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.
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  
Rae Walter  
Sinead Glennon  
Gareth Baynam  
Shoma Mittra  
Leticia Grant  
Hayley Lajczscak  

Executive Director (0.8 FTE)  
Senior Project Officer (0.2 FTE)  
Senior Project Officer (0.4 FTE)  
Project Officer (0.4 FTE)

Governance

Recognising that GaRDN provides services to all 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 and
- developing sound project planning and reporting, with a focus on outcomes based reporting to support our contractual requirements.
ABOUT GaRDN

VISION

This year the Board has worked hard to develop a new strategic plan that reflects the changing nature of the environment in which GaRDN operates and meets the needs of Western Australians living with genetic and rare disease.

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 Goals:
- 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
- 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 Priorities:
- Deliver services that enable people living with genetic and rare disease to attain the best possible outcomes
- Elevate the profile of genetic and rare disease to enable improved outcomes
- 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

GaRDN values underpin all we do
CONNECT INFORM SUPPORT EMPOWER
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; and
  - 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
  - Referring to 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.
CHAIR'S REPORT

Having lived with rare disease for the last sixteen years, I know only too well the challenges of obtaining a diagnosis, accessing effective treatments, navigating the health and related sectors and maintaining my health whilst living a full life. That's why, for me, organisations like GaRDN are so critical to the experience of people whose lives have been affected by genetic and rare diseases. GaRDN supports and empowers people with information about conditions, specialists they can access, provides a voice on broader issues and advocates for greater understanding and awareness of genetic and rare diseases.

Attending my first Rare Disease Day event with GaRDN and our partners at the Symposium and Awards event on 28 February, I was personally touched to meet so many of the hardworking and passionate individuals, family members, member organisations and professionals who live the genetic and rare disease experience daily. These events were a great opportunity to showcase Western Australian (and Australian) activities and ambassadors in and for genetic and rare disease.

As this year comes to a close and the new one starts, I'd like to take the opportunity to thank the Board for their tireless efforts with both GaRDN, and, for many of them, with their own organisations. We have made tremendous progress this year in ensuring GaRDN can continue to deliver its services in a contemporary way, with an eye on future opportunities.

We congratulate Rae Walters on her retirement, and subsequent departure from the Board - we will miss her considered and passionate input on health sector activity and experience of peak body/associate organisations working relationships. We are grateful to Rae for her expertise as Deputy Chair and wish her all the best with new endeavours outside the workplace.

I'd also like to thank the GaRDN team, who work so hard to respond to the individual needs of many 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 advocate for and reach a positive health outcome in their own journey.

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

Melissa Devlin
Chair
EXECUTIVE DIRECTOR’S REPORT

This year has been a landmark one for genetic and rare disease. There are so many national and international advances this year that suggest the tide is turning and people living with these conditions can hope that diagnosis, treatment and outcomes will improve. Just some examples of this include; the first mention of rare disease at the World Health Organisation, funding for research into rare disease announced by the Federal Minister for Health as part of the $20 million Medical Research Futures Fund. This was followed by a further $20 million funding for a pilot project into preconception carrier screening.

In a rapidly changing technological environment and with so much funding being directed toward genetic and rare disease research it is critically important to understand the community perception about these activities. The ethical and social implications are significant and need discussion and thought to ensure they are well considered and the concerns reflected in the finished product.

GaRDN has been actively seeking the input of our members and providing commentary on behalf of the WA genetic and rare disease community on a number of key policy and project activities that are outlined throughout this report. We have also been tackling the ethical and social issues through our representation on panels and written submissions.

We’ve worked hard to improve the information we provide via our website, based on an analysis of the information people living with genetic and rare disease have sought from us over recent years and increased our social media profile to provide a platform for people to connect, engage, inform each other, and lend their voice to our activities.

We provide information to people every working day to support them on their genetic and rare disease journey. This can range from where they can obtain testing, to how to access respite care for the people they care for, support to help them move on when they have lost someone, and everything in between. Thank you to the phenomenal team who make this possible.

