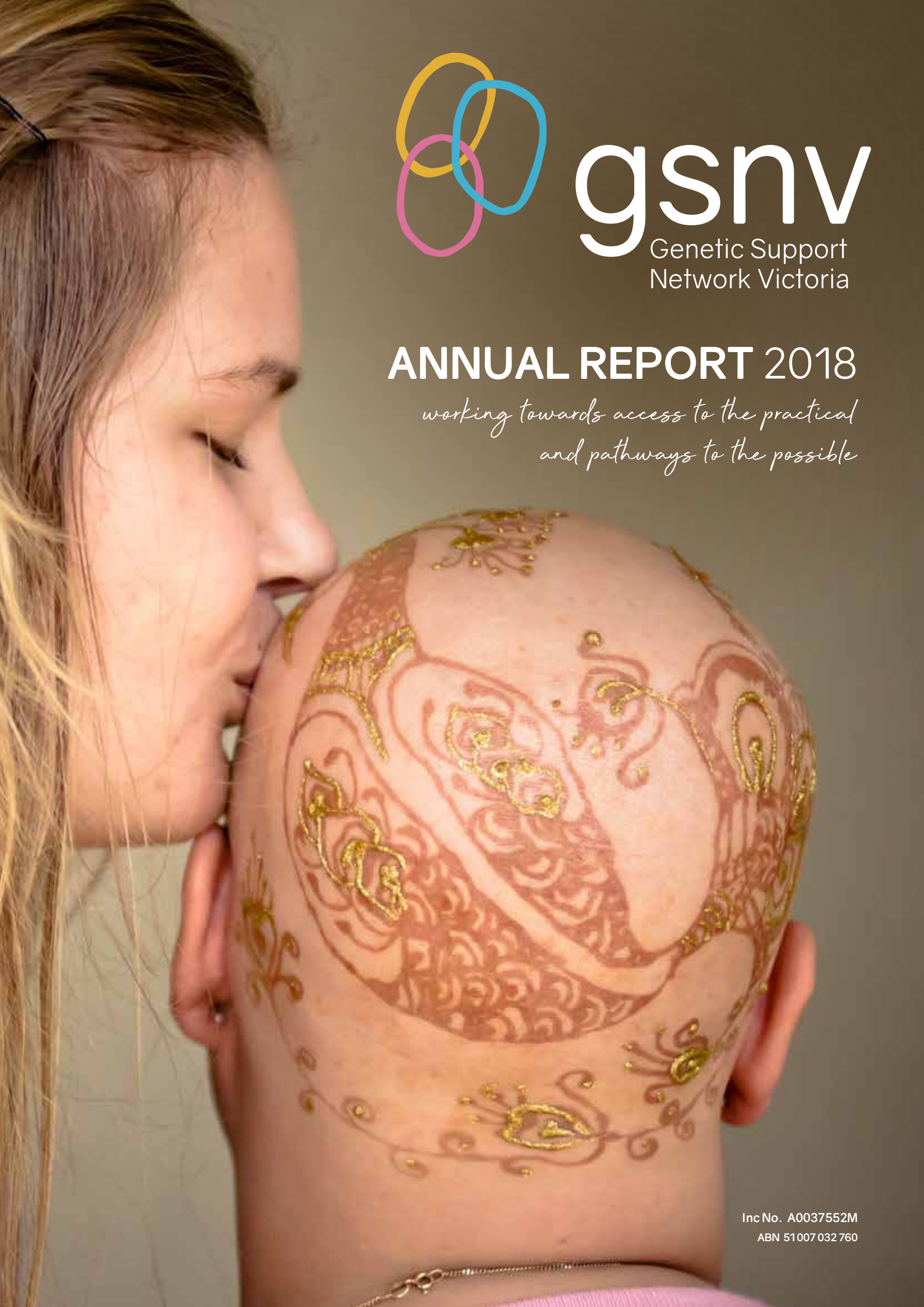


gsnv

Genetic Support
Network Victoria

ANNUAL REPORT 2018

*working towards access to the practical
and pathways to the possible*





genetic support network of victoria

Campus partner of Murdoch Children's Research Institute

Murdoch Childrens Research Institute
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*working towards access to the practical
and pathways to the possible*

WELCOME TO THE GENETIC SUPPORT NETWORK
OF VICTORIA INC. (GSNV INC.) ANNUAL REPORT
FOR THE PERIOD 1 JANUARY 2018 TO THE
FINANCIAL YEAR ENDED 31 DECEMBER 2018.

As we reflect on the year in review, 2018, 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. The number of rare diseases identified is increasing every day, with the tally so far at more than 10,000. It is expected that all these statistics will continue to grow!

We live in an age where we are unlocking some of the secrets of our genetic 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 or change which occurred inexplicably, just for us. We are also beginning to explore the relationship between our environment and our genes in an already complex space.

Discovery can bring hope and possibility; understanding and knowledge; fear and despair. Lack of diagnosis can bring frustration and isolation.

The Genetic Support Network of Victoria (GSNV) was established in 1997 in response to a changing complex environment; in recognition of the importance of a broad consumer voice in genetic health; acknowledgement of a gap in existing support for many rare, undiagnosed and genetic conditions and to increase awareness of the challenges faced by people with genetic conditions and those who support them.

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 and those who support them. Our work is underpinned by clarity of strategic direction, values and principles and is developed with a focus on Education, Advocacy and Support.



OUR VISION

A Victoria where
everyone can flourish!

OUR MISSION

To empower people to
make decisions about
their health and wellbeing

To collaborate for equity
and cultural change

To seek to improve
interactions between
the health and wellbeing
sector and users

To facilitate 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 2018 and Victoria introduced a Framework outlining Genetic and Genomic Healthcare for Victoria 2021.

Victoria has 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.

In 2018, 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 provided a focus in 2018.

The GSNV continued 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.



CEO MESSAGE

Thank you to all those who supported the work of the GSNV in 2018. We have had a really busy and rewarding year and will be working hard in 2019 to make a real difference in the lives of people with genetic conditions and those who support them. Thank you for all you do in this area too, together we make a stronger team.

In 2018 we focussed on listening to the needs of the support sector, recognising that our sector is under increasing pressure as the genomics and genetic juggernaut gathers momentum. We are seeing increased demand and increased pressure on existing support structures.

A highlight of the year was our Strengthening the Support Sector event where the support sector in Victoria came together to develop a plan for future collaboration to educate and inform, to support ourselves, our sector and people with genetic conditions and advocate for the people that we serve. It was a day where we came together and confirmed our commitment to a collective voice. This event has informed the priorities of the GSNV in 2019.

As I reflect back to 2018, I am so encouraged by the positivity, the drive of our sector to take action and use our collective voice and the amazing support and empathy we share for each other. We began our focus on issues that will continue to thread their way through 2019, issues such as mental wellness for people with genetic conditions and those who support them, ageing for people with genetic conditions, increasing focus on family impact of diagnosis or non-diagnosis, NDIS experience etc. We also commenced a

discussion with the health professionals around patient exit strategies – what role is played by the health system and professionals to ensure that patients exit the health system with the best chance of not coming back!

This report is full of what has been achieved and creates a sense of how much there is to go. I'm thrilled by the collaborative nature of my colleagues and the commitment to maximising the resources we have available. 2019 will see us move forward and build on this strong foundation.

I'm looking forward to doing that together.

Monica Ferrie,

GSNV Chief
Executive Officer





OUR COMMITTEE

The GSNV has had an extraordinary 2018, facilitating workshops, discussions and events for the genetic and rare disease community.

The GSNV committee has worked hard to ensure that the program of the GSNV translates to individuals and communities benefiting from the rapidly changing world of genetic and genomic technologies.

I would like to thank my fellow committee members for their contributions and enthusiasm over the past year.

I will also like to thank our out going President Abbie Kinniburgh for role on the GSNV committee. Abbie has been an integral part of the board for a very long time and we will miss her unique and thoughtful perspective.

