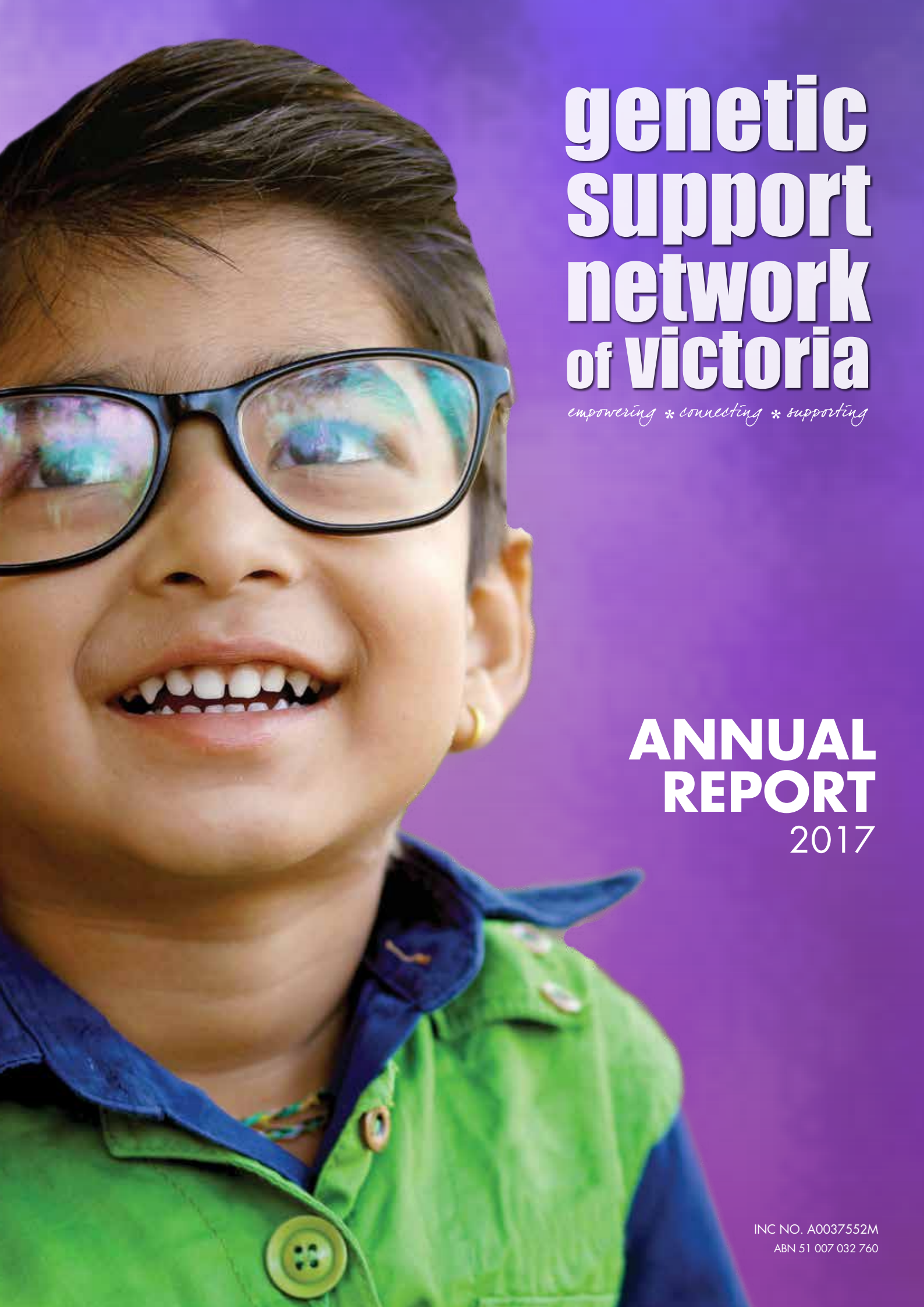

genetic support network of victoria

*empowering * connecting * supporting*

ANNUAL REPORT 2017

INC NO. A0037552M
ABN 51 007 032 760

CONTENTS

genetic support network of victoria

genetic support network of victoria

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WELCOME TO THE GENETIC SUPPORT NETWORK OF VICTORIA INC. (GSNV INC.) ANNUAL REPORT FOR THE PERIOD 1 JANUARY 2017 TO THE FINANCIAL YEAR ENDED 31 DECEMBER 2017.

As we reflect on the year in review, 2017, we will highlight some of our major achievements, challenges and outcomes; including an overview of governance and financials.

EMPOWERING THE GENETICS COMMUNITY

In Australia, it is estimated that 60% of the population will be affected by a condition which has some genetic contribution. Current conservative estimates indicate that approximately 6-8% of Australians are affected by a rare disease, 80% of which are genetic in origin. We have currently identified approximately 10,000 rare diseases, a number that is increasing each day. All these statistics can be expected to grow.

We live in an age where we are unlocking some of the secrets of our genomic code, beginning to understand that we have coded sequences that are sometimes optimal, sometimes not – because of the pre-programmed pattern we follow or because of an unexplained mutation/change which occurred inexplicably just for us. Discovery can bring hope and possibility; understanding and knowledge; fear and despair. Lack of diagnosis can bring frustration and isolation.

Diagnosis of a genetic condition – a change in your DNA that is part of you, challenges and ignites deep and intimate beliefs and questions about ourselves, those who came before us and those who come after.

The GSNV was established in 1997 in recognition of a gap of a broad consumer voice in genetic health, acknowledgement of a gap in support for many genetic conditions, a dearth of community education around genetic conditions and to serve as an interface between the community voice and health professionals.

We are a state wide service and we serve all genetic conditions – taking an inclusive approach to what is common across all conditions – for people with conditions, health professionals and support structures. We also work with specific condition related groups to harness learning and expand reach of resources, information, support, advocacy, and education.

OUR VISION

A Victoria where everyone can flourish!

OUR MISSION

We empower people to make decisions about their health and wellbeing.

We collaborate for equity and cultural change.

We provide an interface between people with genetic and rare conditions and health professionals to improve the general patient experience.

We create access to the practical and pathways to the possible.

THE GSNV IN CONTEXT

The GSNV operates within a changing and challenging environment. On a national level, the Commonwealth released the National Policy Framework for Genomic Health in 2017 while Victoria continued to evolve as a world leader in genomic medicine and research, making additional funding and resources available to genetic clinics and supporting the flagships of Melbourne Genomics and the Australian Genomic Health Alliance.

In 2017, the GSNV continued our commitment to become an integral force in educating and supporting for people with genetic conditions and those who support them. Education for empowerment and equity, advocacy for opportunity and possibility, and support for inclusiveness and choice remain pillars of GSNV practice.

As the world is becoming increasingly knowledgeable about genetics, with greater expectations on what can be delivered in genetic health, our role takes on even more importance. New technologies and increases in testing and diagnostic capability can mean more choice, and as the consumer voice in the genetics community we remain determined to support consumers through whatever choice is made.

The commercial applications and accessibility of genetic testing continue to increase and general community education provides a focus in 2018.

The GSNV will also continue our focus on the important synergy between clinical services, research and consumers; playing our role as an interface between the health system and health professionals, and the genetics consumer.

*empowering * connecting * supporting*

THE YEAR IN REVIEW

IN THE 2017 FINANCIAL YEAR, OUR VISION AND MISSION HAVE LED TO OUTSTANDING ACHIEVEMENTS. HERE'S A SNAPSHOT...

4 POSITION STATEMENT DRAFTS

3 GSNV SMALL GRANTS AWARDED

4 SUPPORTING THE SUPPORTERS EVENTS HELD

INITIATED THE LIVED EXPERIENCE GROUP

7 GSNV PRESENTATIONS

22 GSNV VOLUNTEERS

19 SUPPORT GROUPS ASSISTED THROUGH VOLUNTEERS

360 BITS AND PIECES SUBSCRIBERS

368 GSNV NEWSLETTER SUBSCRIBERS

4 GENETIC HUB NEWSLETTERS SENT OUT

176 ENQUIRES

526 LIKES

497 FOLLOWERS

NEW ACCOUNT

OVER **2522** MINUTES OF ENQUIRY SUPPORT

ABOUT THE GSNV

OUR WORK IN PRACTICE

Since establishment, the GSNV has remained committed to improving the lived experience of Victorians impacted by a genetic and/or rare condition. We are focused on assisting individuals with the processes of genetic testing, diagnosis, support and advocacy. Our practice is focussed on striving for a Victoria where everyone can flourish.

Education

- We provide information and resources through a range of mediums to all our stakeholders
- We stay informed and educated ourselves
- We maintain and update a resource library
- We maintain professional collaborations and memberships
- We up-skill people, support groups and communities
- We provide a range of educational opportunities to individuals and their families, health professionals and the wider community

Support

- We connect families and individuals sharing a common experience
- We maintain a support group and network database
- We maintain and facilitate the Supporting the Supporters Network
- We are at the end of the telephone, helping people in crisis
- We stand beside to empower, assist, encourage and collaborate with condition specific groups and communities
- We facilitate peer support
- We empower individuals and their families to reach positive health and life outcomes
- We empower people to act as community representatives
- We assist with the establishment of new support groups and the expansion of existing groups.

Advocacy

- We represent a community voice on numerous stakeholders committees and groups
- We represent the interests and views of individuals affected by genetic conditions to the community as well as the State and Federal governments
- We promote and facilitate consumer participation and feedback
- We convene the Lived Experience Group to listen to lived experience and seek to take action for positive change
- We write articles and actively engage in debates
- We advocate on behalf of others

In August 2016, our very own Louisa DiPietro was inducted into the Victorian Disability Award Lifetime Achievement Honour Roll in recognition of here work in health and disability. The award was presented at an inspirational ceremony and the GSNV remains so proud of all Louisa's achievements and congratulates her on her well-deserved award.

OUR VALUES

Integrity

We are ethical, tolerant and strive to deliver

Respect

We respect choice and the right to choose. We welcome diversity of individual opinions and approaches to inform.

We listen and learn from lived experience

Empowerment

We strive to educate and inform people for empowered decision making.

We seek to facilitate an environment where all individuals can flourish and every life has possibility

We seek opportunities to provide the voice of lived experience

We develop and deliver education and support strategies

Connectedness

We seek collaboration for outcomes

We engage with communities to learn

We provide opportunities for people to network

We share lived experience

We link people to resources and support

WHO DO WE SERVE?

- People who are impacted by a genetic condition.
- Support Groups and Stakeholders who represent or support people with genetic conditions or those who support them
- Service providers
- Government
- Communities
- Health Professionals

WHAT DO WE NEED TO BE TO SERVE SUCCESSFULLY?

- Values Driven
- Strong, clear and consistent
- Connected to influential people
- Representative: informed by lived experience
- Smart, discerning and current: informed by research and best practice
- Respectful and grateful, active and engaged
- Know when to lead and when to follow

WE ARE PART OF A LARGER COMMUNITY

The GSNV is a member of the Human Genetics Society of Australasia (HGSA). We have had long term representation on the HGSA Education, Ethics and Social Issues Committees (EESIC).

We are members of the ASGC Special Interest Group (SIG), the HGSA Victorian and Tasmanian Branch and many Victorian support groups.

We proudly sit on the Melbourne Genomics Community Advisory Group, the Victorian Clinical Network Group, and have been contributors to the establishment of National Implementation Committee planning for the National Genomics Policy Framework.