It was a pivotal moment on February 28 this year for the GaRDN team to be able to recognise the great work of Western Australians through the inaugural GaRDN Rare Disease Day Awards. We often get feedback about how helpful individuals have been and we look forward to continuing to recognise these efforts.

Amanda Samanek
Executive Director
2017-18 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 throughout the patient 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:

Rare Disease Day

In an effort to foster collaboration between people living with genetic and rare disease, researchers and policy-makers GaRDN asked our constituents what they were interested in for a Rare Disease Day Event on 28 February 2018.

There was overwhelming support to host an event and 85% of respondents were interested in hearing about WA genetic and rare disease research.
GaRDN successfully secured partnerships with Western Australian Health Translation Network (WAHTN), Western Australian Register of Developmental Anomalies (WARDA) and Rare Voices Australia (RVA) to host a full day Symposium ‘WA Insights in Lights’ and inaugural Rare Disease Day Awards to mark Rare Disease Day.

The Symposium highlighted the following themes; Patient and Researcher Collaboration, key WA research, national rare disease plan initiatives and a vision for 2020.

These themes, through speakers and panel/workshop discussions, aimed to connect the rare and genetic disease community to facilitate an understanding of what constitutes integrated, coordinated health care and support.

Seventy-one people attended the Rare Disease Day Symposium and Awards 2018. Attendees were from all sectors of the community but mainly from not for profit organisations, research groups and the advocacy sector.

Evaluation of the event showed overwhelmingly that attendees were satisfied with the planning and delivery of the Rare Disease Day Symposium and Awards 2018.
Rare Disease Day Awards

The awards were an opportunity to acknowledge the extraordinary work of Western Australians amongst the genetic and rare disease community. The winners at our inaugural Rare Disease Day Awards Evening included:

**Patient Advocacy and Support Award: Sue Scott**

Sue Scott was awarded the inaugural Rare Voices Australia (RVA) GaRDN Rare Disease Day Patient Advocacy and Support Award in recognition of the extraordinary difference she has made through advocacy and patient support in genetic and rare diseases in Western Australia. Sue was awarded for her excellent work over the past 20 years running, single-handedly, the Cystinosis support group for Australian families, all while raising and supporting her now adult daughter, who is affected by cystinosis.

**Researcher Award: Professor John De Roach**

Professor John De Roach was awarded the inaugural GaRDN Rare Disease Day Researcher Award in recognition of the extraordinary difference he has made through research in genetic and rare diseases in WA. Professor Roach was awarded for his research work on Inherited Retinal Diseases (IRD) and establishing the Australian Inherited Retinal Disease Registry and DNA Bank.

**Clinical Professional Award: Professor Merrilee Needham**

Professor Merrilee Needham was awarded the inaugural GaRDN Rare Disease Day Clinical Professional Award in recognition of the extraordinary difference she has made through clinical practice in genetic and rare diseases in Western Australia. Professor Needham was awarded for her excellent work as a consultant neurologist, and her contribution to the rare group of inflammatory myopathies.

**Honorary Lifetime Membership of GaRDN: Dr Gareth Baynam**

Dr Gareth Baynam was awarded honorary lifetime membership of GaRDN in recognition of his tireless efforts and the extraordinary difference he has made to people with genetic and rare diseases and the advancement of collaborative approaches to improve diagnosis, treatment, management and resultant outcomes.
Research and Registries

This year we have been involved in research on respite care amongst carers of people with rare diseases, preconception carrier screening and facial mapping (this was part of our Rare Disease Day event too).

We have developed a repository of patient registries https://gardn.org.au/registries/ to enable people with rare conditions to access information about registries and any associated trials to support them in their rare disease journey. We now have fifty-seven registries listed and continue to contact more registries as they are identified.

Example of a registry.