We are looking to welcome new members on the board, particularly those with a lived experience of a genetic or rare condition. The GSNV prides itself on empowering patients and families to lead the way in shaping policies and the direction the GSNV. We would love to collaborate with more members of the genetic and rare disease community, so

please contact us for more information if you are interested.

On behalf of the GSNV committee, we would like to thank our current members for their continued support into 2019.

As developments in genetics continue to bring exciting opportunities, as well as raise important considerations, we hope to work with our diverse community towards ensuring support is available to all those who need it.

Anna Jarmolowicz,

Associate Genetic Counsellor
Victorian Clinical Genetics Services



WHO WE ARE

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

President	Vacant
Vice President	Rebecca Purvis
Treasurer	Rachel Pope-Couston
Secretary	Anna Jarmolowicz
Committee Member	Lucas Mitchell, Maree Maxfield, Abbie Kinniburgh, Chris Richards

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.

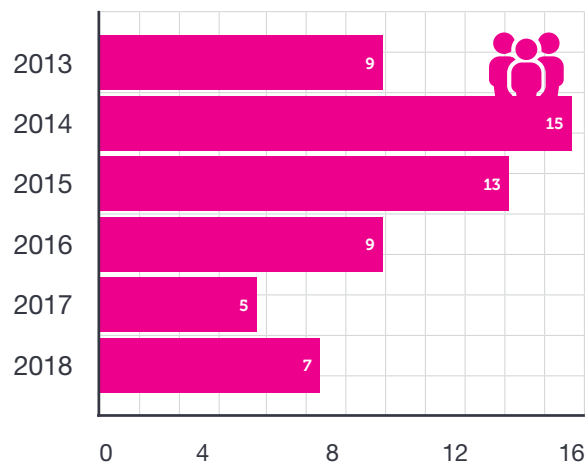
“ – The GSNV is leading the push to facilitate a collective voice for the support sector. The strengthening the support sector event was the first step in the process, which will facilitate the sharing of resources and allow greater advocacy and impact beyond what individual organisations can achieve alone.

Chris Richards, GSNV Committee Member

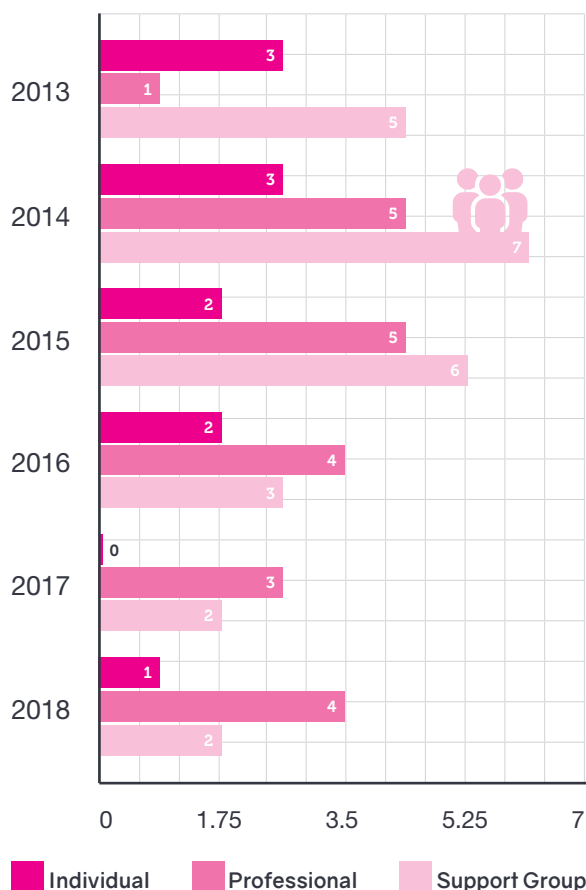
– In 2019 the GSNV continues to grow from strength to strength, forging new links and helping those with rare and genetic conditions become more connected and receive greater recognition. The collaborative formation of GUARD will see an exciting new national focus, taking us another step closer to a national framework for rare and genetic conditions, which collectively affect many Australians but have long been under-represented.

Maree Maxfield, GSNV Committee Member

COMMITTEE MEMBER NUMBERS 2013-2018



COMMITTEE COMPOSITION 2013-2018





OUR ORGANISATION

The GSNV is an organisation underpinned by values and principles. These impact both our priorities and practice.



OUR VALUES

Fairness and Equity

- We believe that every individual has an equal right to access information and services that impact the possibility and potential to live their life.
- We believe in equal opportunity to make an informed choice and to have that choice supported.

Empowerment

- We strive to educate and inform people to empower informed decision making
- We seek opportunities to provide the voice of lived experience
- We build capacity by developing and delivering education and support strategies

Respect

- We believe in the possibility and potential of all life
- We respect choice and the right to choose
- We seek diverse opinions and approaches
- We listen and learn from lived experience

Integrity

- We are ethical, tolerant and strive to deliver

Connectedness

- We collaborate 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

OUR ADVOCACY PRINCIPLES

We advocate for:

- Support as an indispensable component of an inclusive health and wellbeing system jointly considered in practice, planning and policy development
- Access and equity for all – of information, of expertise, of care, of consideration, in research, in environment and in all things
- Recognition and action to build mental strength for people with genetic conditions and those who support them
- The Importance and recognition of identity and individuality in care, decision making and support – Differences are of value
- The right to Knowledge, Education and Information for decision making and choice
- A collaborative approach with State and National organisations
- These values and principles are also evidenced in the individuals who make up the GSNV team. We were thrilled to add to our team through the recruitment of Kari Klein in 2018 and saddened to say farewell to Nancy Amin who has been a long term staff member of the GSNV. Nancy left us to explore opportunities in Western Australia and we are very grateful to have her skills and knowledge for a number of years.

The GSNV Team

- Kari has brought some new skills to the GSNV, as an experienced trauma counsellor this brings a unique perspective as well as sensation skills at keeping our projects moving and keeping us all organised.
- I would like to thank Louisa DiPietro and Keri Finlay (Pereira) for their valued support and hard work and also an outstanding year of contribution.
- The GSNV operated within our budget with a maximum of 2.5EFT (equivalent full-time) with all staff members classed as part-time. We actively recruited volunteers to support our work and support group projects as in the past.
- The GSNV Committee of Management and team would like to recognise the contribution of the volunteers over the past year. They have been outstanding. The Committee would also like to highlight the hard work of the GSNV team, who demonstrate such dedication, passion and commitment to our vision and mission.
- Through our commercial arrangement with the VCGS, the GSNV adopts MCRI corporate services policies and procedures who provide our Finance, HR, Payroll, Facilities and IT support. We extend our thanks for their continued support and professionalism. Our organisation would also like to extend our gratitude to Martin Delatycki, Medical Director of VCGS for how ongoing support.

EFT ALLOCATION AS AT 31 DECEMBER 2018

NAME	POSITION	CLASSIFICATION	EFT
Monica Ferrie	Chief Executive Officer	PT	0.4
Louisa DiPietro	Education and Advocacy Strategist	PT	0.25
Keri Pereira	Genetic Support Coordinator	PT	0.4
Kari Klein	Administration Assistant	PT	0.6

**TOTAL 1.65
EFT 2.0**



OUR MEMBERS

GSNV financial members make it possible for us to serve our most important stakeholder group – people with genetic conditions. Our strength is our people; the feedback, ideas, and contribution we receive from them is vital, as it enhances and supports our work.

Our current members include:

- Support groups
- Individuals and families impacted by genetic conditions
- Health professionals
- Students
- Interested individuals
- Members of the community

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

The GSNV has a wide range of members, consumers, stakeholders, and professional affiliates. GSNV membership offers the opportunity to gain access to information on research, support group activities and support, information, connection, advocacy and education, peer support training, volunteers, newsletters and to be represented on issues relating to genetic health.

working towards access to the practical...



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 tasks.

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

Our GSNV volunteers have also been an invaluable aid in our office administration tasks as well, including assistance in event planning, memberships, data mining, logging contacts, mail outs and more.