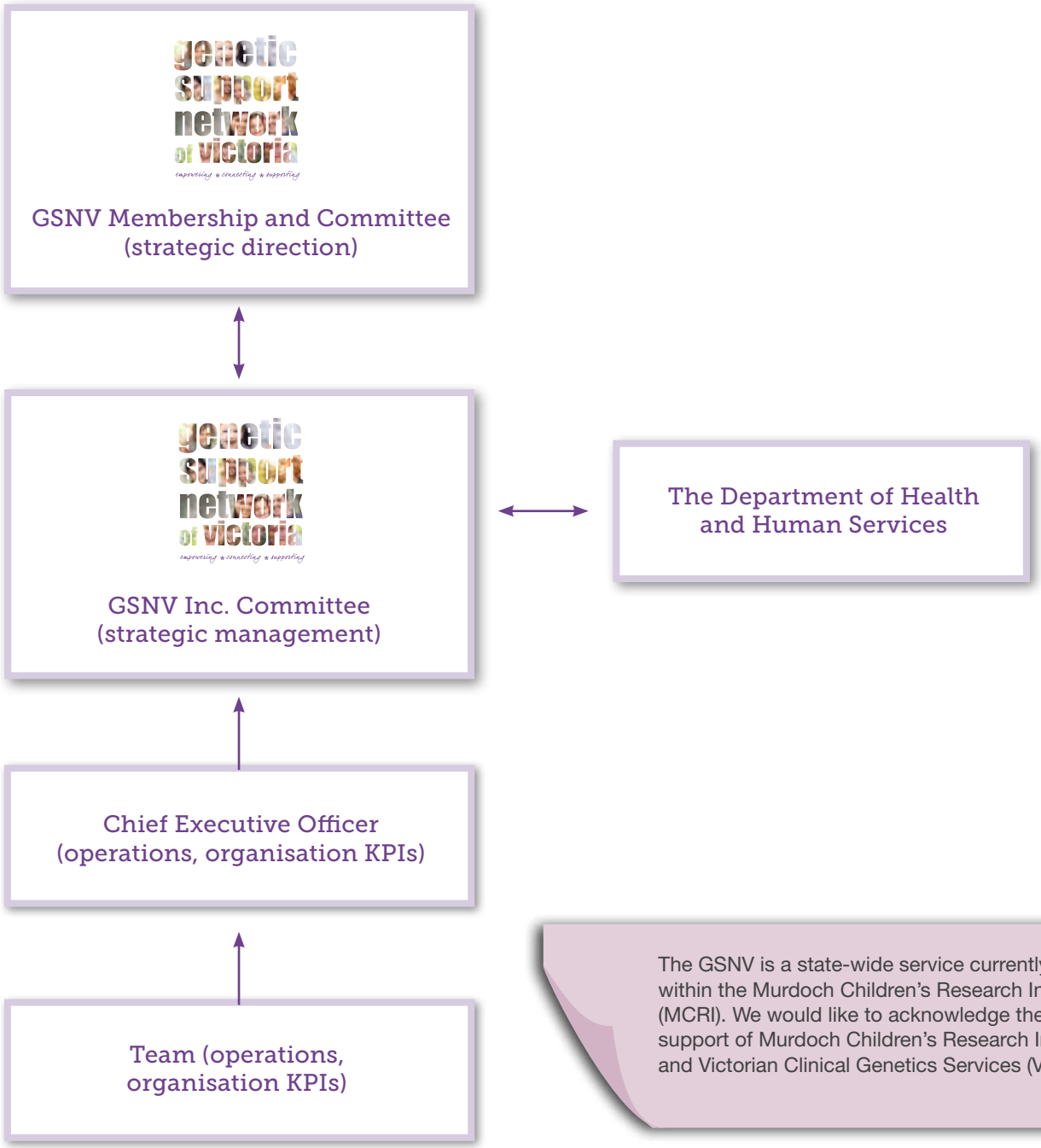
We also work in support of the Genioz project and the Better Indigenous Genetic Health Services (BIG) project.

We are one of hundreds of genetic support and professional societies around the world.

1. ASHG – American Society of Human Genetics
2. CAGC – Canadian Association of Genetic Counsellors
3. CCMG – Canadian College of Medical Geneticists
4. IFHGS – International Federation of Human Genetics Societies
5. ESHG – European Society of Human Genetics
6. NZOrd – New Zealand Organisation for Rare Disorders
7. HGSA – Human Genetics Society of Australasia
8. EuroDis – Rare Diseases EuropeRare Connect
9. Genetic Alliance UK
10. Genetic Alliance US
11. ICHG – International Congress Human Genetics
12. SIGU – Italian Society of Human Genetics
13. Dutch Genetic Alliance
14. GA-SA – Genetic Alliance South Africa
15. International Genetic Alliance
16. GaRDN – Genetic and Rare Disease Network
17. GAA – Genetic Alliance Australia
18. AGHA – Australian Genomics Health Alliance
19. MGHA – Melbourne Genomics Health Alliance
20. South America – Argentine Society of Medical Genetics
21. Ibero – American Society of Human Genetics of North America
22. India – Indian Society of Human Genetics
23. Hong Kong – Hong Kong Society of Medical Genetics
24. Japan – Japan Society of Human Genetics
25. South Korea HUGO – Human Genome Organisation

OUR PEOPLE

GSNV ORGANISATIONAL CHART



The GSNV is a state-wide service currently located within the Murdoch Children's Research Institute (MCRI). We would like to acknowledge the valued support of Murdoch Children's Research Institute and Victorian Clinical Genetics Services (VCGS).

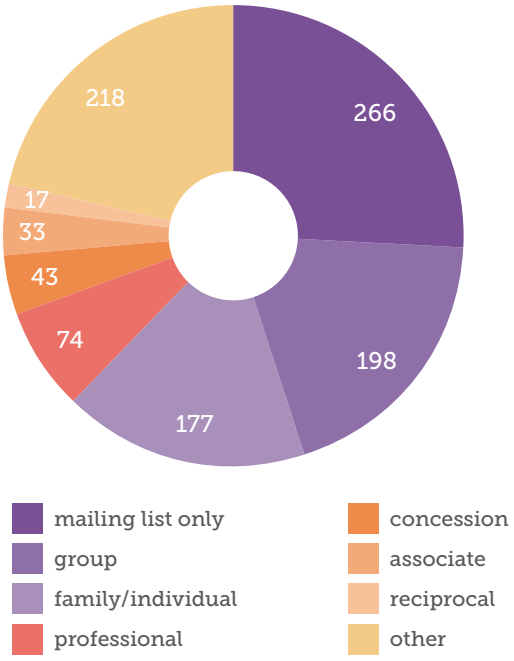
OUR MEMBERS

GSNV financial members make it possible for us to serve our most important stakeholder group – people with genetic conditions. Beyond paid members, we have a network and community that comprises the general, lay, genetics professionals and trainees, rare diseases communities professional organisations/networks/alliances, biotech/pharmaceutical companies, and researchers.

Our strength is our people; the feedback, ideas, and contribution we receive from them is vital, as it enhances and supports our work.

The GSNV would like to say a huge thank you to all members, and we look forward to a continuing positive and engaging relationship.

MEMBERS COMPOSITION 2017



The GSNV has a wide range of members, consumers, stakeholders, and professional affiliates. These include:

GENETIC AND ALLIED HEALTH

- Clinical geneticists
- General practitioners
- Researchers
- Social workers
- Genetic counsellors
- General Practitioners
- Allied healthcare professionals

GOVERNMENT BODIES

- Victorian Department of Health and Human Services (DHHS)
- Public hospitals
- Local councils
- Funding bodies

COMMUNITY

- Individuals
- Families
- Carers
- Students
- Community groups
- Maternal and Child Health Centres
- Early intervention education
- Corporate business
- Charitable organisations
- Philanthropic societies
- Culturally and linguistically diverse groups

NETWORKS

- Not for profit organisations
- Support and advocacy groups
- International advocates and alliances
- Health networks and organisations

GSNV membership offers the opportunity to gain access to information on research, support group activities, patient information, peer connection, advocacy and education, and to be represented on issues relating to genetic health.

OUR COMMITTEE

PRESIDENT'S REPORT

I was honoured to be elected as GSNV President and have watched the organisation continue to flourish. The GSNV is a leader in the support of people and organisations connected with genetic conditions and rare diseases.

The GSNV committee has a small but dedicated group of people with commitment and skills who continue to grow the connections with the rapidly changing world of genomics.

Two new exciting groups were established in 2017 and have met regularly.

The first, coordinated by Keri Pereira, is Supporting the Supporters, which is made up of representatives from support groups and focuses on collaborating through ideas, resources and approaches for our support groups.

The second, coordinated by Louisa Di Pietro, is the Lived Experience Advisory Group which gives opportunities for those with rare and genetic conditions to share their experiences and advocate for improvements in recognition and opportunities. Monica Ferrie is leading the highly motivated staff team who are always there to support our committee, our many associated support groups and individuals with genetic and rare conditions.

We welcomed Louisa Di Pietro back in her new role as Education and Advocacy Strategist. We were so proud of her induction to the Lifetime Achievement Honour Roll at the 2017 Victorian Disability Awards, recognising her years of commitment to equity and fairness for people with genetic conditions. I would like to congratulate her on such a prestigious and well deserved award. I am honoured to work with her and have her as a mentor.

As we continue to keep pace with the rapidly developing world of genomics, our team is working hard to achieve our vision that all those who have rare and genetic conditions are able to flourish.

Abbie Kinniburgh
GSNV President

REFLECTIONS

Secretary

I am pleased to say that, guided by the Strategic Plan for 2017-2020, the GSNV has continued to provide critical services to support and empower the genetic support community in Victoria this year.

A key focus of the Strategic Plan for 2017-2020 is ensuring that individuals and communities benefit from the rapidly changing world of genetic and genomic testing. Advances in technology have the power to change the lives of many patients, however concerns about access, equality and patient preferences need to be addressed. Through collaboration with government, clinical services and the community on several initiatives such as the National Genomics Framework Policy and several advisory groups, the GSNV aims to bring the patient voice to the attention of key stakeholders. The GSNV is also committed to highlighting the needs of the genetic and rare disease community in various education and training courses, to groups such as students, genetic counsellors and GPs.

The GSNV staff have put a tremendous amount of effort into the GSNV over the past year to achieve all of this.

Monica Ferrie in particular has worked tirelessly to establish collaborations and projects for the future. Also a huge congratulations to Louisa Di Pietro whose ongoing dedication to the GSNV was recognised this year as she was inducted into the lifetime achievement honour roll at the 2017 Victorian Disability Awards. The GSNV and committee is very lucky to have the support of these two amazing women.

I would also like to thank my fellow committee members for their contributions and enthusiasm over the past year, as well as extend a warm welcome to our incoming members. We cannot wait to see what this year brings.

Anna Jarmolowicz
Associate Genetic Counsellor, VCGS

Vice President

As a committee member of many years now, I feel that we are always moving forward and reflecting the rapid changes in genetics and genomics. It is certainly a brave new world, albeit more humanitarian in reality than Aldous Huxley envisioned in 1931. We live longer. We have many choices.

Global health is improving and we have groups of people constantly advocating for changes that represent a more equitable, inclusive and knowledgeable society. GSNV is one such group. With strong leadership and compassionate employees, committee members and supporters the future is exciting and will assist people and groups connected with genetic and other rare conditions to flourish.

Maree Maxfield
AusDoCC Secretary

Committee

I have really valued being part of the GSNV since 2012, initially as a Genetic Counselling student, then as an employee, and for the past 18 months as member of the committee.

Reflecting back on 2017, I have been thrilled to see the enthusiasm and efficiency of both the GSNV staff and committee including in redefining the strategic plan, engaging professionals and consumers in a variety of new ways, and working towards more funding. It has been a pleasure working with Abbie in her role as the President, and the rest of the committed team including the always-inspiring, Monica.

I am looking forward to seeing the GSNV's work continue to flourish in 2018.