**Australian Bleeding Disorders Registry**

<table>
<thead>
<tr>
<th>Information</th>
<th>The Australian Bleeding Disorders Registry (ABDR) is a registry for patients in Australia with bleeding disorders. It is used on a daily basis by clinicians in all Australian haemophilia treatment centres to assist in managing the treatment of people with bleeding disorders and to gain a better understanding of the incidence and prevalence of bleeding disorders. This information will also be used to understand demand for, and to facilitate ordering of, clotting factor product.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registry Location</td>
<td>Australia</td>
</tr>
<tr>
<td>Registry Participation</td>
<td>Voluntary</td>
</tr>
<tr>
<td>Registry Contact</td>
<td>ABDR is managed in collaboration with the Australian Haemophilia Centre Directors’ Organisation (AHDCO), Haemophilia Foundation Australia and all Australian governments and is overseen by a Steering Committee, chaired by Dr John Rowell from the Queensland Haemophilia Centre. E: <a href="mailto:info@ahcdo.org.au">info@ahcdo.org.au</a></td>
</tr>
<tr>
<td>Adding New Patients to Registry</td>
<td>Doctors need to register their patients by completing one of the ABDR Patient Registration Forms found on the website.</td>
</tr>
<tr>
<td></td>
<td>ABDR Patient Registration Form (pdf) (354.92 KB)</td>
</tr>
<tr>
<td></td>
<td>ABDR Patient Registration Form (docx) (36.2 KB)</td>
</tr>
<tr>
<td>Please see the website for more information</td>
<td>blood.gov.au</td>
</tr>
</tbody>
</table>
2017-18 IN REVIEW CONTINUED

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.

GaRDN Website

Our online presence is critical to our visibility and as a means of providing information to people with genetic and rare conditions. 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 and the majority of email inquiries are 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 (new)
- Over fifty information packs for people newly diagnosed with rare and/or genetic conditions (new)
- Over fifty registries that are related to rare and/or genetic conditions that enable people with those conditions to become involved in research (new)
- 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 (new)
- Information about genetic and clinical services
- An overview of the Life Saving Drugs Program and the drugs available (new)
- 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 genetic and rare diseases to be active in the management of their care.

**Patient Information Packs**

GaRDN worked closely with a UWA student completing a practicum at the WA Register of Developmental Anomalies (WARDA) in October-November 2017, to develop Information Packs.

The Information Packs are designed to support individuals and their families living with diagnosed and undiagnosed genetic and/or rare conditions. The types of supports offered in the Information Packs include: information on genetic and 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.
Social Media Strategy

In late 2017, GaRDN staff thoroughly reviewed our social media presence and usage. We have focused on Facebook and Twitter platforms in the first instance, with LinkedIn becoming our focus in 2018. We have developed a comprehensive social media strategy to manage our Facebook page, Twitter account and LinkedIn profile. This strategy ensures we are setting clear goals and objectives, regularly posting to each platform, and providing a variety of content, in an effort to increase engagement with our followers.

Along with our eNews and website, our social media pages have been of considerable use to us and our members as a means of promoting events, providing information and opportunities to be involved in research and obtain funding.

Since implementing the strategy our engagement on social media has increased significantly. GaRDN has been performing well when compared with other state based organisations in Australia.
Genetic and Rare Disease Health Professional and Register

GaRDN is continuing to develop the Genetic and Rare Disease health professional register - a list of health professionals and researchers with specialised knowledge and experience in rare and genetic diseases. We now have 152 health professionals listed on our site, including researchers, a veterinarian, allied health professionals and clinicians - both general practitioners with an interest in genetic and rare conditions and specialists with an interest in these conditions. People with genetic and rare conditions are encouraged to provide details from the register to their general practitioner to enable referrals.

Research institutions will be the next group of stakeholders we send out the survey to. The survey has been amended to ask for the respondent to provide any relevant research articles. We will then link the articles to the researcher’s information displayed on the GaRDN website.

Additionally, we are sourcing and linking articles/online information on respondent's special interests. This will provide further resources for health professionals on specific conditions.
GaRDN offers support to individuals, families and groups in a number of ways:

- Support, information and assistance to the general community
- Link Line for rare conditions
- Providing advice to people about specialised services/organisations
- Health professional inquiries
- Service inquiries
- Network inquiries.

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 are being contacted more frequently by health professionals seeking information and 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 specific condition information and advice about support and allied health services.