– Marta has been such an asset in helping our group with setting up timely and frequent communications. Marta is very efficient, friendly, lovely and has been a breath of fresh air in our community. Thank you Marta!

Evan Englezos, Williams Syndrome Family Support Group (Victoria)

– Gratefully Leukodystrophy Australia has been privileged and thrilled to be a beneficiary of the GSNV Volunteer Program over the past few years. In the last 12 months, we received help from 2 volunteers who have provided a wonderful boost to our always limited resources by way of:

1. Researching drug matching to Leukodystrophy type (a skilled and complex job)
2. Redesign and update of our brochure and information sheets, (time consuming and requiring design talent)

Without such help – well, much of it, just wouldn't get done within timelines and budget. Thank you GSNV, and valuable, delightful volunteers, you are doing a great service.

Bronwyn Byrne, Office Manager Leukodystrophy Australia

...and pathways to the possible

The GSNV Volunteer Program

We currently have 20 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. Some examples of volunteer-support group matches in 2018 were:

VOLUNTEER ORGANISATION	VOLUNTEER MATCH	ACTIVITY
Children's Tumour Foundation	2	NF Hero March and Community Information Day
Leukodystrophy Australia	2	Researching drug matching to Leukodystrophy type, redesigning and updating brochure and information sheets
Usherkids Australia	1	UsherKids Conference
Williams Syndrome Family Support Group Australia	1	Participating in events such as camp, christmas party, cricket match and rare disease day
Australia Alopecia Areata Foundation	2	AAAF Annual Victorian Trivia Night and office administration
Syndromes Without A Name	2	Assistance with Undiagnosed Children's Awareness Day
Genetic Support Network of Victoria	4	Memberships, GSNV events, GSNV database, Genetic Link

– The Australia Alopecia Areata Foundation Inc. (AAAF) has been engaging the GSNV's volunteer program for several years. We have accessed volunteer assistance for once off event support, and for ongoing administration assistance of programs like our Hair Donation Program. We've had such an excellent experience with the volunteers from GSNV and feel very positive about all the volunteers who we have worked with. We really appreciate the assistance and support this program has given our small charity - it has made a huge difference for us and allows us to continue to support our community.

Georgia Gardner, AAAF Secretary

– Being a part of forward-thinking forums and helping support groups through the GSNV volunteer program has been enlightening as well as rewarding. It has taught me a lot about the current climate of genomics in healthcare, how individuals have benefited from such advancements and what needs to be improved upon in this realm as well. The fact that I have been able to give back to the community has been extremely fulfilling too.

Kim An, GSNV Volunteer

– I have been really grateful for the opportunity to volunteer with the GSNV - I've had the invaluable experience of working together with like-minded individuals who are so passionate about the cause, to hopefully make a difference in the lives of those involved with and affected by genetic conditions. Thanks so much!

Mariana Louwetta, GSNV Volunteer



CORPORATE GOVERNANCE

The GSNV commenced 2018 with 5 committee members which increased to 8 at the Annual General Meeting in May. We were thrilled to welcome Rebecca Purvis, Chris Richards and Lucas Mitchell who bring diverse experience and skills to the Committee.

We farewelled Emily Higgs with sadness and excitement as Emily left the Committee to pursue her career in the United States early in 2018.

The committee also farewelled Abbie Kinniburgh, a long term member who brought insight and experience to our team.

The GSNV is so fortunate to have dedicated Committee members with a very high meeting attendance record and great engagement. We will continue to seek new Committee

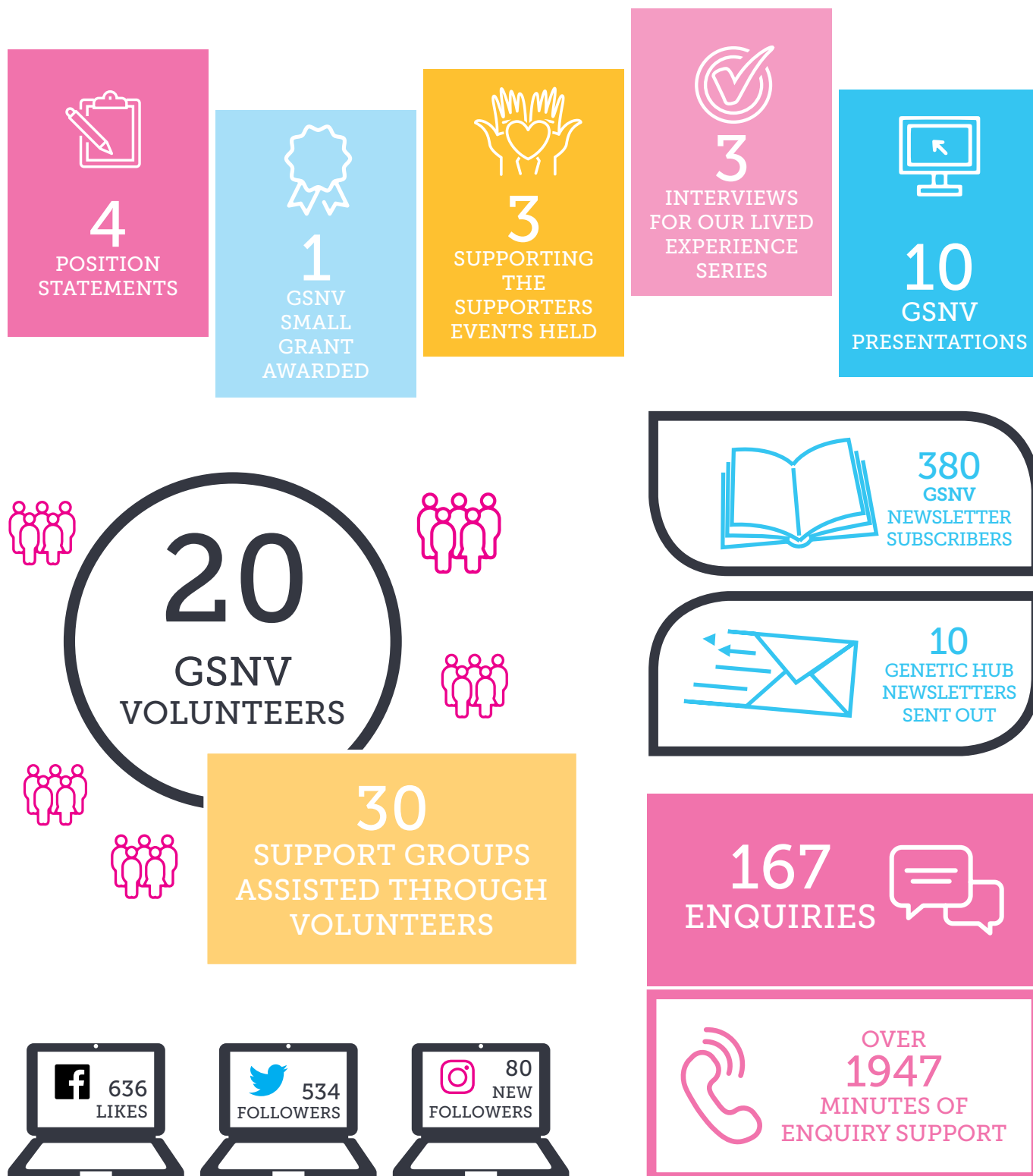
members with a goal to increase diversity and representation. Strong governance will remain a focus in 2019.

In the period since the previous AGM, the GSNV Committee of Management has met on the third Tuesday of each month at the Royal Children's Hospital. Each meeting has a central theme and supports the strategic plan and business objectives. Reporting on actions delivered and actions planned is a key feature with reports provided in advance to the Committee.

...and pathways to the possible

YEAR IN REVIEW

In the 2018 financial year, our vision and mission have led to outstanding achievements. Here's a snapshot...



HIGHLIGHTS FROM A PRODUCTIVE YEAR



Strengthening the Support Sector

What a great day! We brought together the support group sector to reflect on current common issues and to explore how together we could impact them. This day resulted in a collective platform and a plan to guide the work of the GSNV over coming years to support the sector, to develop capacity and to facilitate collaboration. This day will become an annual event.