Emily Higgs
Committee
Genetic Counsellor, VCCC Familial Cancer Centre

WHO WE ARE

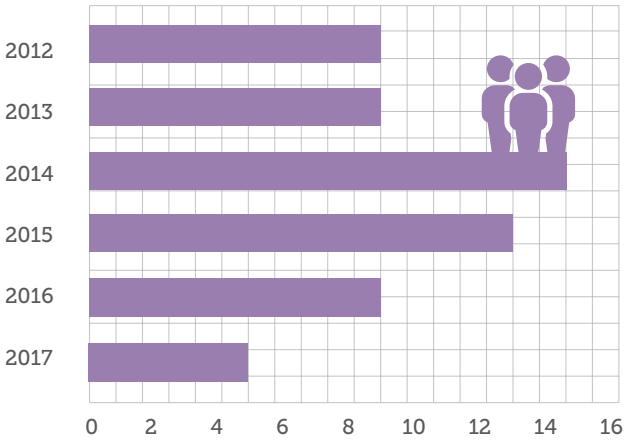
The members of the Executive and Committee who held a position at any time during or since the previous AGM are:

Abbie Kinniburgh	President
Maree Maxfield	Vice President
Rachel Pope-Couston	Treasurer
Anna Jarmolowicz	Secretary
Emily Higgs	Committee

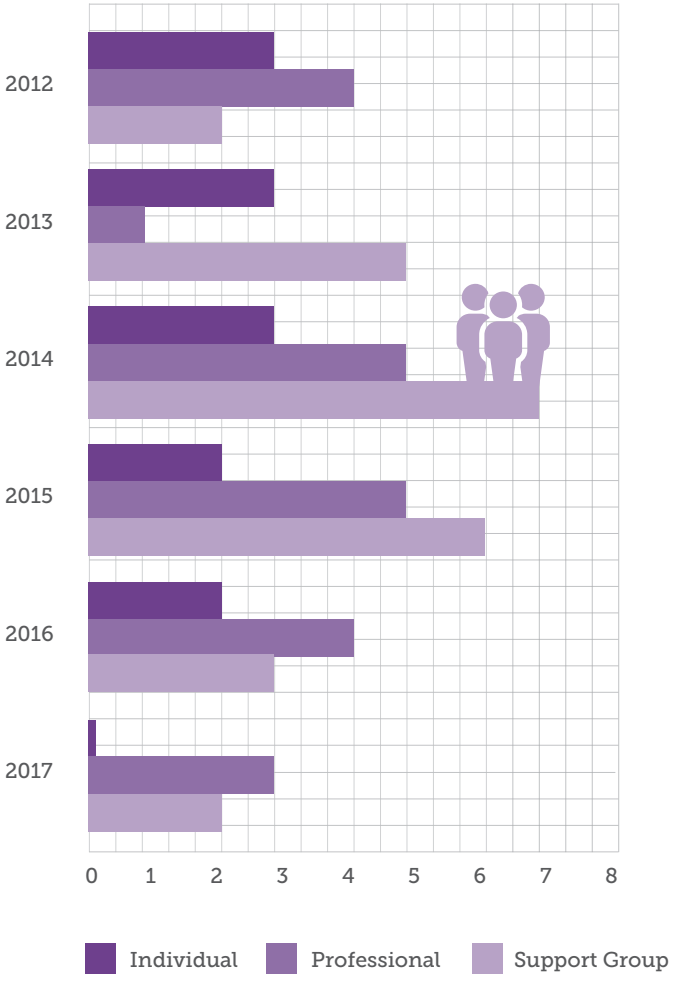
The Committee of the Genetic Support Network of Victoria (GSNV) Inc. operates through an Executive and General Committee with delegated authority and terms of reference (TOR) according to the ***Associations Reform Act 2012*** Model Rules. In line with our essential role in the community and our status as an Incorporated Association, GSNV Inc. is committed to maintaining the highest standards of corporate governance.

The GSNV Committee is responsible for the governance of GSNV Inc. and establishes the key strategic priorities and organisational performance indicators. Key business objectives are delegated to the GSNV Group Leader and staff.

COMMITTEE MEMBER GROWTH



COMMITTEE COMPOSITION 2012-2017



CORPORATE GOVERNANCE

For most of the reporting period the GSNV Committee of Management has consisted of five members with the loss of Catherine in May 2017. We are so fortunate that the strong commitment and dedication of the Committee ensured that most meetings were attended by all Committee members.

We will continue to seek new Committee members to share the load. It is our goal to have a diverse Committee that represents individuals living with or affected by genetic conditions, health professionals, researchers, educators, and interested community members. We also seek to have gender and cultural diversity, and hope to be more representative in the future. We value and appreciate our volunteer Committee members and extend our gratitude.

In the period since the previous AGM, the GSNV Executive and Committee have general met the third Tuesday of each month at the Murdoch Children's research Institute (MCRI). Each meeting has a central theme, supporting the strategic plan and business objectives. Reporting of actions taken and actions planned is a key feature of the meetings with reports provided to the Committee in advance of all meetings.

Over the reporting period, these have included:

- Fundraising
- International Partnerships
- Financial Management
- Education
- Advocacy
- Strengthening Support groups

The Finance Sub-Committee was disbanded in 2017 as the Treasurer and Chief Executive agreed to work very closely together to monitor all financial transactions and ensure comprehensive reporting. The Treasurer also chaired a fundraising group supported by volunteers.

PROFESSIONAL DEVELOPMENT

The GSNV recognises the value of the ongoing professional development of our staff and committee. Examples this year have included:

Staff Member	Program
Keri Pereira	**HGSA 41st Annual Scientific Meeting (Brisbane)** The theme of the conference was 'next generation: coming of age'. The program focused on the genetics of chronic disease and also had a strong emphasis on the education of non-genetics health professionals with a full day session dedicated to 'Genetics Education'.
Keri Pereira, Nancy Amin	**9th National Paediatric Bioethics Conference (Melbourne)** The theme of the conference was 'Patient and family-centred care: Reality or Rhetoric?'. The event covered topics such as what does patient and family centred care really mean?, when the interests of child and family come apart, professional relationships and boundaries and who is the family?
Keri Pereira	**The Australian Genomics Health Alliance National Conference** 150 delegates representing more than 70 Australian Genomics partner organisations gathered in Brisbane for the Australian Genomics National Conference; the first national meeting of Australian Genomics since being awarded a $25million research grant to provide evidence for the sustainable mplementation of genomic medicine into Australia's healthcare.
Keri Pereira	**Annual Australian Clinical Genomics Symposium** The symposium explored current challenges in practice, mainstreaming, genomic screening and personalised prevention. The event began with speakers highlighting the growing scope of contemporary clinical genomics practice in Australia and across the world, and the challenges arising from this expansion.
Keri Pereira, Nancy Amin, Emily Allen, Victoria Rasmussen	**Grand Rounds** Grand Rounds is a weekly seminar held at the Royal Children's Hospital. It is a flagship educational meeting designed to be informative and dynamic, with weekly guest speakers from around the world.
Keri Pereira, Nancy Amin, Emily Allen	**VCGS Friday Functional Genomics Seminars & Clinical** Laboratory Interface Meetings Fortnightly seminars are organised through the Victorian Clinical Genetics Services, aimed at the clinicians and aboratories who work within the genetics sector. The meetings raise thought and discussion around particular cases, new research, new approaches as well as community issues.
Nancy Amin	**REDCap Introductory Training Course**
Nancy Amin	**Rare Voices Australia 'Building Your Advocacy Capacity' Workshop** Support group members from a variety of patient led condition specific support groups met to learn about ways to approach members of parliament and how advocate on behalf of their membership base.
Nancy Amin	**Ancestry and Other Direct-to-Consumer Genetic Testing:** **What to Consider Before Mailing that DNA (webinar)** This seminar discussed the pros and cons of DTC testing, and highlighted issues that consumers should be made aware of when considering DTC testing.
Nancy Amin	**Cortical Connections 2017 – A symposium on brain development**
Nancy Amin	**AXYS Information Seminar** Talks focused on what it is like getting a prenatal diagnosis, raising children with an X or Y chromosome variation, support needs, men's issues, and available supports and funding. I presented a talk about XXX and participated in a round table discussion about prenatal testing.
Committee Member	**Program**
Maree Maxfield	**Master of Public Health at Melbourne** Continuing to study a Master of Public health at Melbourne University which included conducting a yearlong qualitative research project exploring the lived experience of Australian adults with a disorder of the corpus callosum (DCC). This provided the first research studying this cohort and the results highlighted a need for greater recognition, expertise and support for adults with a disorder of the corpus callosum. I am being encouraged and assisted to prepare my report for publication.

Committee Member	Program
Maree Maxfield	**National Conference for Disorders of the Corpus Callosum** Designing and coordinating the program for a national conference for disorders of the corpus callosum which was held over a weekend in Melbourne in May (Connections 2017). Our support group, AusDoCC gathered 250 Australian and international researchers and clinicians together with adults with a DCC, parents of kids with a DCC, their kids and other family members and professionals, to connect and learn more about the disorder, its causes, presentations and effective management. The highlight of Connections 2017 was seeing the connections made. Some families and individuals had never met another person with a DCC.
Maree Maxfield	**AusDoCC National Face to Face meeting** Planning and attending a national Face to Face meeting of our volunteer committee which manages the support group, AusDoCC (Australian disorders of the corpus callosum). During this 2 day event with all 12 members present we drafted a new strategic plan, set our 2018 goals, evaluated the conference, allocated individual roles and spent rare, valuable, social time together as we were gathered from 5 states and only physically meet up annually.
Catherine Beard, Emily Higgs, Anna Jarmolowicz	**HGSA Conference**
Catherine Beard, Emily Higgs	**Familial Cancer Centre Seminar Series, The Royal Melbourne Hospital (RMH) Grand Rounds, Functional Genomics Seminars at Murdoch Childrens Research Institute (MCRI)**
Emily Higgs	**World Congress on Genetic Counselling (Cambridge UK)** This was an extremely valuable professional development opportunity for me as a Genetic Counsellor. This was the naugural World Congress. The program focussed on communication and counselling research and included an impressive selection of international speakers. I had the opportunity to present my wok, 'Measurable Outcomes in Genetic Counselling' as a poster. I also really enjoyed the opportunity to network with Genetic Counsellors from around the globe (24 countries were represented!) and learn about the similarities and differences in our practice.
Anna Jarmolowicz	**Grand Rounds at Royal Children's Hospital**
Anna Jarmolowicz	**Additional Genomic Findings How do we counsel our patients?** Practical workshop, hosted by the Melbourne Genomics Health Alliance and facilitated by Elly Lynch and Professor Kelly Ormond. Experienced genetic counsellors engaged in roleplays and facilitated group discussion about approaches to pre-test counselling for additional findings.
Anna Jarmolowicz	**State Wide Genetic Counsellor Meeting – Grief and Bereavement Counselling for genetic counsellors** Keren Ludski, counsellor and counselling educator from the Australian Centre for Grief and Bereavement, delivered a practical session on assisting patients experiencing grief and loss.
Anna Jarmolowicz	**Patient and family centred care for adolescents RCH presentation** Carly Findlay, appearance activist and writer, and Jax Jacki Brown, disability and LGBTIQ+ right activist, spoke about the importance of an individual defining themselves as more than their disability and the need for health care providers to see their patients in the context of their whole life and identity.

* All GSNV new recruits must successfully complete compliance training modules under the i-manage and i-know systems under the on-boarding process

Professional meetings

Human Genetics Society of Australasia Conference

In Early April the annual HGSA scientific meeting was held in sunny Brisbane. The program focused on the genetics of chronic disease and also had a strong emphasis on the education of non-genetics health professionals with a full day session dedicated to 'Genetics Education'.

There were a number of interesting presenters at the meeting including Dr Jehannine Austin from Canada, who spoke about genetic counselling in the psychiatric field, A/Prof Ainsley Newson and Kate Dunlop who discussed changes in the field brought about by the introduction of genomics. One of the key messages that seemed to keep coming up at the meeting was that genetic counselling is not the same as genetic testing and in genetic counselling practice helping people adapt to genetic information is extremely important.

The GSNV presented two posters at the conference, showcasing data from the Master of Genetic Counselling student projects, which were very well received. The interest in these posters highlighted the need for further research in this area.

Annual Australian Clinical Genomics Symposium

The AACGS was held in Melbourne in mid-November and was a collaboration between the Garvan Institute of Medical Research and the Australian genomics Health Alliance.

This symposium was held to update and inform health professionals on the latest developments in genomic medicine.

Local and international speakers presented at the seminar to an enthusiastic audience.

Much of the discussion centred on where the genetics and genomics field was heading in the next few years and what changes will be required to ensure best practice.

There were a number of lively debates looking at the ethics of using genomics testing in practise and international speaker Les Biescker gave the audiences a lot to think about when he presented his talk on 'myth busting' genomics.

STAFF AS AT DECEMBER 2017

The GSNV has a recruitment policy that focuses on meeting our salary budget and maximising the staff profile to access diverse skills and experience and providing opportunities to build an expanding range of skills in core functions.

