committee (MSAC) has requested GaRDNs attendance at three meetings considering applications for Medicare numbers in this period. The applications were:

- Medicare number for multidisciplinary teams
- Sentinel lymph node biopsy for intermediate thickness melanoma
- Non-Invasive Prenatal Testing (NIPT) for common trisomies (21, 18 and 13)

GaRDN had provided written submissions on the first and third application on behalf of members.

The invitation to attend meetings is recognition of our considered input to these submissions and of GaRDN as a peak community representative organisation.
Consumer representation on the Western Australian Newborn Screening Committee

GaRDN has been asked to join the WA Newborn Screening Committee as the consumer representative. Newborn Screening is a key issue for people living with genetic and rare disease and we have therefore accepted the invitation as it represents an opportunity to reflect the views of our members in health policy and strategic decision making in this area. We attended our first meeting in December and have offered to provide consumer review of documents currently being considered for development.

Rare Voices Australia – Rare Disease Day Parliamentary Event

The Executive Director was invited to and attended this event in February 2019 in Canberra to provide the summary presentation about rare disease in the context of the National Disability Insurance Scheme (NDIS). The event was well attended with over seventy people at the lunch. It was a great opportunity to have the ear of Federal politicians and highlight the opportunities for improving the way in which the NDIS could better support people living with rare disease. The intended outcomes of our involvement were to encourage consideration of the person rather than the condition and called for greater coordination between government departments to ensure assistance is made available in as seamless a way as possible. Feedback from the Chief Executive of RVA indicates these points have gained traction with the Ministers who were in attendance.

Australian Patient Organisation Network – inaugural meeting

The Executive Director attended this event in May in Sydney and it proved an invaluable opportunity to network and connect with many of our Perth and interstate member organisations. It provided a platform to talk about GUARD (refer below) and the work that we are doing as a collaborative and this has been very well received by the support organisations. The number of requests for assistance from support groups has increased since this event. The intended outcome of being involved in this event was to obtain some perspective on national activities in the patient advocacy arena and identify opportunities for improvement in the way GaRDN represents its member organisations. We consider this was achieved as a result of our attendance and members have been more willing to consult since this event.
2018-19 IN REVIEW - EMPOWER CONTINUED

Human Rights Commission – Medical interventions

GaRDN has facilitated discussions with relevant member organisations and the Australian Human Rights Commission to provide input to the Medical interventions project – people born with variations in sex characteristics.

Human Genetics Society of Australasia – Education, Ethics and Social Issues Committee

GaRDN has been a member of this committee for the last two years and in this reporting period has been part of two working groups – one reviewing the Direct to Consumer Genetic Testing position paper and one developing a panel session for the August 2018 conference. The Direct to Consumer Genomic testing position paper is nearing completion and the panel session is on track.
# 2018-19 FINANCIALS

### GENETIC SUPPORT COUNCIL WA INC.
**ABN: 63 614 315 270**

### STATEMENT OF FINANCIAL PERFORMANCE FOR THE YEAR ENDED 30 JUNE 2019

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### EXPENDITURE

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<td>Consulting Fees</td>
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<td>5,580</td>
</tr>
<tr>
<td>Depreciation</td>
<td>678</td>
<td>1,658</td>
</tr>
<tr>
<td>Equipment Purchases &lt; $1000</td>
<td>80</td>
<td>3,520</td>
</tr>
<tr>
<td>Rare Disease Day Event</td>
<td>805</td>
<td>5,537</td>
</tr>
<tr>
<td>WARDA Contract</td>
<td>18,182</td>
<td>11</td>
</tr>
<tr>
<td>Forum &amp; Event Expenses</td>
<td>470</td>
<td>289</td>
</tr>
<tr>
<td>Insurance</td>
<td>6,832</td>
<td>4,640</td>
</tr>
<tr>
<td>Interest</td>
<td>420</td>
<td>-</td>
</tr>
<tr>
<td>Memberships / Subscriptions</td>
<td>665</td>
<td>501</td>
</tr>
<tr>
<td>Meeting Expenses</td>
<td>1,057</td>
<td>718</td>
</tr>
<tr>
<td>Office Expenses</td>
<td>928</td>
<td>452</td>
</tr>
<tr>
<td>Computer Expenses</td>
<td>166</td>
<td>812</td>
</tr>
<tr>
<td>Web Development</td>
<td>327</td>
<td>1,209</td>
</tr>
<tr>
<td>Stationery</td>
<td>595</td>
<td>1,162</td>
</tr>
<tr>
<td>Postage / Courier Fees</td>
<td>118</td>
<td>835</td>
</tr>
<tr>
<td>Rent</td>
<td>-</td>
<td>2,941</td>
</tr>
<tr>
<td>Sundry Expenses</td>
<td>18</td>
<td>1,425</td>
</tr>
<tr>
<td>Telephone / Internet</td>
<td>1,699</td>
<td>2,201</td>
</tr>
<tr>
<td>Travel &amp; Accommodation</td>
<td>5,319</td>
<td>3,499</td>
</tr>
<tr>
<td>Provision: Annual Leave</td>
<td>2,098</td>
<td>6,883</td>
</tr>
<tr>
<td>Provision: Long Service Leave</td>
<td>895</td>
<td>5,321</td>
</tr>
<tr>
<td>Superannuation</td>
<td>18,961</td>
<td>24,383</td>
</tr>
<tr>
<td>Wages &amp; Salaries</td>
<td>199,708</td>
<td>240,052</td>
</tr>
<tr>
<td>Other expenses</td>
<td>201</td>
<td>1,524</td>
</tr>
<tr>
<td><strong>TOTAL EXPENDITURE</strong></td>
<td>266,707</td>
<td>318,096</td>
</tr>
</tbody>
</table>

### NET SURPLUS /(DEFICIT) FOR THE YEAR

<table>
<thead>
<tr>
<th></th>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NET SURPLUS /(DEFICIT) FOR THE YEAR</strong></td>
<td>31,802</td>
<td>(32,021)</td>
</tr>
</tbody>
</table>

This Statement of Financial Performance should be read in conjunction with the accompanying notes.
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
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
Huntington’s WA (Inc)
Hypersomnolence Australia Inc
Immune Deficiencies Foundation Australia (IDFA)
Kawasaki Disease Foundation Australia
Klinefelter’s Support Group WA
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)
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
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
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Email: hello@gardn.org.au
Web: www.gardn.org.au
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