Mental Health First Aid

We are increasingly concerned with the impact of genetic diagnosis, non-diagnosis, treatment, non-treatment etc on genetic health patients, their families and their other support networks and structures. In 2018, we supported the delivery of Mental Health First Aid program to 6 support organisations to understand the value this training could add to the support sector. We will undertake to do this again in 2019.



Margaret Sahhar Grant

In 2018, the Margaret Sahhar Grant was awarded to AusDOCC (Australian Disorders of the Corpus Collosum).

This grant was awarded to allow AusDOCC to continue their great work by bringing experts together to develop fact sheets for their members at various life transition stages.

These fact sheets were developed to be handed out to people who need to know and to stop endless explanations and questioning by institutions, agencies and government.



Genomics in Practice

We are extremely grateful to 10 organisations who hosted Masters in Genetic Counselling students for the Genomics in Practice unit. This unit seeks to ensure future genetic counsellors understand the role of support groups and community in supporting the health and wellbeing of people with genetic conditions. Both organisations and students found this to be an incredibly valuable experience with overwhelmingly positive feedback. We were thrilled to hear in student reflections that many felt that their practice would be positively impacted by what they had learnt.



Lived Experience Interviews

In 2018, we commenced our Lived Experience Series. This connected us to some amazing individuals to whom we are very grateful. Ayman, George and Phoebe shared their stories to inform, to influence and to engage a broader community in the challenges and struggles, the ups and downs of living with genetic conditions. We are very thankful for their honesty and openness.



International, National and Local Networking

2018 has seen the GSNV engaged across many levels in many places as we participated in, advocated at and educated ourselves while forming and strengthening important relationships.

In the international arena we were present at the European Meeting on Psychosocial Aspects of Genetics and the Rare Disease Conference in Europe, engaged and involved in the Rare Disease Summit in Melbourne, worked with Australian Genomics, Melbourne Genomics, Genetic Alliance Australia, Genetic and Rare Disease Network in WA and Rare Voices Australia on common issues and our support groups on a range of activities.

We find ourselves better informed at the completion of December and look forward to continuing to build this knowledge and platform.

...and pathways to the possible

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 14 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
- Facilitate the mechanics of lobbying to address specific issues.

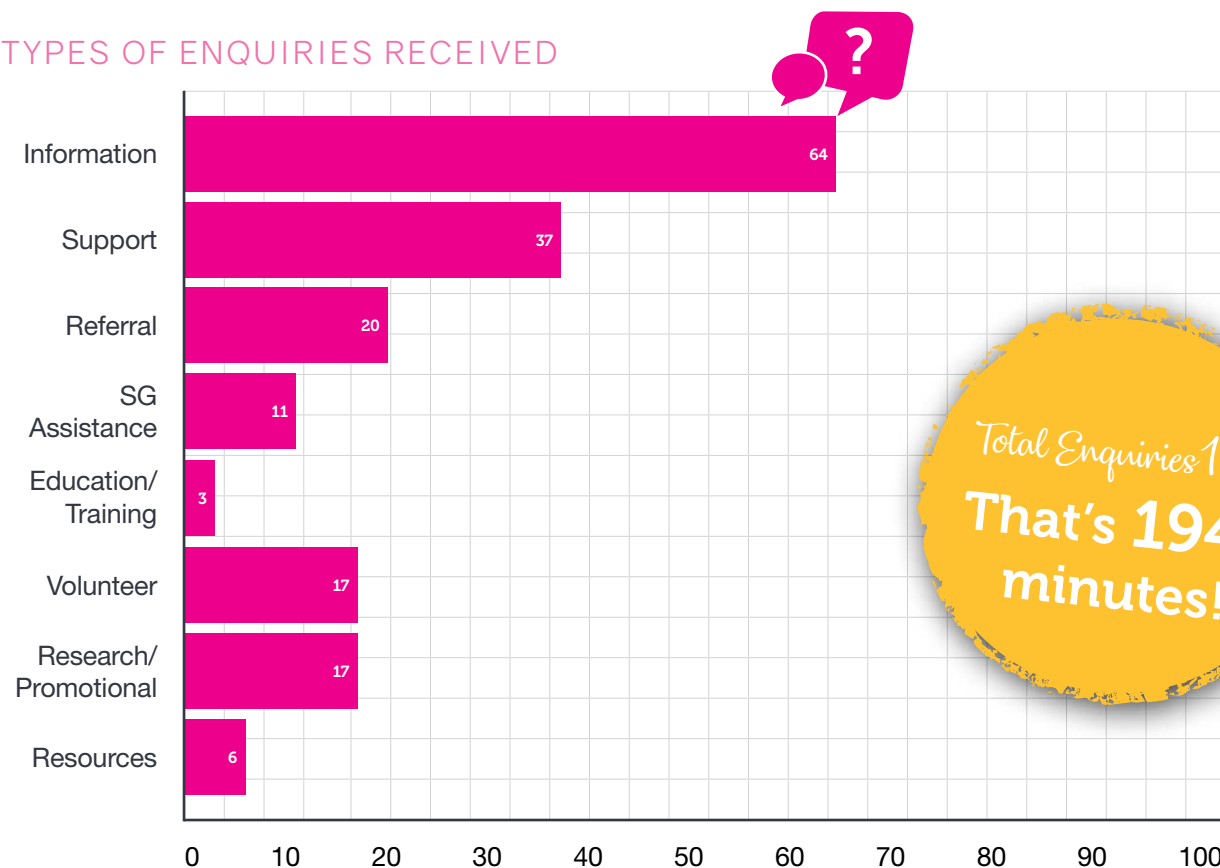
Providing support for support groups is a significant part of our role. We can aid support groups in the following ways:

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

Over the year will have assisted a number of groups including the following:

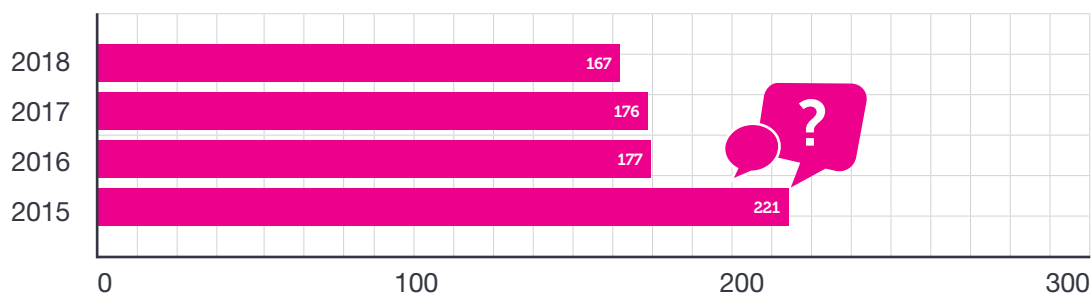
- UsherKids Australia
- Leukodystrophy Australia
- Porphyria Association
- Syndromes Without a Name
- Williams Syndrome Family Support Group
- SMA association of Australia
- Cystic Fibrosis Australia
- Fabry Australia
- Children's Tumour Foundation Australia
- Alopecia Association of Australia
- Thalassemia Australia
- Huntington's Victoria
- AusDocc Inc