In 2017, staffing was consolidated with two changes to the previous year. We welcomed back Louisa Di Pietro when health allowed and we were delighted to do so. Louisa has returned on a return to work plan ensuring the GSNV is able to utilise Louisa's broad skill base while facilitating the measured increase in work and output for Louisa. We also said goodbye to Victoria Rasmussen who moved to a fulltime role interstate.

The GSNV operated with a maximum of 2.5 EFT (equivalent full time) with all staff members classified as part-time or casual. The GSNV continues to actively recruit volunteers from graduates, students and prospective students of the Master of Genetic Counselling course and we have been able to ensure placements with support groups in 2017 as well.

The GSNV Committee recognises and appreciates the contribution of the GSNV staff and volunteers over the past year. Their dedication, passion and commitment to the work of the GSNV and those we serve continues to be outstanding and delivers extraordinary results. Thank you.

We also take this opportunity to extend a formal thank you to GSNV staff – Louisa Di Pietro, Keri Pereira and Nancy Amin for their support of our new Chief Executive – Monica Ferrie.

Together this team is poised for more great results. We'd also like to publicly congratulate Louisa for her inclusion on the Victorian Disability Honour Roll – more about that elsewhere in this report.

Through our commercial arrangement with the VCGS, the GSNV adopts the MCRI corporate services policies and procedures and delegates authority to MCRI to facilitate corporate services on our behalf. We thank all of corporate services – Finance, HR, IT and payroll in particular for their ongoing support to our team and their assistance in helping us to run an efficient and effective operation.

We would also like to extend our gratitude and appreciation to Martin Delatycki, Medical Director of the VCGS for his ongoing support.

Professional development remains a key focus for all GSNV staff ad Committee and in 2017, this has achieved many positive outcomes for us all.

EFT Allocation as at 31 December 2017

NAME	POSITION	CLASSIFICATION	EFT
Monica Ferrie	Chief Executive	PT	0.4
Louisa Di Pietro	Education and Advocacy Strategist	PT	0.2
Keri Pereira	Genetic Support Coordinator	PT	0.5
Nancy Amin	Communications Coordinator	CS	0.4
Victoria Rasmussen	Research Assistant	PT	0.2
Emily Allen	Administration Assistant	CS	0.4
		TOTAL	2.1
		TOTAL Budgeted EFT	2.5

WE ARE WINNERS!

I am very pleased to announce that the people and the work of the GSNV has been recognised this year by way of two achievement awards.

Influencing genomic medicine
The Melbourne Genomics Health Alliance Community Advisory Group (MGHACAG) ***Outstanding Achievement by a Volunteer – Better Care Victoria Innovation Award***

The GSNV's Louisa Di Pietro is a founding member and original architect of the CAG. One of the world's first community-based groups to advise major clinical implementation initiative in genomics, MGHACAG has led the way in ensuring community perspectives have been taken into account. The Community Advisory Group has played an essential role in MGHA's development of a proven, world leading model for providing genomic sequencing to people in the health care system.

Community Advisory Group Chair Jane Bell says the award is a wonderful affirmation and validation of the tireless effort from all group members—many of whom have children with genetic issues—and their contributions to the field of genomics. 'We're a patient-connected, grassroots group of individuals, with a variety of skills, knowledge and networks. Yet we all have a clear idea on what we want to achieve, and we go about doing that with passion and commitment—all in our own time,' says Jane.Formed within weeks of the founding of the Melbourne Genomics Health Alliance (MGHA), these volunteers have contributed as public speakers, actively influenced government policy, advocated for patients, directly influenced genomic research, and increased connections to benefit the work of MGHA. The MGHA model is now being adopted nationally and internationally.

I am so pleased our work has been recognised in this way and the foundations for a shift in the perceived role and benefits of a consumer advisory group are now in place. We have done some great work and the recognition of it as innovative and effective is excellent for consumers all round in the health sector.

Life Time Achievement – Louisa Di Pietro

In August this year I was honoured to be inducted into the Victorian Disability Award Lifetime Achievement Honour Roll in recognition of my work in health and disability. It came as a great surprise and was a wonderful thing to happen after a somewhat difficult year. I was extremely humbled by the award presented by Kym Peake, Secretary of Department of Health and Human Services and the amazing words of congratulations and joy, and for me that came from everywhere. The awards ceremony was truly inspiring and I am truly moved to now be in a category of people who have made an enormous difference to many lives.

The award reflects on my career and advocacy work to date, but also reflects well on the GSNV and the opportunities afforded to me through my work. The GSNV is an amazing facilitator for personal growth and professional achievement and my award would not exist without it.
Louisa Di Pietro

HEALTH DATA IN THE NEXT TEN YEARS

HeLEX@Melbourne Workshop October 19, 2017

Innovative technologies in health such as genomics, stem cell research and CRISPR-mediated genetic modification is the main focus of the newly established HeLEX@Melbourne research project launched by the University of Melbourne Law School earlier this year. By Louisa Di Pietro

The HeLEX@Melbourne Research program was officially launched with an October workshop and an impressive participant list, bringing together academic, legal, health, clinical and research professionals.

The GSNV was invited to participate as a respected advocacy organisation in Victoria, and because of its work with the Melbourne Genomics Health Alliance. The workshop teased out specifically the ethical, legal and social implications of health/technology data sharing from a public health perspective.

As a representative of the genetics and rare disease community in particular however, I was intent on highlighting that there is significant impact on this population, and that the impact is on multiple areas relating to individual and family health rights, access, equity, privacy, information, knowledge transfer, etc.

It's an ambitious endeavour to draw together technology, data and the law and explore how they can be best managed within our existing legal/regulatory framework, but certainly relevant given the pace of new advances in health technology.

For a robust health system that can grow and remain ethically sound it is indeed vital we look at how our law needs to accommodate the potential benefits and mitigate the risks that new health technologies pose. HeLEX is poised to do just that with its research mandate. The workshop presentations from a number of different professional perspectives provided an overall context for the break out discussions.

Key presentations were from:

- Professor Jane Gunn of the University of Melbourne, Department of General Practice
- Professor Kazuto Kato of Osaka University department of Biomedical Ethics and Public Policy

The overwhelming concerns drawn from the key speakers and the breakout groups were easily identified as:

- Quality of data
- Access and equity of access to data
- Data security and regulation
- The need for a paradigm shift to a post consent world – informed consent almost impossible in a rapidly changing medical/technological landscape

These issues in fact represent the key legal questions that I think need to be resolved in a future where data sharing will become standard medical/research practice. The medico-legal synergy will be a vital ingredient in ensuring protections of the consumer/patient all the way along.

OUR VOLUNTEERS

The GSNV launched a successful Volunteer Program in May 2013. This program remains an opportunity for support groups to source suitable volunteers to help them with various small tasks.

Volunteers are generally students from the Masters of Genetic Counselling, or students interested in applying for the Masters and seeking some hands-on experience in the genetic health and support community.

The GSNV Volunteer Program

We currently have 45 volunteers and approximately 30 support groups we have assisted. Potential volunteers apply through the GSNV website and are then invited for an orientation at the GSNV. Volunteers are then matched with a support group based on mutual skills and interests.

Examples of volunteer-support group matches in 2017 are:

Volunteer organisation	Volunteer match	Activity
PEERS (Pediatric Evaluation of Emotions, Relationships and Socialization) study - Royal Children's Hospital	2	Assistance with the research project by visiting schools and administering cognitive measures and data entry.
Klippel-Feil Support Group	1	Assistance with web-page design
The Aussie Hands Foundation	1	Assistance with marketing and social media
Scleroderma Victoria	3	Assistance with mail-outs, designing flyers, and fundraising stalls
Alpha-1 Association of Australia	1	Assistance with fundraising and grants
Australia Alopecia Areata Foundation	2	Assistance with trivia night
Syndromes Without A Name	2	Assistance with Undiagnosed Children's Awareness Day

The GSNV has received encouraging feedback from both parties and is continuing to recruit more participants.

Hi, I'm Jo Martinussen and I've been fortunate enough to volunteer with the GSNV since mid 2017.

My role, which I believe I hit the jackpot with, has been assisting Louisa Di Pietro with her various projects at the GSNV. During our first meeting Louisa was showing me around the GSNV and MCRI offices, and the warmth in which people greeted Louisa with really gave me a sense of just how fortunate I was to have an opportunity to work with someone who is so well respected and at the forefront of the sector. One of the projects I've been assisting Louisa with is the facilitation of the Lived Experience Advisory Group (LEAG) meetings. These meetings are an opportunity for members who are living with a genetic condition to freely voice issues they may be confronted with. Whilst also offering opinions on the wider genetic health space. Having the opportunity to sit in on these meetings and hear such perspectives has helped me develop a richer understanding of the challenges faced by those living with a genetic condition. It has also emphasised just how important the advocacy work of the GSNV is.

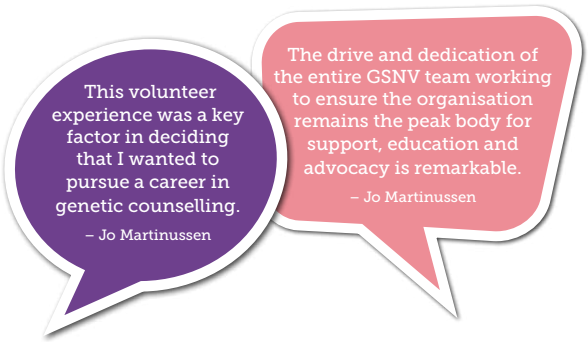
Another project Louisa and I worked on was researching potential grants that the GSNV may be eligible for in the hope of obtaining some funding to further the work done by the organisation, in particular the LEAG. Alongside the LEAG a focus of the work we did last year was working to form a collaborative partnership with a tertiary institute. The goals of such a partnership are two-fold.

Firstly that through such a partnership we could offer students insight into working for a non-for profit organisation, harnessing the skills learnt in the classroom and applying them to a real-life project. Secondly that this would result in the GSNV digital interface being updated, modernising it to reflect the changes in the genomics sector.

This volunteer experience was a key factor in deciding that I wanted to pursue a career in genetic counselling. I was fortunate enough to be offered a place in the Masters course and am now loving my first year of study.

It has been a privilege seeing how successfully Louisa harnesses her passion, enthusiasm and experience into achieving real change for those affected by a genetic condition. Moreover the drive and dedication of the entire GSNV team working to ensure the organisation remains the peak body for support, education and advocacy is remarkable. I have no doubt that this will continue to translate into positive outcomes for not only those directly affected by a genetic condition but the wider community.

I would like to take this opportunity to thank Louisa and the GSNV team for being such a supportive environment in which to volunteer and I can't recommend the volunteer program highly enough.



GSNV VOLUNTEERS KEY TO CONFERENCE SUCCESS

In May 2017, AusDoCC held its second ever family conference for individuals and families affected by disorders of the corpus callosum (DCCs). By Melissa Bell

The conference was held over the weekend of the 6th and 7th of May. AusDoCC was able to attract leading Australian and international speakers to enlighten our community with updated information about the latest research into the causes of DCCs, the range of impacts of DCCs, guidance regarding appropriate management of the condition. A specialised adults' programme was offered.

While AusDoCC offered childcare during its inaugural conference in 2015, in its 2017 conference AusDoCC provided a special childrens' programme for children with DCCs and their siblings. This programme was facilitated by Purple Soup, an external provider who specialised in providing camp style activities for groups with medical conditions and disabilities.

AusDoCC is committed to minimising the cost to individuals attending its conferences, so programme selections are limited by budget. The Purple Soup was a significant part of the conference costs, but the AusDoCC committee felt that it was a valuable offering for a group of children who are often isolated and marginalised by their disability.

A key part of AusDoCC's ability to provide the Purple Soup childrens' programme was the availability of GSNV volunteers. Purple Soup required 5 volunteers for the childrens' programme.

AusDocc also provided childcare for young children who were too y oung to participate in the Purple Soup programme. One of GSNV's volunteers assisted in providing the childcare over the course of the weekend conference.

GSNV volunteers also assisted with some of the back of house activities, such as the oversight of the audio-visual equipment.

