

# Metropolitan Region

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## ANNUAL REPORT 2020

*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 2020 to the Financial Year ended 31 December 2020.**

As we reflect on the year in review, 2020, we will highlight some of our major achievements, challenges and outcomes; including an overview of governance and financials.

COVER: This image is of Harry Feller aged 10 and has been provided with the consent of Harry and his parents. He was born with Usher syndrome, a rare genetic condition that is the world's leading cause of deaf blindness. This image shows him accepting his medal for coming first in the Victorian State Championship Breaststroke Age 9/10 Swimming Event this year. He was able to compete at this level with a classification of multiclass, providing equity to participate in sport for children in Victoria with a disability. Harry has agreed to share his story with the Genetic Support Network of Victoria and you as he wants everyone to know how much taking part in these sporting events has meant to him this year. Living with a rare disease is not an any easy journey in life and often physically and/or mentally you are confronted with limitations that you just don't want to acknowledge. Being part of organisations that provide advocacy, equity and awareness of rare disease and genetic conditions have helped Harry live his best life and flourish.

### **Genetic Support Network of Victoria**

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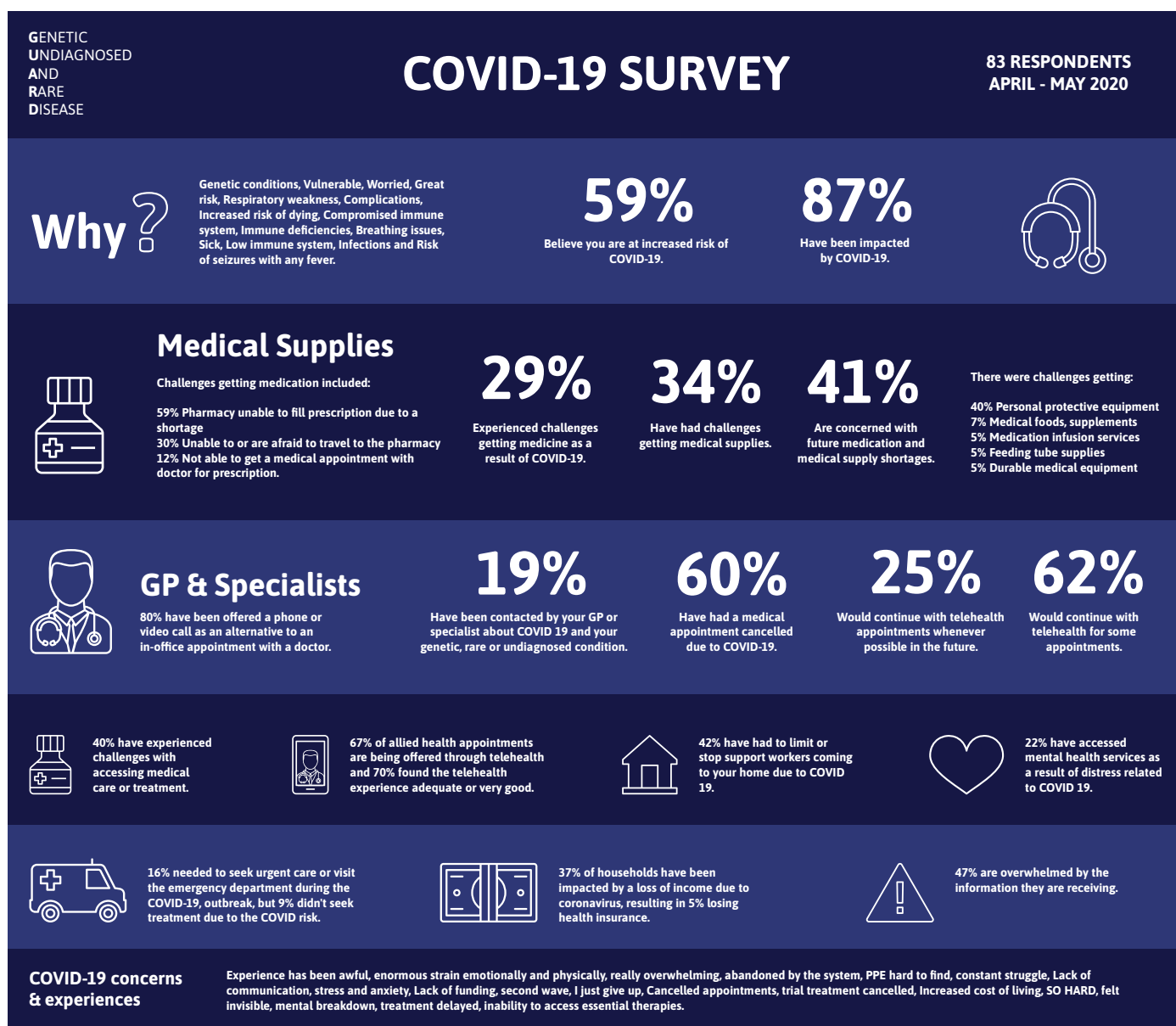
## 2020 – A YEAR OF CHALLENGE AND INSPIRATION