Some of the information we have provided this year by email and phone has included:

- RESEARCH TRIALS
- FINANCIAL SOLUTIONS
- SUPPORT GROUPS
- SPECIALISTS/GP’S
- TREATMENT OPTIONS
- CONDITION SPECIFIC EDUCATION
- GENETIC TESTING/COUNSELLING
- EDUCATION – PRESENTATIONS
- ADVOCACY SUPPORT
- EDUCATION INFORMATION
- DISABILITY INFORMATION
SOME OF THE COMMENTS WE HAVE RECEIVED INCLUDE:

“Thank you for your quick response to my query. I am extremely grateful.”

“Thank you very very much for this, I’m sooo happy and full of hope now.

“Thank you for your help, it was also great to find out about this Facebook group and relate to other women”

“Thank you very much for the information. You are wonderful connection.”
EMPOWER

The Genetic and Rare Disease Network 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:

- GaRDN undertook the research and drafted the document to support Rare Voices Australia in their national advocacy efforts for a National Framework for Rare Diseases. As a direct result of this document there has been funding awarded for nine rare disease research trials through the Medical Research Future Fund of the National Health and Medical Research Council.

- Provided feedback, of which around 70% was included in the final version, to the draft National Health Genomics Policy Framework. The Framework is a commitment between Commonwealth and states and territories to work collaboratively to integrate genomics into the health system over time. We believe our input has significantly improved the document, ensuring there is increased focus on patients as the central tenet and improved health outcomes.

- Represented our members at a number of workshops and meetings with a view to developing a definition of rare diseases which is a critical foundation to support the development of measurement and monitoring systems. We are eagerly awaiting the release of the definition by the Office of Population Health Genomics.
Provided a written submission to the Australian Department of Health, representing our patient support organisations, on the public consultation paper for the development of a Framework for Secondary Use of My Health Record Data. The key issues GaRDN highlighted were the importance of ensuring information is appropriately protected but to still enable use for international research given the limited number of Australians who will present with a rare condition.

Provided a submission to the WA Dept of Health, representing our patient support organisations, on the independent review of the Western Australian Human Reproductive Technology Act 1991 (HRT Act) and the Surrogacy Act 2008. The key issues we highlighted were that for people known to be at risk to carry or to be predisposed to a genetic condition, disease or abnormality there is a specific requirement to have access to assisted reproductive technology and practices.

Provided a submission to the Senate Standing Committee on Community Affairs, representing our patient support organisations, on the science of mitochondrial donation and related matters. Issues we highlighted included access and equity, education, counselling and ethical considerations such as the requirement for informed community debate and the rights of the donor and the rights of the child to know the donor. We recognise the importance of this science for families that already have a child with a mitochondrial condition.

Provided comments to the Australian Government Department of Health Therapeutic Goods Administration regarding the communication plan for patients and health professionals on priority and provisionally registered medicines. Overall the objectives, implementation, target audience, key messages were generally supported.

Provided a written comment to the Australian Genomics National Consent Working Group on the draft national consent form for genomic testing. This resulted in overall general support to the content of the consent form and information sheet with some comments made regarding the sequence of information presented, consistency of language and more explicit statements regarding intention and risks needed.

Provided a written submission on the NHMRC draft ‘Consumer involvement’ module for ‘Guidelines for Guidelines’. The comments made will be considered by the NHMRC’s Advisory Group on the Synthesis and Translation of Research Evidence. GaRDN’s review concluded that the guidelines are a positive approach to including consumers in the development of guidelines that will impact them.
2017-18 IN REVIEW - EMPOWER CONTINUED

- The GaRDN Executive Director was invited as a member of the final panel discussion at the Human Genetics Society of Australasia – 4th biennial Athel Hockey Symposium: Reproductive carrier screening in WA – the path forward and provided the perspective of those affected by genetic and rare conditions during the lively and robust discussions.


- Provided a response to Direct to Consumer genetic testing draft position statement developed by WA Health (through OPHG) and focused on the importance of providing information to consumers in a way that supports informed decision making and awareness of the broader implications of obtaining results from direct to consumer genetic tests.