Had AusDoCC been unable to utilise the kind services of the GSNV volunteer, we would have needed to engage an external provider at considerable expense.

A GSNV volunteer also provided assistance with front of house operations such as the manning of merchandise stands, assisting with directing attendees to particular rooms for presentations and appointments and acting as a general assistant.

The GSNV volunteers were punctual, helpful, well presented and a key part of our conference success. Some of the activities that they were asked to complete for us were tedious and unexciting. For example, my then five-year old son was cared for by our childcare providers, assisted by one of the GSNV volunteers. I know how challenging it can be to care for him, so I was very impressed by the eagerness of the GSNV volunteer who spent the whole weekend in a small room with my son and four other young children with high care needs!

As an organisation, AusDoCC was thoroughly impressed and grateful for the willingness of the GSNV volunteers to do what was asked of them without complaint, despite the tediousness of their roles. Without GSNV volunteers, this conference simply could not have gone ahead. This is not an exaggeration; AusDoCC does not have the financial capacity to pay for the services that were provided by the volunteers.

Therefore, in terms of impact, the GSNV volunteers had a very significant impact indeed. We are grateful to GSNV for facilitating this service to a small, under-resourced organisation like ours.

SUPPORTING LEUKODYSTROPHY AUSTRALIA

Early in 2017, Leukodystrophy Australia received delightful news from GSNV; we were successful in our Small Grants Scheme Application for $1000, to assist in our objective to complete the final stage of our brand new LOCUS Database.

Happily, we engaged and trained our own volunteer, but it soon became evident, as we ploughed through the process that the job was much bigger than we thought. Our database was growing at the rate of almost one new family per week, and, we had to upload existing information. The target date for completion – 30 June 2017 came and went. Still we toiled, but our volunteer had to leave and work slowed.

Late 2017 GSNV once again came to the rescue with our new volunteer Amy Ruscigno, who is now training up and far too fast for my rusty brain. She has been outstanding in her interest and capacity to achieve. Then, hey presto, just this year we are including Lucas Mitchell to our team. Two science students who both are most generous with their time, enthusiasm, and professionalism. We are hoping our project will be complete by 30 June 2018...however, we will miss our marvellous volunteers Amy and Lucas and we wish them well in their endeavours.

As Office Manager, I am delighted! As a NFP organisation, we are eternally grateful. We have been called upon several times to pull up reports both internally and externally, and with additional thanks to Tonic (donors of our tailor made LOCUS database), this has been achievable in a timely and professional manner.

When talking to families, accurate and up-to-date information is at our fingertips, as we build our relationships and support in achieving our goal to assist families living with Leukodystrophy. Thank you GSNV, Amy and Lucas, for your ongoing and varied support!

We would like to mention also, our gratitude for the Supporting the Supporters network group facilitated by GSNV. This connection has made such a difference to our little organisation – Leukodystrophy Australia, supporting families across Australia. Go GSNV!

CEO'S MESSAGE

It was my privilege to lead the GSNV in 2017, and what a year it proved to be. The genomics juggernaut continued to gain momentum as the science runs ahead of the community, of the practical application, of the ethics, of the technology, and even the human capacity for understanding.

2017 was our 20th year of operation and how the world has changed during that time. This fact gave us pause for reflection throughout the year, and motivated us to achieve even more. We commenced the year with a new strategic plan, a new vision as we committed to a Victoira (and world) where 'Everyone can Flourish'.

We reviewed our focus and benchmarked it against the vision. Was the activity taking us towards our vision? What to start doing, what to keep doing and what to stop doing were all questions that occupied our thoughts at the commencement of the year.

We were also fortunate to receive the results of the evaluation project, which had been commissioned. This led us to review our communications and profile, and we changed as a result.

We commenced two major initiatives in 2017 – we convened the Lived Experience Group and the Supporting the Supporters Network. These key activities allowed us to better understand the issues that are important for people with genetic conditions and those who support them, and also what we can do to assist. We were able to develop our position on a variety of key issues and look forward to publishing these in 2018.

We expanded our leadership role in assisting support groups by the establishment of the Supporting the Supporters Network. This includes the sharing of information and experience and the ability to put current concerns, current issues on the table for a broader discussion in a supporting and informed environment.

I'm particularly pleased with these two elements as they have given a voice where it is needed, involved volunteers, supported our agendas for advocacy and education and delivered some practical outcomes which we will build upon. This report features these activities on pages 20, 26 and 29.

In 2017, the GSNV activity participated in national projects and on state and national committees. These include contributing to the National Implementation Committee for the National Policy Framework, the Victorian Clinical Advisory Group, the Genioz Project, the Better Indigenous Genetic Health Services project,

This report is full of our achievements as all annual reports bring together the activities of the year that was. When I look back, I am satisfied with our achievements and excited about the foundation we have built.

2018, here we come!

Monica Ferrie
GSNV President

SOME HIGHLIGHTS FROM A PRODUCTIVE YEAR INCLUDE

RESOURCES FOR PARENTS

We brought together a resources package for parents to explain genetics and genomics and the personal application to their children what was happening. We received some great feedback from clinicians and parents.

RARE DISEASE DAY – 2017

We were very fortunate to have the Parliamentary Secretary for Medical Research Mr Frank McGuire MP at our Rare Disease Day event in February. The focus was on research and how research is a bridge to hope, it can provide access to different treatments and options. Our event was a collaboration with Australian Genomic Health Alliance, Rare Voices Australia and the GSNV coming together. We invited and encouraged researchers, clinicians and the community to join together and raise awareness of rare disease and the experience of families in Victoria.

GSNV EVALUATION

In 2017, the GSNV evaluation report was delivered, detailing some areas of improvement for the GSNV and some validation of activities. Areas of improvement identified included the need to increase the GSNV profile so that clinicians, community and people with genetic conditions are more aware of how the GSNV can assist.

SMALL GRANTS

In 2017, the GSNV awarded the inaugural Margaret Sahhar Grant. This grant of $1000 was awarded to Leukodystrophy Australia. Two $500 grants were also awarded:

- The Maree Maxfield grant was awarded to the Williams Syndrome Family Support Group
- The Vassie Dandanis grant was awarded to Australia Alopecia Areata Foundation Inc.

MATERNAL AND CHILD HEALTH ENGAGEMENT

In 2017, we reached out to the Maternal and Child Health network at a national and Victorian level. The GSNV presented at the national conference and participated as an exhibitor at the Victorian conferences to ensure that MC&H Nurses are aware of our services and how we can assist their parents. We received lots of positive feedback and have become a point of reference.

GSNV PEER SUPPORT TRAINING

The GSNV ran a Peer Support Training Session for support group members in November as part of our important role in education. The session was coordinated and delivered by a trained professional and the feedback was outstanding.

GENOMICS IN SCHOOLS

We delivered a pilot program into the Mooroolbark High School taking Year 11 students through an introduction to genomics and its application to them at a personal level. It got them thinking a great deal and received some wonderful feedback.

SNAPSHOT

Murdoch Childrens Research Institute
Healthier Kids. Healthier Future.

The Genetic Information Needs of People Who Are Adopted: Professional Perspectives

Rhiana Spinosa[1,3], Jan Hodgson[1,3], Margaret Sahhar[2] and Keri Pereira[2,4]
1. The University of Melbourne, Melbourne, Australia. 2. Murdoch Children's Research Institute, Melbourne, Australia. 3. Victorian Clinical Genetics Service, Melbourne, Australia. 4. Genetic Support Network of Victoria, Melbourne Australia

genetic support network of victoria
empowering * connecting * supporting

VCGS Leaders in Genetic Health

Background

A large proportion of the Australian population has had some experience with, or exposure to, adoption and the potential associated issues (Kenny, Higgins, Sweid, & Soloff, 2013).

Adoptees may face many different challenges from the psychological impact of adoption to the difficulties associated with having a limited knowledge of their family medical history.

In genetics, family history has long been considered an important tool in determining an individual's risks of some genetic conditions. The clinical and psychosocial implications of a limited or no knowledge of family history, as well as the genetic counselling strategies employed by genetic health professionals to support these clients has not been explored.

Research question

What are the experiences of genetic health professionals when counselling clients who are adopted?

Research aims

- Explore the experiences of genetic health professionals when counselling adopted clients.
- Develop a greater understanding of the issues posed, and the counselling approaches and strategies employed by genetic health professionals when working with clients with limited knowledge of their family history.

Methods

Ethics approval for this study was granted from the University of Melbourne Health Sciences Human Ethics Subcommittee.

The study took a mixed methods approach comprising quantitative and qualitative data collection.

Phase 1 Survey

A survey of the Australasian Society of Genetic Counsellors and the Australasian Association of Clinical Geneticists, open to members who had worked clinically in the last 5 years regardless of whether they had seen an adopted client. Survey data informed the qualitative phase including recruitment of professionals for phase two.

Phase 2 Interviews

Semi-structured interviews with genetic health professionals who had seen an adopted client, enabled in-depth exploration of participants' experiences with adopted clients.

Interviews were transcribed and coded using thematic analysis to allow themes to emerge from the data.

Results (Phase 1)

Table 1: Participant demographics

Variable	Responses (n=68)	%
Profession		
Genetic Counsellor	62	91.2%
Clinical Geneticist	6	8.8%
Gender		
Female	61	89.7%
Male	7	10.3%
Other	0	
Number of practicing years		
1-5 years	26	38.2%
5-10 years	18	26.5%
10-15 years	7	10.3%
15+ years	17	25%
Location		
Victoria	34	50%
New South Wales	18	26.5%
ACT	1	1.5%
Queensland	6	8.8%
Western Australia	5	7.4%
South Australia	2	2.9%
Northern Territory	0	
Tasmania	0	
New Zealand	2	2.9%
Specialty area of practice		
Cancer	23	33.8%
Pre-natal	9	13.3%
General	23	33.8%
Neurological	2	2.9%
Paediatric	11	16.2%
Practice in an additional area		
Yes	43	63.2%
No	25	36.8%

Table 2: Experience with adopted clients

Variable	Responses (n=68)	%
Adopted client		
Yes	61	89.7%
No	7	10.3%
Number of adopted clients	n = 61	
1	4	6.5%
2-5	20	32.8%
5-10	17	27.9%
10-15	10	16.4%
15+	10	16.4%
Equipped to assist an adoptee		
From Experience	n = 61	
Unequipped	0	
Somewhat unequipped	4	6.5%
Somewhat equipped	43	70.5%
Fully equipped	14	23%
Hypothetically	n = 7	
Unequipped	0	
Somewhat unequipped	1	14.3%
Somewhat equipped	5	71.4%
Fully equipped	1	14.3%

Results summary

The majority of survey respondents were female genetic counsellors with who had been practicing over a broad range of years. Of the 68 respondents, 61 had seen an adopted client with nearly all of these respondents indicating that they had seen more than one adopted client throughout their career. Regardless of whether respondents had seen an adopted client or not, the majority responded that they would feel somewhat equipped to assist an adoptee in the clinical setting.

The importance of family history

Respondents stated that family history will continue to play an important role despite advancing genetic testing technologies. The role of family history in result and variant interpretation and the process of collecting the history as rapport building exercise was described.

> "Wherever possible, a family history will, I think, always be very important in risk assessment, diagnostics, genetic counselling and interpretation of results."

> "...family history and genetic testing are separate pieces of the puzzle you need both to be incorporated together."

> "I use the family pedigree as the cornerstone of the genetics appointment. In a general context I use it for gathering information, but also rapport building."

Discussion/Conclusion

Overall, the findings from the survey suggest that:

- Almost all genetic health professionals will work with an adopted client throughout their career
- Limited training is provided to genetic health professionals in relation to adoption
- Despite advances in genetic testing technologies, family history will continue to play an important role in the clinical genetics setting

The results from survey have been used to recruit and inform the qualitative phase of the study where eight genetic counsellors have been interviewed about their experience of working with clients who are adopted.

By incorporating the findings from both phases, this study hopes to inform clinical practice and develop resources for both people who are adopted and genetic health professionals.

This study was completed in partial fulfilment of the requirements for the Master of Genetic Counselling, University of Melbourne, Victoria, Australia.