TYPES OF ENQUIRIES RECEIVED

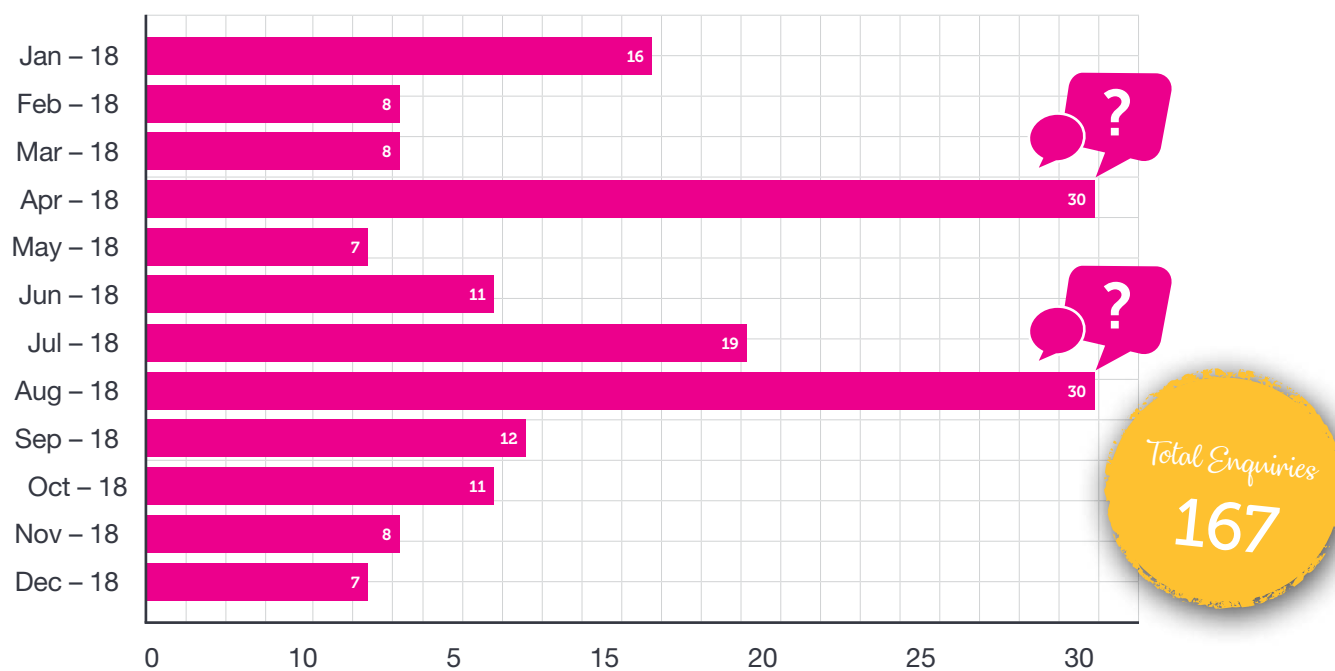


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ANNUAL ENQUIRIES

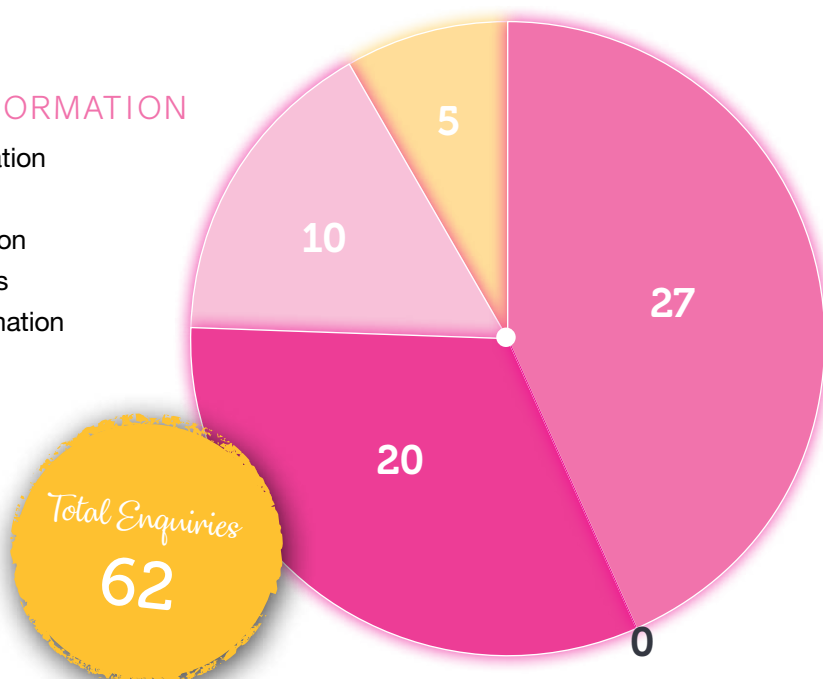


ENQUIRIES BY MONTH



TYPES OF INFORMATION

- Funding Information
- Other
- Health Information
- Genetic Services
- Condition Information





EDUCATION

Education is a vital part of the core work of the GSNV. Education activities are grouped as follows:

Professional • Community • Student

Professional

MCHN conferences

In 2018 we hosted an exhibitor table at the State-wide Maternal Child Health Conference in March and October. 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

Royal Children's Hospital Campus Education Week, Panel Discussion October 9, 2018

The GSNV was engaged to participate in a session designed to explore the topic – "Patients as teachers, clinicians as learners".

The panel was chaired by Professor Lynn Gillam, with each panellist providing their unique perspective based on their lived experience, professional experience and or observation as a carer, worker or supporter.

Panellists

- **Louisa Di Pietro**
Genetic Support Network of Victoria
- **Helen Codman**
Manager of Education Outreach Nursing and Allied Health
- **Elizabeth Prentice**
Anaesthetist, specialist in patient centred care
- **Ayan Xusen**
CHIPS representative

The discussion focused on questions such as:

- How can we learn from our patients and their families?
- How can we engage patients in the education process, as part of patient-centred care?
- Can you provide an example of how this has worked well for you (as a clinician or a patient/parent)?
- What are the barriers to positioning patients as our teachers in practice?

Students

Genomics in Practice

The GSNV is proud to be directly involved in education and contributing to the training and education of health professionals in Victoria. In collaboration with the University of Melbourne (UoM), Master of Genetic Counselling, the GSNV has provided coordination of the Genomics in Practice (GIP) subject, Community Placements Program. The Community Placements experience and a reflective report are a formal learning requirement of the Genomics in Practice subject.

The two tasks meet the following learning outcome/s for this subject:

- Develop an understanding of the multidisciplinary nature of health care
- Demonstrate an understanding of how support organisations can be incorporated into genetic health care
- Demonstrate an understanding of the impact of disability on an individual and their family

Community placements are designed to maximise experiential learning and promote the concept that support, is an essential component of the genetic health sector but knowledge and understanding of how it is offered and where it is, is limited amongst health professionals. The GIP program has moved forward with incorporating an understanding of 'support' and the 'support sector' as an important learning outcome area and one that will heighten the student awareness of impact on families and individuals.

Under the Community Placement students assign themselves to a host support/advocacy organisation and work in pairs. There is much autonomy to negotiate the placement arrangements with hosts, including tasks and work assigned to them.

The Community Placement program offers an opportunity for the support sector to influence health professionals training and have some input into the awareness and understanding of the huge contribution they make to genetic health care. The GSNV is privileged to be a leader in the coordination of that exchange and believe it to be even more relevant in a changing health and support landscape.

We felt extremely fortunate to meet and work with two students as part of the Masters in Genetic Counselling Placement. Both made a valuable contribution to our organisation and we would welcome the opportunity to participate in the program again.

We were hesitant to participate at first as we are quite a small organisation. But the flexibility of the program and the willingness of the students meant we were able to collaborate on various projects which were beneficial for all involved.