- As part of the Human Genetics Society of Australasia, Education, Ethics and Social Issues Committee (HGSA EESIC), the Executive Director coordinated a response in support of the Medical Services Advisory Committee (MSAC) application for a Medicare number for multidisciplinary teams. We are particularly supportive of this application as it is well recognised that rare conditions require a multidisciplinary approach to diagnosis and treatment and a Medicare item number for this will only serve to support this approach by providing reimbursement for it.

Vision Document

The vision document we’ve drafted contains 12 chapters outlining the current environment for a number of aspects of the pathway of genetic and rare conditions and accompanying recommendations for the future. The topics are relevant for patients, families, carers and health professionals. The chapter topics include genetic screening and testing, treatment, respite care, palliative care, mental health impacts, transitional care, registries, diagnoses, psycho-social health impacts, research, epidemiology, and knowledge.
My Lived Experience Stories

GaRDN is building on previous endeavours (such as the GAPPS booklet) to publish more stories from the genetic and rare disease community about their personal lived experiences. These personal accounts by people and their families will explore genetic and rare diseases and conditions, considering aspects of health, disability, mental health, family impacts and reflection on experience, knowledge and what lies ahead. It is anticipated that sharing these stories with the wider community will ensure the view of the lived experience has an impact on strategic and policy decision making.

GaRDN aims to share the lived experience stories to:
- Enable people to see they are not the only one dealing with a condition or a situation
- A means in which to provide advice and information to people
- Allow people to link up and put them in contact with each other.
## 2017-18 FINANCIALS

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

**STATEMENT OF FINANCIAL PERFORMANCE FOR THE YEAR ENDED 30 JUNE 2018**

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<tr>
<td>Telephone / Internet</td>
<td>2,201</td>
<td>2,878</td>
</tr>
<tr>
<td>Travel &amp; Accommodation</td>
<td>3,499</td>
<td>5,010</td>
</tr>
<tr>
<td>Provision: Annual Leave</td>
<td>6,883</td>
<td>826</td>
</tr>
<tr>
<td>Provision: Long Service Leave</td>
<td>5,321</td>
<td>6,647</td>
</tr>
<tr>
<td>Superannuation</td>
<td>24,383</td>
<td>18,225</td>
</tr>
<tr>
<td>Wages &amp; Salaries</td>
<td>240,052</td>
<td>157,690</td>
</tr>
<tr>
<td>Other expenses</td>
<td>1,524</td>
<td>36</td>
</tr>
<tr>
<td><strong>TOTAL EXPENDITURE</strong></td>
<td>320,404</td>
<td>219,246</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>NET (DEFICIT)/SURPLUS FOR THE YEAR</strong></td>
<td>(34,329)</td>
<td>58,539</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
Albinism Fellowship of Australia
Alpha-1 Association of Australia
Alzheimer’s Australia WA
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)
Australia Alopecia Areata Foundation
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
Diabetes WA
Down Syndrome WA
Dyslexia SPELD Foundation WA Inc
OUR MEMBERS CONTINUED

Dyspraxia Perth Ectodermal
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
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
Learning and Attentional Disorders Society of WA (LADS)
Leukodystrophy Support Group, Australian
Liver Foundation of Western Australia
LQTS Support Group WA
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
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)
Spinocerebellar Ataxia Australia Inc
Syndromes Without a Name (SWAN)
Tarlov Cyst Disease Society of Australia
Thalassaemia and Sickle Cell Society of Australia Inc
Thyroid WA Support Group 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
OUR MEMBERS CONTINUED

ASSOCIATE MEMBERS

Activ Foundation
Association for the Wellbeing of Children in Healthcare
Asthma Foundation of WA
Cancer Council Helpline
Carers Association of WA Inc
Centre for Genetics Education
Children and Young People with Disability Australia
CLAN WA
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
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)
OUR MEMBERS CONTINUED

Speak Easy Association of WA
Technology Assisting Disability WA (TADWA)
The Neurological Council of WA
Therapy Focus

INDIVIDUAL ASSOCIATE MEMBERS

Mitch Messer
Robyn Hendriks
Prof Anja Ravine
Prof Charles Watson
Anja Hermann
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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• ABN: 63 614 315 270