Acknowledgments

Dr Jan Hodgson

Ms Margaret Sahhar

Ms Keri Pereira

All the individuals that participated in the study

REFERENCES

Kenny, P., Higgins, D., Sweid, R., & Soloff, C. (2013). Past adoption experiences: Impacts, insights and implications for policy and practice. Communities, Children and Families Australia, 7(1), 35.

EDUCATION AND SUPPORT

EDUCATION

Education is a vital part of the core work of the GSNV.

Education activities are grouped as follows:

- Professional
- Community
- Student

Nancy and Monica

PROFESSIONAL

MCHN conferences

In 2017 we hosted an exhibitor table at the State-wide Maternal Child Health Conference in April and November. We spoke to nurses about how the GSNV could assist them with supporting their families with genetic conditions. The nurses were interested in a potential educational course about genomics, and signed up to receive our communications.

COMMUNITY

Pre-Pregnancy Planning Presentations

This year the GSNV continued to participate in the education of couples prior to pregnancy through the Pre-Pregnancy Planning seminar. This education session was run by the Epworth Freemasons Hospital.

The GSNV presentation focused on genetic screening during pregnancy including the new non-invasive prenatal screening and informed decision making.

Other topics presented at the seminars included preparing your body for pregnancy, preparing your finances and infertility.

Peer support training

Professional Counsellors are helpful, but there is nothing more powerful than talking to someone who has been 'in the same boat' as you. Peer support training is available for all individuals, including staff from support groups.

The GSNV runs an annual half day workshop aimed to help individuals feel empowered to listen and talk to others who are facing genetic challenges, and to share their wisdom and experience. In 2017 we collaborated with Cystic Fibrosis Victoria to bring a fresh perspective to our training.

Training is free for GSNV financial members, and upon completion attendees receive a certificate as well as a peer support contract with the Genetic Support Network of Victoria.

STUDENTS

Genomics in Schools Program

This year the GSNV developed an education program for high school aged students that encourages an understanding and awareness of the utility of genomic medicine and its potential to deliver personal empowerment in health and wellbeing decision making.

The GSNV piloted this program with three Year 11 classes from Mooroolbark College. Given the class time restrictions we presented an abridged version, covering basic genetics and genomics and a personal story from the GSNV's own Louisa Di Pietro. These sessions were very well received and the student were engaged with the activities that were part of the program. We received great feedback from the teachers involved which highlighted the areas that worked well for the students.

We learnt a lot from the 3 pilots and are now looking at further developing the program into a half day/full day excursion for students, with a number of interactive activities.

GSNV RESOURCES

The GSNV is committed to providing useful, practical and up to date information. The GSNV provide generic information packs for health professionals, disability professionals, and for the community.

The packs include a range of information sheets and brochures about genetic testing, pathways to genetic diagnosis, and access to services.

These packs have played an essential role in raising the profile of the GSNV as a peak support organisation. These information packs support our presentations to various health professional and community groups.

While on placement with the GSNV one of our students reviewed a number of materials for parents to use when explaining genetic consent and genetic conditions to children. We collated this information and placed in on the website for families and health professionals to use. These have been very well received by genetic counsellors to assist them with young families.

FACILITATING INFORMATION AND SUPPORT

The GSNV offers support to individuals, families and groups in a number of different ways:

- Support, information and assistance to an average of 19 people from the general community per month
- Includes connecting individuals in similar circumstances
- Referring people to specialised service and organisations
- Health professional enquiries
- Service enquiries
- Network enquiries

Through the work of our genetic support team we aim to provide a point of contact for families and individuals affected by genetic conditions to:

- find the most appropriate support group,
- ensure that they are supported in all areas,
- have appropriate support and information available to them immediately to reduce feelings of isolation and confusion and
- Facilitate the mechanics of lobbying to address specific issues.

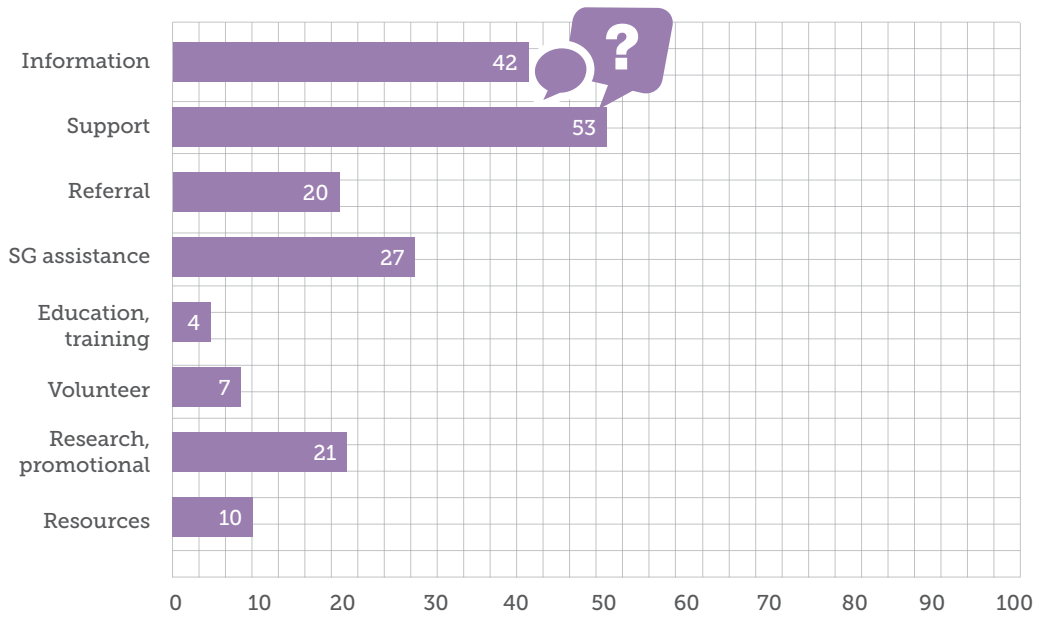
Providing support for support groups is a significant part of our role. We can aid support groups in the following ways:

- Assisting new groups in setting up
- Incorporation
- Finances
- Communications
- Corporate Governance
- Peer Support
- Information dissemination
- Strategic Planning and Workshop Facilitation

Over the year we will have assisted the following groups:

- AusDocc
- Leukodystrophy Australia
- Hereditary Spastic Paraplegia
- Porphyria Association,
- Australian X & Y Spectrum support
- Syndromes without a name
- Sisters for Love, MRKH Foundation
- Acute Necrotising Encephalopathy

TYPES OF ENQUIRIES RECEIVED



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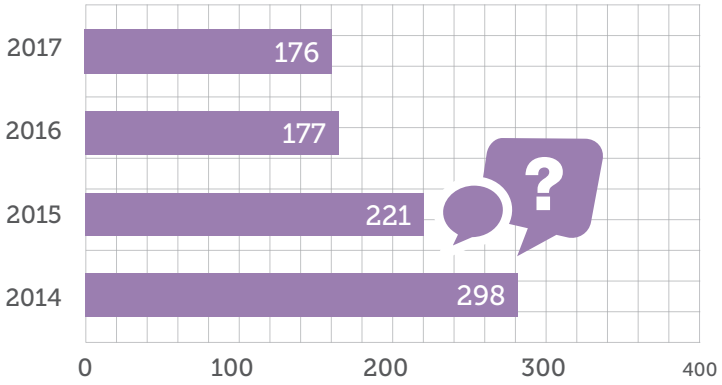
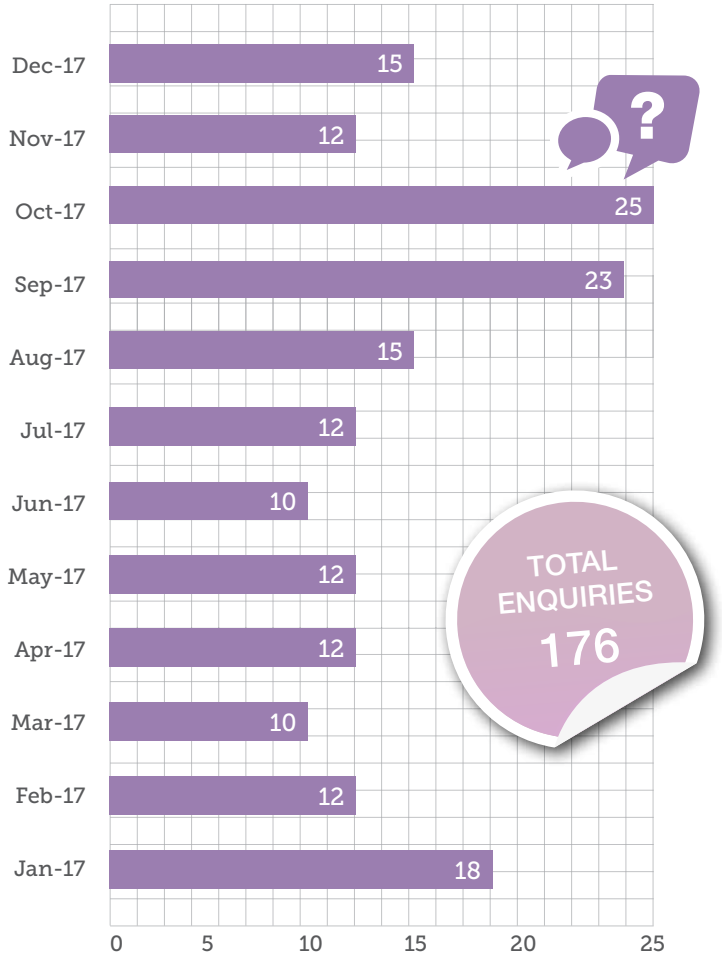
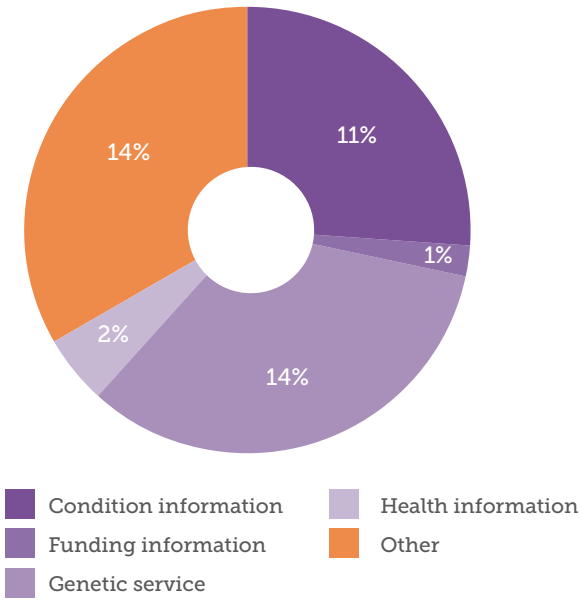


2017 ENQUIRIES BY MONTH



TYPE OF INFORMATION REQUESTED



ADVOCACY

KNOWLEDGE THROUGH INSIGHT

The Power of a Lived Experience Advisory Group (LEAG)

An advisory group of people with lived experience can be instrumental to forming recommendations and offering solutions related to a support agencies advocacy strategy, or actions designed to support the needs of their community. These contributions serve to strengthen the organisation while perhaps improving the quality of life for group members with the benefit of peer exchange. By Louisa Di Pietro

A Lived Experience Advisory Group (LEAG) can deliver expertise not just because of the 'skills' each member has, but also importantly because of their 'insight'.

Most commonly, a person is considered to be an 'expert' on a topic area because they have completed a certain level of formal education or training, or have extensive work and/or research experience in a particular area.

People who have lived experience of a condition or set of conditions, and the health service interactions that manage it all hold an equally significant type of expertise. They are intimately familiar with many of the systemic and personal issues, and hold valuable perspectives about how to tackle them.

For the GSNV the benefit of establishing an advisory group that consist of people with lived experience of a genetic/rare condition include: The voices of people who have genetic/rare disease experience that are traditionally missing from the planning, program and policy development processes.

It is important that the systems, services, programs and policies that impact and address this area of health include and are accountable to people who are impacted by and have health system experience. People who are marginalised are resourceful and have strengths and assets that must be acknowledged in human service and policy-making.