Emily Shepard, Usherkids Australia

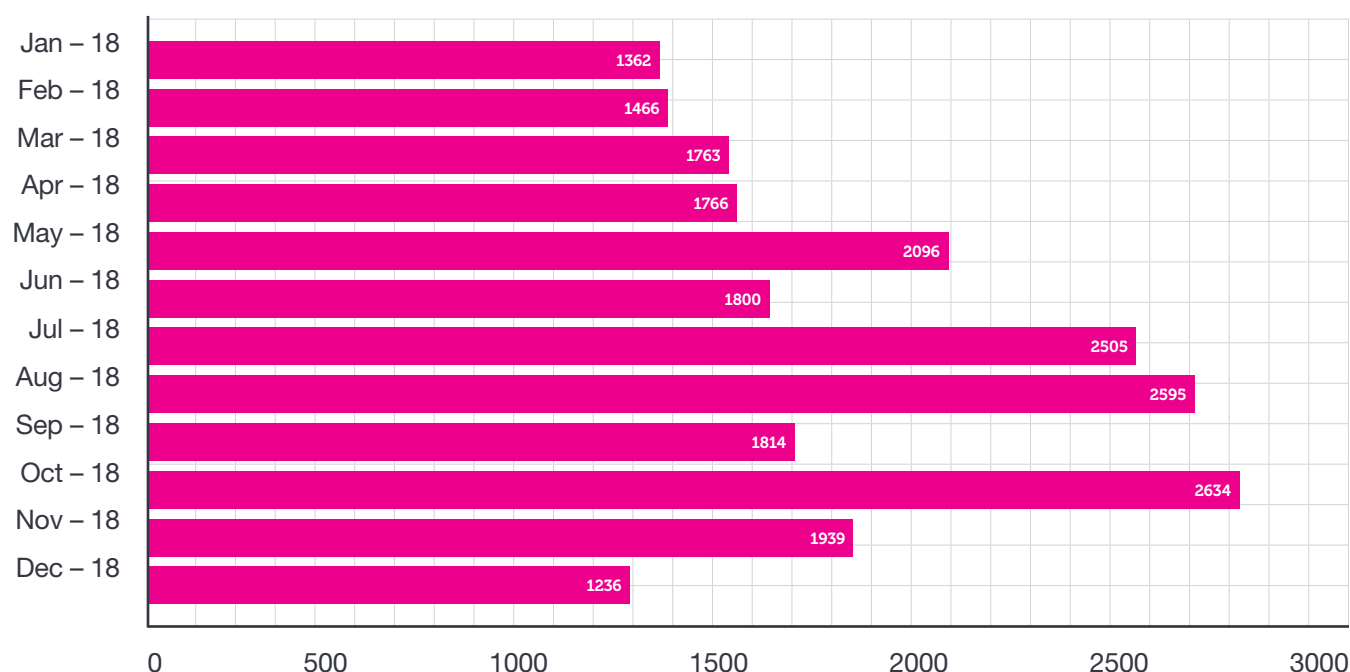
WEBSITE, DATABASE AND SOCIAL MEDIA

Social media remains an important tool in reaching our community with what is in the media in regards to news, research, events and sharing what information is within our network.

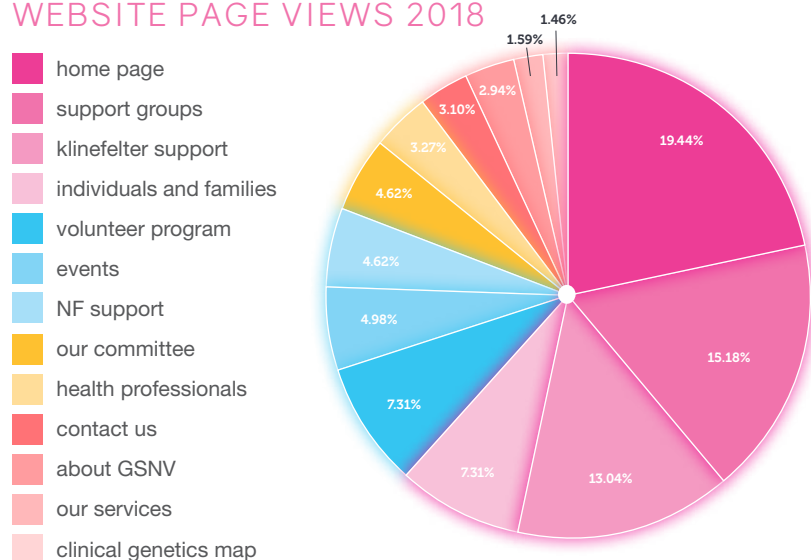
In 2018 the GSNV used social media to highlight our important events and information. Social media has been incorporated into the GSNV communications policy, using platforms such as Facebook, Twitter and Instagram. The GSNV seeks to follow trend on social media and subscribes to over 2,000 pages on twitter and has over 600 followers on

Facebook, which is 100 more than in 2017. It is anticipated that social media will require further time and resources in the future as the GSNV has just launched an Instagram account to support the support groups who are regularly engaged with the GSNV and members by advertising events as well as publishing live video stories.