The GSNV Approach to a LEAG

At the GSNV, we are totally committed to the right of every individual to flourish but we can never know what that means for each person.

Unless we have a genetic condition that impacts our health and wellbeing, we can never imagine what it feels like to live with something that can make us different, feel different or create uncertainty for us and others.

A connection to lived experience is critical to our work at the GSNV – what we do and how we go about it, what we prioritise, what we advocate for, and how we allocate our resources. It makes us relevant and weighs our value, keeping us accountable to those we serve.

A connection to lived experience is also critical for others living the same experience. Sharing a moment, an experience, a life… can empower and support others.

We recognise that people who live with genetic or rare disease can provide important and invaluable insights into the healthcare system, government systems, and support and community resources.

The GSNV Lived Experience Advisory Group was formally set up in September 2017 to do just that. It aims to draw from this wealth of knowledge, seeking to inform and influence practice and policy and positively impact the lives of people with genetic conditions and rare conditions.

The LEAG is charged with exploring the concerns and priorities of its members, and harnessing some of that thinking to inform action items and advocacy strategies delivered by the GSNV. It's a conversation piece, but our goal is to generate some real outcomes delivered by the GSNV and as recommended by the LEAG.

The aims of the GSNV LEAG are:

- To share experiences among the group, and the wider community
- To increase awareness for health professionals, and the broader community of the lived experience of people with genetic conditions
- To build a connection bank that can connect people with a condition to a lived experience of someone with the same condition
- To strengthen the community of people with genetic conditions and those who support them by building a living library of reference that is relevant
- To inform the advocacy priorities for people with genetic/rare conditions.

This group meets every six weeks throughout the year to discuss a range of issues from a viewpoint of their experience.

The list of issues and topics explored has and will change as the group identifies key areas that they would like to record and share to inform and support others with genetic conditions.

In the future and with the hope of some seed funding by way of a grant, we also hope to enable group members to record their stories, through a journey interview process. These interviews will be made available as a resource and living library.

The contribution of the GSNV LEAG will result in:

- Shared experience across a range of genetic conditions informing and developing new understanding and commonality
- Clarity around the advocacy priorities for people with genetic conditions
- Solutions developed from experience and learning shared
- An inclusive approach to the community of people with genetic conditions, which will assist to inform research, policy, and treatment priorities.
- A library of video conversations covering specific topics outlining experiences, and how to successfully navigate different environments and challenges
- Podcasts that can be downloaded at any given time providing immediate assistance or information – a just-in-time support mechanism

The GSNV LEAG is charged with simply exploring the concerns and priorities of its members, and harnessing some of that thinking to inform action items and advocacy strategies delivered by the GSNV.

Advisory groups of people with lived experience of genetic and rare conditions can provide strength to our cause. Advisory groups provide a forum for peers to interact, reducing isolation, and supporting personal growth and leadership development opportunities.

COMMUNICATIONS

The GSNV has over the last four years consolidated its communications into three main publications:

- A bi-annual Newsletter
- Monthly E-News Bulletin –'Bits and Pieces'
- Monthly Genetic Services Bulletin

Our communications are sent to more than 700 individuals, groups and professionals with our newsletter readership also extended through wider circulation amongst our networks.

At every opportunity the GSNV communicates directly with its members and networks and seeks feedback on what we are doing and how well we meet the needs of those we serve.

Feedback from our members is vital, and we welcome and appreciate every thought and the time taken to communicate them. Some 2017 feedback has included:

'Thank-you – your newsletter is always full of great information. Well done. All the best'

Yvonne Waite – Parent To Parent Gippsland Program Co-ordinator

'Many thanks, your newsletter is a great read, I'm enjoying it. Regards'

Anna Urquhart – Projects and Events, Marketing and Communications | annecto – the people network |

'I have enjoyed reading this month's Bits & Pieces (words by Monica Ferrie). I need time-out!!!!...Please pass on my thanks to Monica for sharing and inspiring me...'

Elizabeth – Founder and Vice President
www.aussiehands.org

'Thanks for your newsletter. Full of interesting 'bits and pieces' as always. You do a great job. Many thanks'

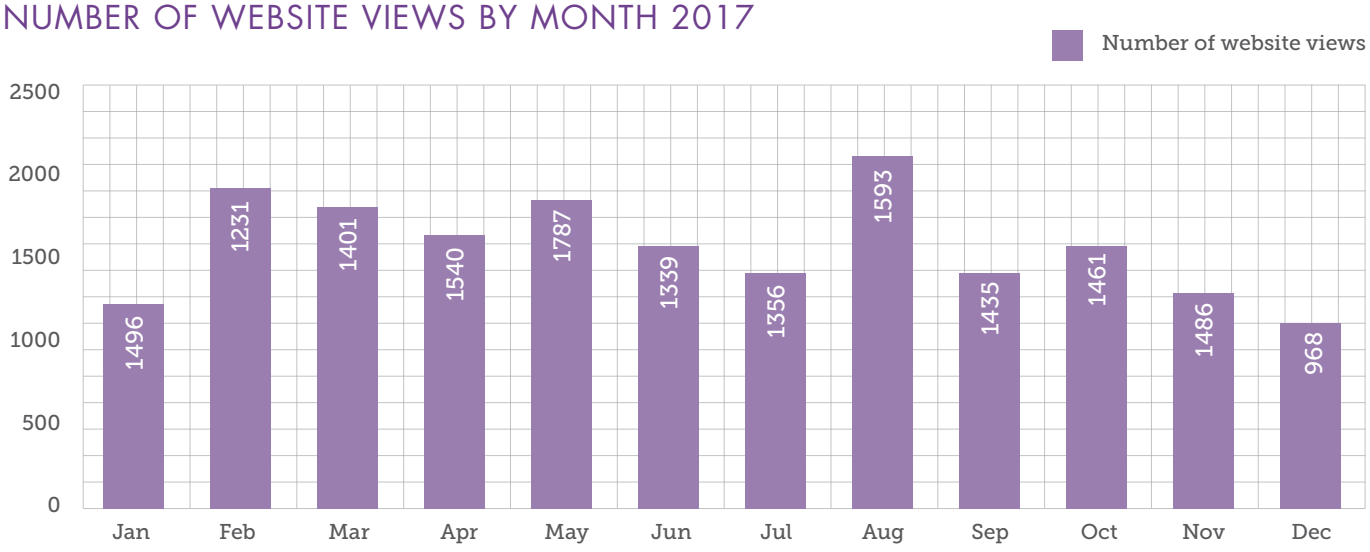
Maree
www.ausdocc.org.au

WEBSITE, DATABASE AND SOCIAL MEDIA

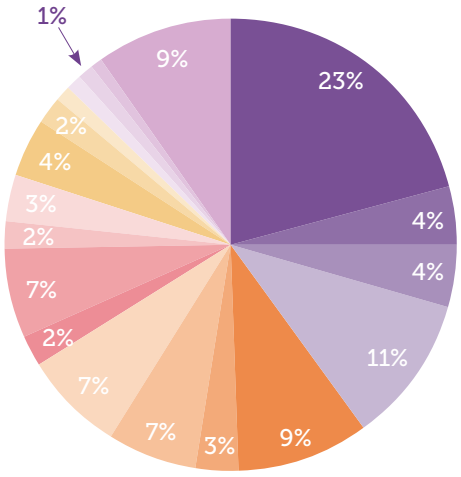
Social media remains an important tool in communicating to our members. In 2017 the GSNV used social media campaigns and blogging to highlight our important events and information. Social media has been identified as an acceptable form of communication both formally and informally and is incorporated into the GSNV communications policy.

The GSNV seeks to follow trend on social media and subscribes to over 30 closed Facebook pages and blogs developed for condition specific support. It is anticipated that social media will require further time and resources in the future and therefore should be considered in future planning and project management.

NUMBER OF WEBSITE VIEWS BY MONTH 2017



WEBSITE PAGE VIEWS



- home page
- 3 parent baby article
- klinefelter support
- support groups
- volunteer program
- contact us
- about GSNV
- events
- newsletter
- individuals and families
- our services
- health professionals
- clinical genetics map
- NF support
- support services for young people
- become a member/donate
- virtual communities
- peer support training
- news and research

NUMBER OF WEBSITE VIEWS

17,093
2017

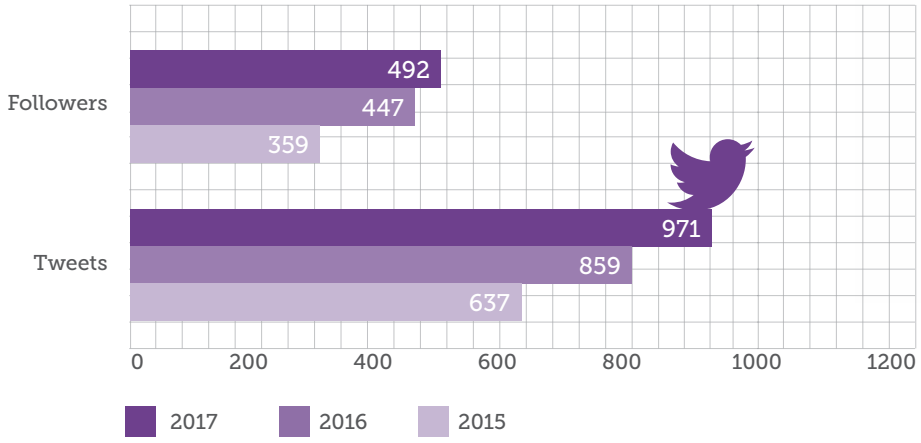
19,124
2016

23,067
2015

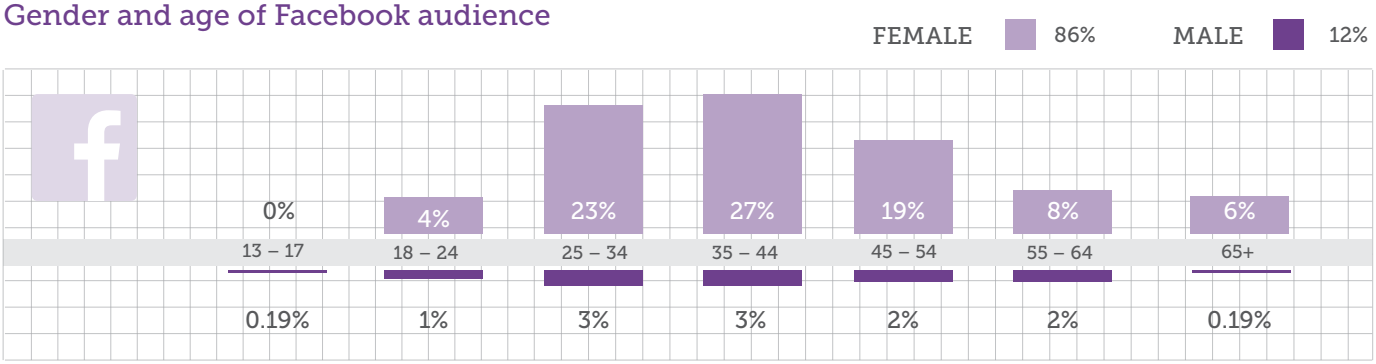
21,014
2014

WHO ARE WE REACHING ON FACEBOOK AND TWITTER?

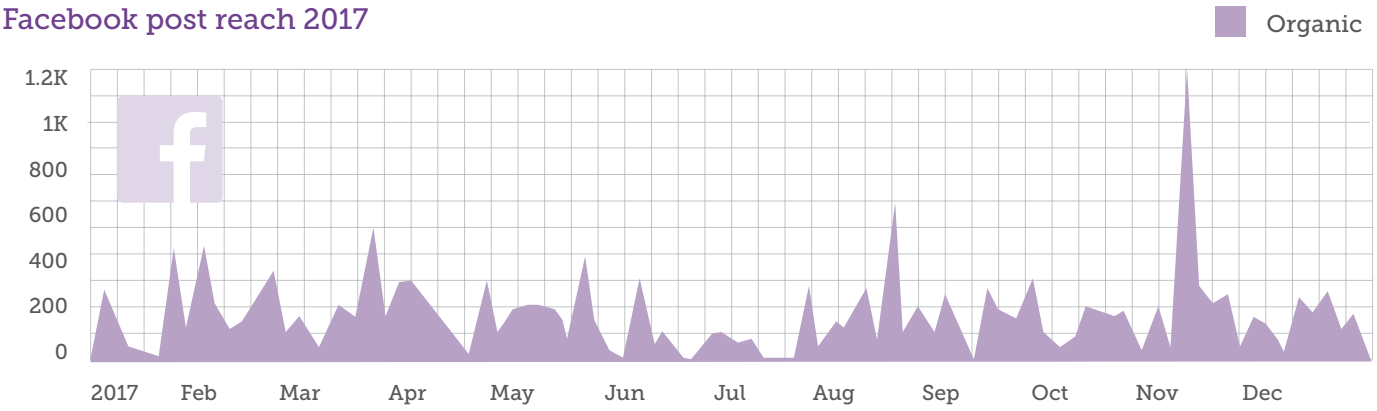
Twitter reach



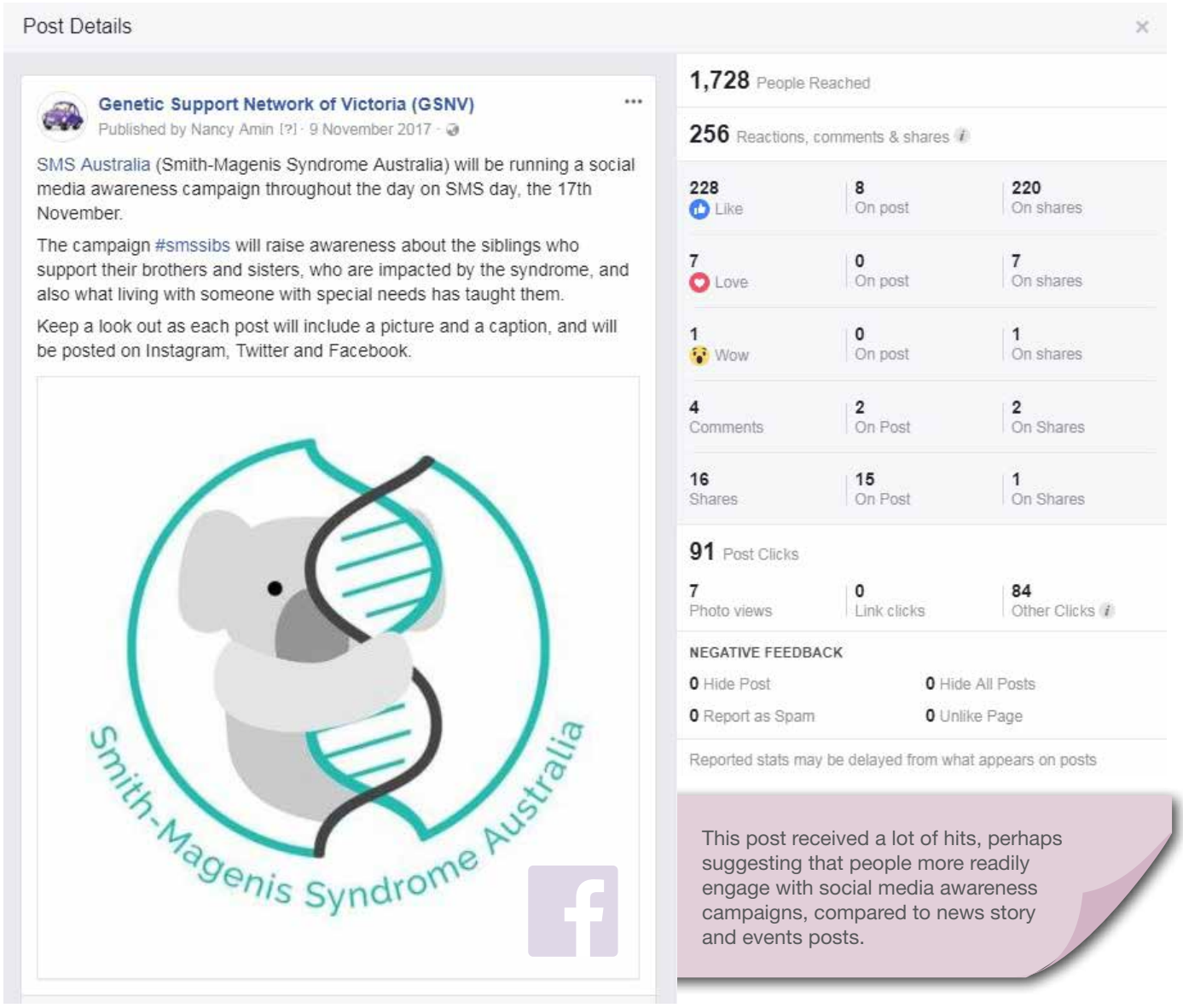
Gender and age of Facebook audience



Facebook post reach 2017



Facebook Highest Performing Post 2017



This post received a lot of hits, perhaps suggesting that people more readily engage with social media awareness campaigns, compared to news story and events posts.

THANK YOU

THE GSNV WISHES TO THANK THE MANY PEOPLE AND GROUPS, INCLUDING OUR MEMBERS AND VOLUNTEERS WHO HELP US DELIVER OUR WORK ACROSS VICTORIA. WE APPRECIATE AND VALUE YOUR GIFTS OF TIME, TALENT, EXPERTISE AND KNOWLEDGE.

We thank those who have donated to us and paid a membership in order that we can continue to provide small grants and give back to those who support us.

We are especially grateful for the ongoing support of the Department of Health and Human Services (DHHS) who continue to provide funding and support for our important work. We thank in particular Dr Paul Fennessy, Alina Tooley, and Marianne Griffin for an ongoing supportive relationship with the GSNV and their wisdom and counsel year in, year out.

We are also thankful for the professional relationship including support and advice from all our stakeholders including people with genetic conditions, clinical services, universities, support groups and so many others. A special mention to Martin Delatycki for his ongoing support and generous time.

FINANCIAL REPORT

ON BEHALF OF THE EXECUTIVE AND COMMITTEE OF THE GSNV INC. I AM PLEASED TO REPORT ON THE FINANCIAL DETAILS FOR THE FINANCIAL YEAR 1 JANUARY 2017 – 31 DECEMBER 2017.

We have continued support from the Department of Health and Human Services (DHHS) in the form of an ongoing grant managed by the Victorian Clinical Genetics Service (VCGS) and through this grant and other small avenues of income, the GSNV Inc. remains a viable and solvent organisation.

I am pleased to report that the increase in funding from the DHHS is ongoing as expected. In addition, a reduction in infrastructure costs has been negotiated by the GSNV going forward into 2018.

As part of the GSNV Inc. infrastructure agreement with the VCGS, accounts for GSNV are audited by KPMG who are the External Auditors for VCGS. KPMG report that the GSNV Inc. concluded the 2017 Financial Year with a surplus of $13,299.74 This surplus combined with the DHHS funding for 2017 means that the GSNV Inc. carries forward a total of $216,299.74 to the current 2018 Financial Year.

FINANCIAL SUB-COMMITTEE

The Financial Sub-Committee (FSC) has undergone several changes across 2017. We no longer have a formal FSC, instead, as Treasurer I am involved with a bright and motivated group of GSNV Inc. volunteers who are particularly interested in focussing on fundraising activities. Our current group of volunteers have a fantastic range of skills and interests to off the GSNV Inc.

Going forward, the GSNV Inc. staff will be taking on the role of actively directly fundraising efforts proposed and carried out by the fundraising volunteer group. In addition, one of the fundraising volunteers will also nominate to the GSNV Inc. committee so that they can keep the committee updated on fundraising projects and also gain a more in depth understanding of the goals and interests of the GSNV Inc.

An exciting development for fundraising activities is that due to the surplus from the 2017 financial year, the committee has voted to set aside a small seed fund to invest in select fundraising activities. We expect that this small investment will reap great rewards in being able to plan and execute fundraising events for the GSNV Inc.

In 2018 we, myself as Treasurer, the GSNV Inc. staff and the fundraising volunteers group, are planning to concentrate on creating and guiding fundraising projects that can be completed by the GSNV Inc. staff and volunteers

Thank you

I would like to sincerely thank the members of the fundraising volunteer group and general committee for the time and consideration they have invested in transitioning from the FSC to fundraising volunteer group in the 2017 financial year and for their ongoing motivation to achieve the best possible outcomes for the GSNV Inc.

Rachel Pope-Couston

STATEMENT OF INCOME & EXPENSES

STATEMENT OF INCOME & EXPENSES FOR THE MONTH ENDED 31 DECEMBER 2017

70680 GENETIC SUPPORT NETWORK (V)

	Actual 2017		Budget 2017	
	For this Period	Year to Date	Year to Date	Year to 31/12/2017
BROUGHT FORWARD BALANCE @ 1/01/2017		7,159.15		0.00
INCOME				
DHS GRANT	12,750.00	203,000.00	203,000.00	203,000.00
FUNDRAISING	0.00	0.00	30,000.00	30,000.00
LORD MAYOR'S TRUST	0.00	0.00	0.00	0.00
MEMBERSHIP FEES	0.00	0.00	0.00	0.00
DONATIONS	0.00	4.00	0.00	0.00
CONFERENCE FEES	0.00	0.00	0.00	0.00
SUNDRY INCOME	0.00	1,972.74	2,000.00	2,000.00
Total Income	**12,750.00**	**204,976.74**	**235,000.00**	**235,000.00**
EXPENDITURE				
SALARIES & RELATED COSTS	8,127.04	81,875.02	90,000.04	90,000.00
COMPUTER HARWARE	0.00	0.00	0.00	0.00
COMPUTER SOFTWARE & EXPENSES	0.00	0.00	0.00	0.00
CONSULTANTS	9,000.00	76,500.00	80,000.00	80,000.00
POSTAL SERVICES	4.48	165.31	500.00	500.00
PRINTING, STATIONERY & PHOTOCOPYING	111.40	4,655.15	8,000.00	8,000.00
BOOKS & SUBSCRIPTIONS	0.00	416.36	1,000.00	1,000.00
TELEPHONE CALLS	0.00	0.00	0.00	0.00
SMALL GRANTS	0.00	0.00	2,000.00	2,000.00
SPECIAL FUNCTIONS – OTHER	0.00	401.82	1,000.00	1,000.00
STAFF TRAINING & CONFERENCES	0.00	1,805.35	10,000.00	10,000.00
TRAVEL	39.43	544.36	5,000.00	5,000.00
CORP SERVICES – IT/HR/FIN	2,500.00	30,000.00	30,000.00	30,000.00
MISCELLANEOUS	0.00	0.00	5,000.00	5,000.00
OTHER ADMINISTRATIVE COSTS	0.00	2,472.78	2,000.00	2,000.00
Total Expenditure	**19,782.35**	**198,836.15**	**234,500.04**	**234,500.00**
OPERATING SURPLUS/(DEFICIT) CARRIED FORWARD @ 31/12/2016		**13,299.74**		**500.00**

AUDIT STATEMENT

VCGS
Leaders in Genetic Health

Victorian Clinical Genetics Services
Murdoch Childrens Research Institute
Flemington Road, Parkville VIC 3052 Australia
P +61 3 8341 6201 F +61 3 8341 6212
W vcgs.org.au ABN 51 007 032 760

Audit Statement

I confirm that the funds belonging to the Genetic Support Network of Victoria are held by the Victorian Clinical Genetics Service (VCGS). The VCGS also currently provides space & infrastructure for carrying out of the services of the GSNV.

The accounts of the VCGS are audited annually by KPMG who are our External Auditors. The accounts for 2017 have been audited by KPMG in accordance with this practice. In the Calendar Year 2017 GSNV recorded a surplus of $13,299.74 which will be carried forward to the current 2018 Calendar year.

Let me take this opportunity to wish you & your team another successful year ahead.

Best Wishes,

Maria Telford BA, CPA
Financial Accountant
Murdoch Childrens Research Institute/
Victorian Clinical Genetics Service.

genetic support network of victoria

genetic support network of victoria

Murdoch Childrens Research Institute
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