NUMBER OF WEBSITE VIEWS BY MONTH



WEBSITE PAGE VIEWS 2018



NUMBER OF WEBSITE VIEWS



22,996
2018

17,093
2017

19,124
2016

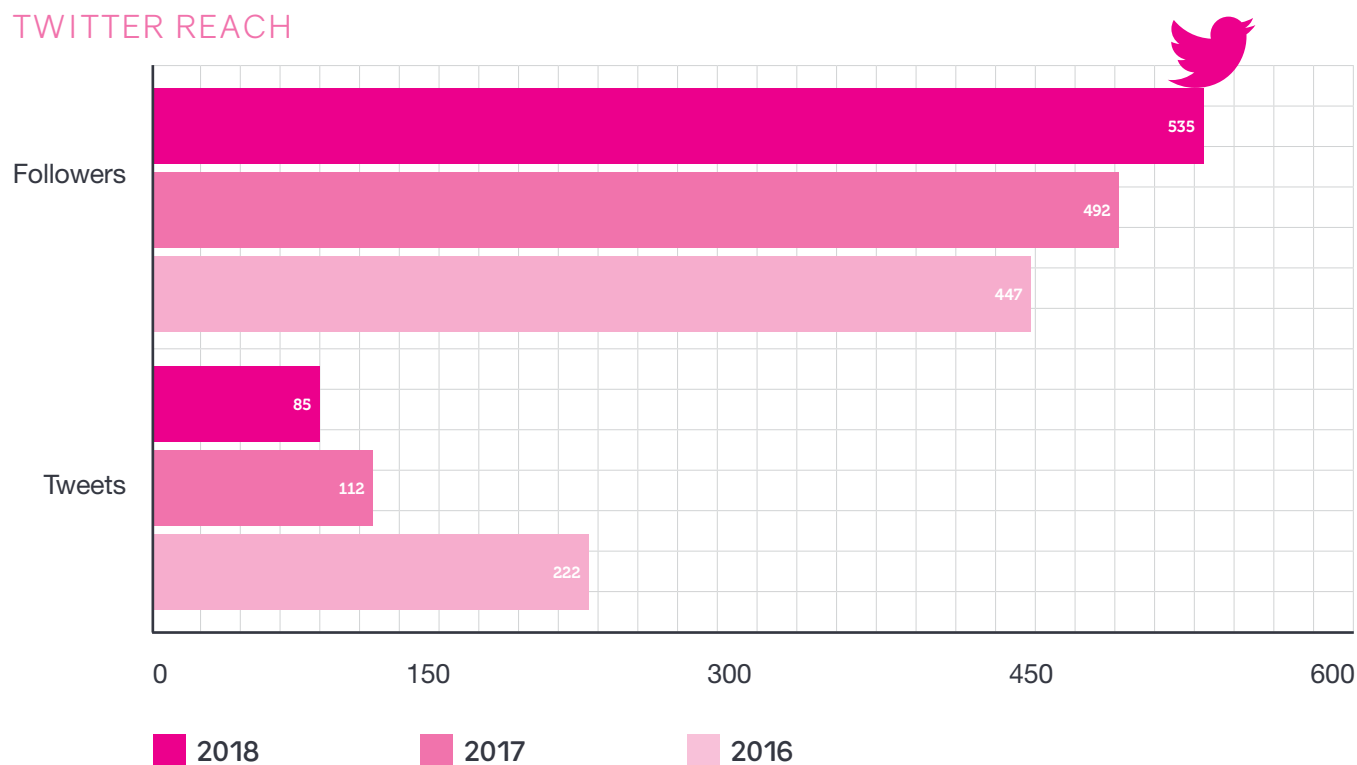
23,067
2015

21,014
2014

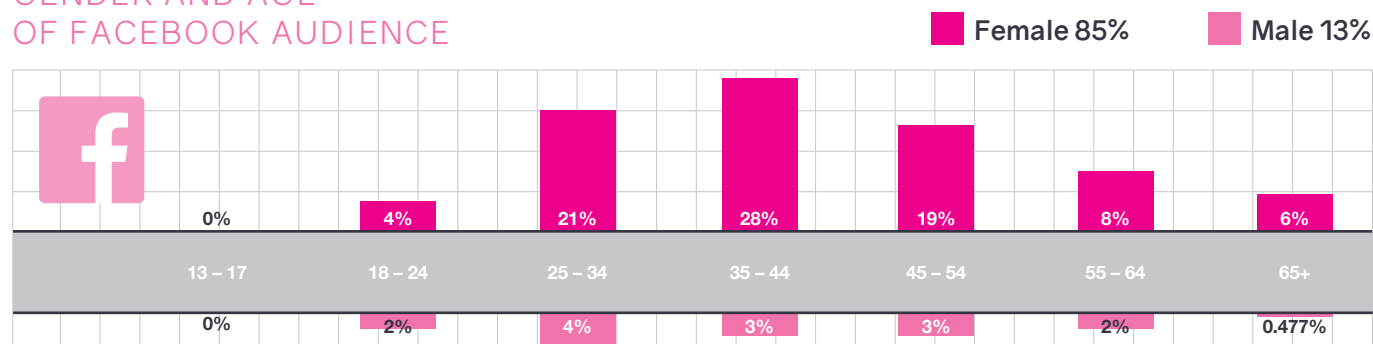


WHO ARE WE REACHING ON FACEBOOK AND TWITTER?

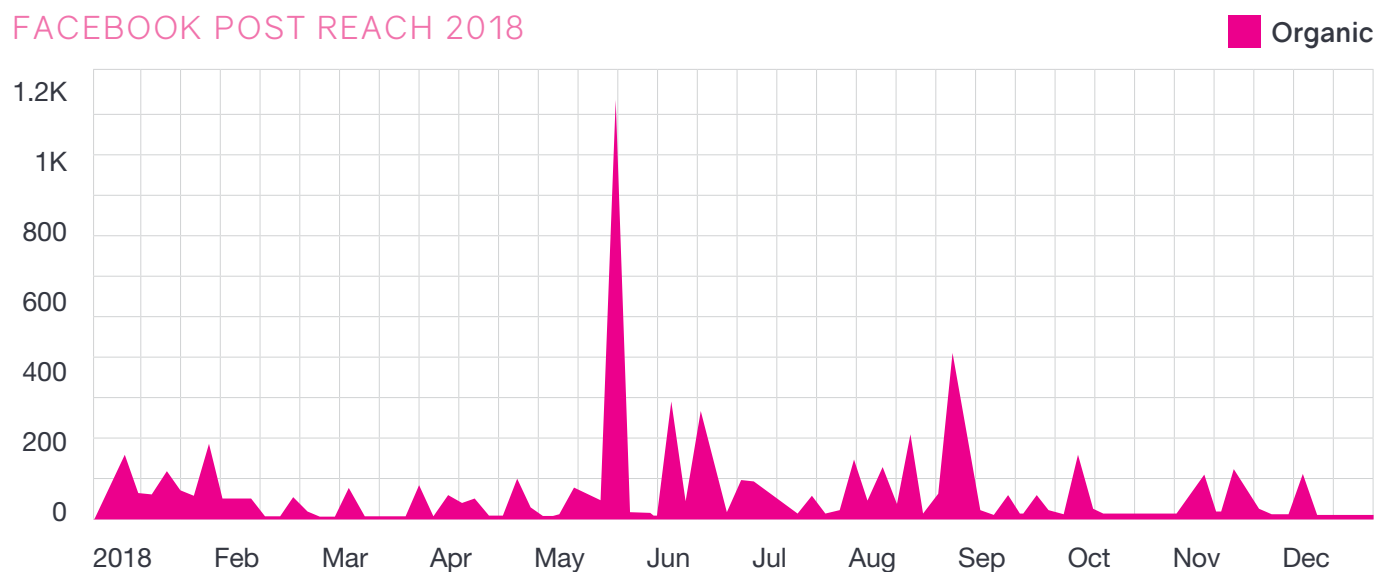
TWITTER REACH



GENDER AND AGE OF FACEBOOK AUDIENCE

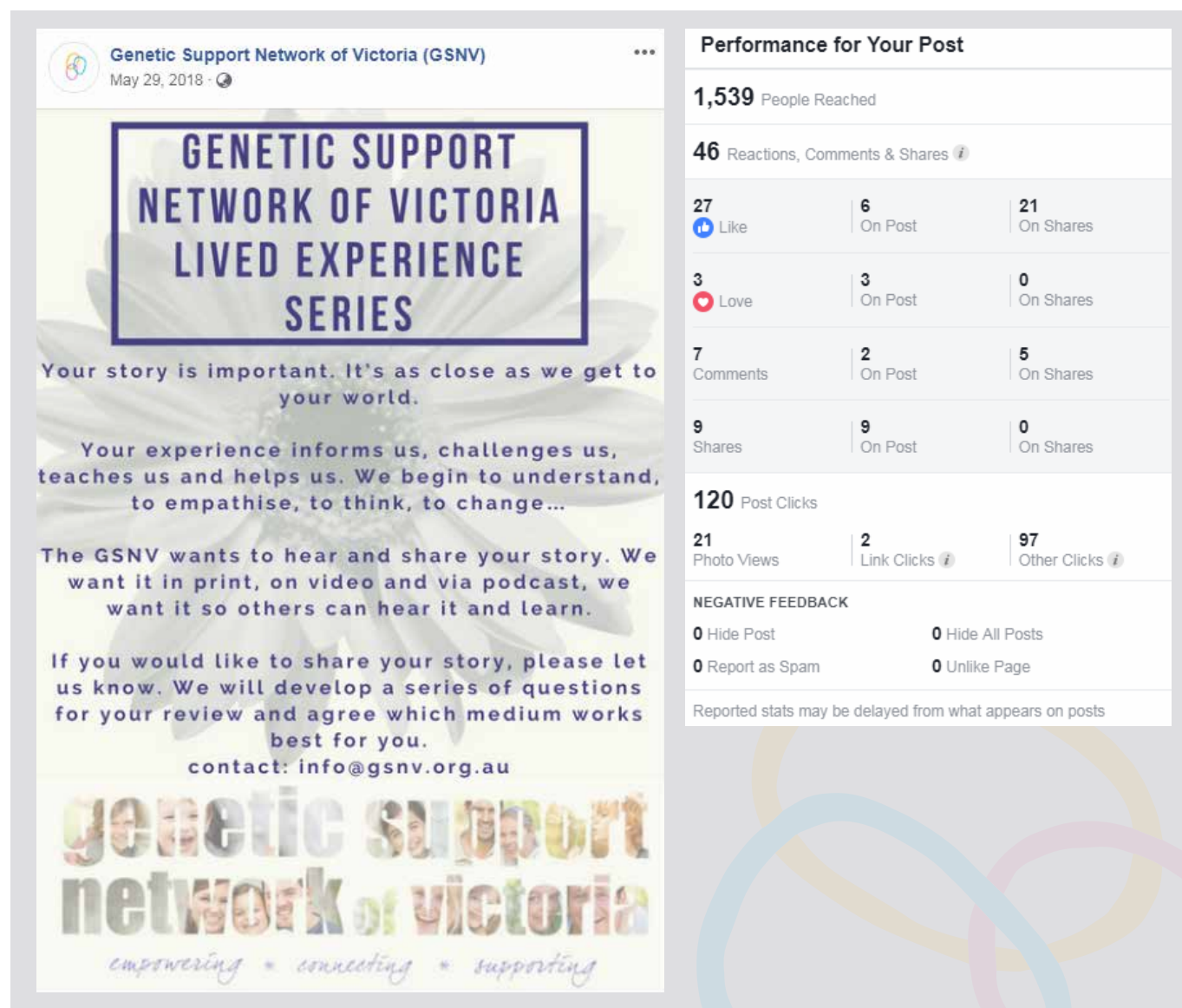


FACEBOOK POST REACH 2018



FACEBOOK HIGHEST PERFORMING POST 2018

Post Details





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, Kirrily Fasham 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 2018

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 2018 – 31 DECEMBER 2018.

We remain grateful to the Department of Health and Human Services who have continued to provide funding to the GSNV through an ongoing grant channelled through the Victorian Clinical Genetics Services (VCGS). It is through this grant and the support of our members that the GSNV remains a viable and solvent organisation. 2018 was a great year for the GSNV as evidenced by this report. The Committee approved the targeting of funds saved through operating efficiencies towards professional development opportunities for the GSNV team. The benefits of this investment will flow through in 2019.

The GSNV has an infrastructure agreement with the VCGS and as part of this agreement our financial accounts are audited by KPMG who are the external auditors for VCGS. This audited report concluded that GSNV will carry a surplus of \$1974.54 into the 2019 year. As Treasurer, I would like to thank my fellow Committee members for their continued dedication, all volunteers and the GSNV team. We continue to work together to achieve the best possible outcomes for GSNV Inc and those we serve.

STATEMENT OF INCOME AND EXPENSES

STATEMENT OF INCOME AND EXPENSES FOR THE MONTH ENDED 31 DECEMBER 2018

70680 GENETIC SUPPORT NETWORK

	Actual 2018		Budget 2018	
	For this Period	Year to Date	Year to Date	Year to Year
BROUGHT FORWARD BALANCE @ 1/01/2018	13,299.74			0.00
INCOME				
DHS GRANT	-17,600.66	210,049.34	243,800.00	243,800.00
FUNDRAISING	0.00	0.00	30,000.00	30,000.00
LORD MAYOR'S TRUST	0.00	0.00	0.00	0.00
MEMBERSHP FEES	0.00	0.00	0.00	0.00
DONATIONS	0.00	11.00	0.00	0.00
CONFERENCE FEES	0.00	0.00	0.00	0.00
SUNDRY INCOME	0.00	1,073.89	2,000.00	2,000.00
Total Income	-17,600.66	211,134.23	275,800.00	275,800.00
EXPENDITURE				
SALERIES & RELATED COSTS	9,945.04	91,042.88	106,000.00	106,000.00
COMPUTER HARDWARE	0.00	1,540.00	2,500.00	2,500.00
COMPUTER SOFTWARE & EXPENSES	0.00	361.24	500.00	500.00
CONSULTANTS	6,000.00	73,219.12	70,000.00	70,000.00
POSTAL SERVICES	0.00	53.68	500.00	500.00
PRINTING, STATIONARY & PHOTOCOPYING	251.04	6,882.77	8,000.00	8,000.00
BOOKS & SUBSCRIPTIONS	0.00	1,426.58	500.00	500.00
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	3,335.75	1,000.00	1,000.00
STAFF TRAINING & CONFERENCES	909.09	15,547.43	6,000.00	6,000.00
TRAVEL	181.19	9,355.85	5,000.00	5,000.00
CROP SERVICES – IT/HR/FIN	1,176.24	14,114.88	14,114.88	14,114.88
MISCELLANEOUS	0.00	0.00	0.00	0.00
OTHER ADMINISTRATIVE COSTS	2,626.55	5,579.25	3,000.00	3,000.00
Total Expenditure	21,089.15	222,459.43	219,114.88	219,114.88
OPERATING SURPLUS/(DEFICIT) CARRIED FORWARD @ 31/12/2018		1,974.54		

Audit Statement



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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.

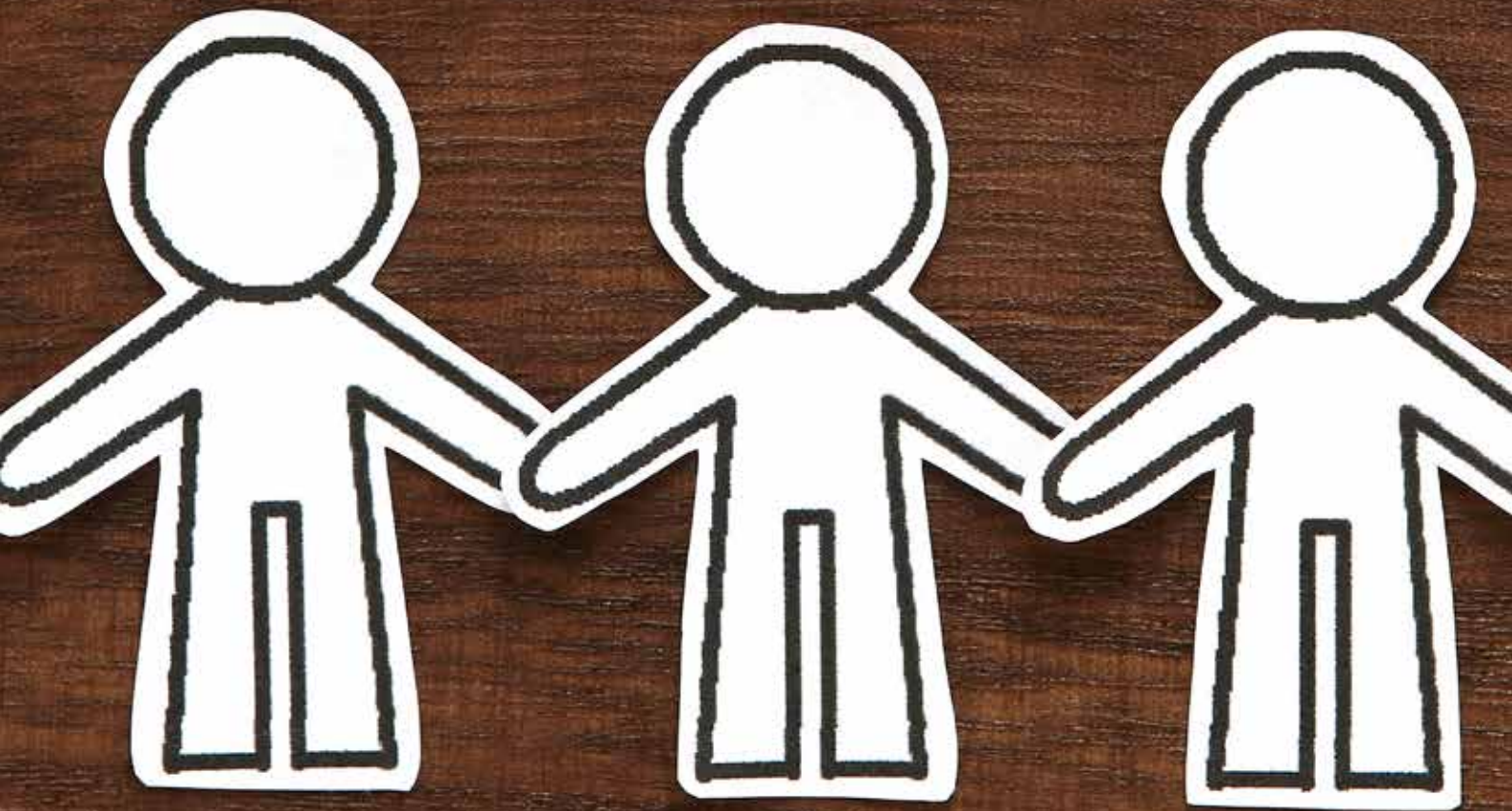
The accounts of the VCGS are audited annually by KPMG who are our External Auditors. The accounts for 2018 have been audited by KPMG in accordance with this practice. In the Calendar Year 2018 GSNV recorded a surplus of \$1,974.54 which will be carried forward to the current 2019 Calendar year.

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.

*working towards access to the practical
and pathways to the possible*





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genetic support network of victoria

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