Dominated by words we could never have imagined being part of our every-day vernacular – lockdown, pandemic, coronavirus, you're on mute.....2020 was a year to remember.

Our community was 'hit for six' in March 2020, as we watched in horror as the COVID-19 pandemic swept firstly across Europe to make it's way into Australia necessitating our first lockdown in March 2020.

It felt like Australian's were disciplined, caring and generally respectful of the task before us and the need to do our bit.

Together with our colleagues within GUARD Collaborative Australia, (Genetic Alliance Australia - NSW, Genetic and Rare Disease Network – WA and Syndromes Without a Name – SWAN Australia) we reached out to understand what was happening in our community.



While our environment has improved, it is clear the watch is not done. As we were then, so we are now – all in this together.

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, rare and undiagnosed 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.



## VISION AND MISSION

In 2020, the GSNV conducted a six-month consultation to create a new strategic plan. Consultation included people with lived experience and those who support them, our volunteer community, patient support organisations, health professionals and other key stakeholders. Facilitated discussions focussed on important topics such as equity and access, integrated care, data, partnerships, diagnostics and treatment, research and clinical trials.

### OUR VISION

People living with genetic, undiagnosed and rare conditions flourish and live their best lives.

### OUR MISSION

To have support included as an integral part of the health and wellbeing care continuum.

To drive fairness and equity of access across testing, care pathways, treatments, research, clinical trials and support.

To be a voice and force for positive change for genetic, undiagnosed and rare disease communities.



## THE GSNV IN CONTEXT

2020 began for us like every other year, prepared and focussed on the year ahead, excited by what we could achieve and totally committed to getting it done. So, some things changed and some things didn't. As the environment we work in changed forever we found that our commitment and focus didn't change. In a year where so many people were hurting and trying to stay strong, we knew that our support was needed more than ever before.

Inspiring our work at the commencement of 2020, was the launch of the Department of Health National Strategic Action for Rare Diseases. This is the first time we have ever had a national policy focus for rare disease that brings together the pillars of Awareness and Education, Care and Support and Research and Data with priorities and actions for each. This plan will need all of us to implement it – without us, it's words on a page, with us – it's opportunity and hope, progress and change. In 2020, the GSNV issued a mid-year and end of year report on our progress to contribute to the delivery of the National Strategic Action for Rare Diseases.

In March, COVID-19 started to impact. The GSNV like just about every other organisation, packed up and headed home. We were still there on December 31st.

As we came to understand the needs of our community, our work was reshaped to support and provide a strong voice during this time.

As a result, GUARD Collaborative Australia issued a collective statement to the Federal and State Governments about the needs of our community and we reached out to international colleagues to share our experiences and to learn from initiatives. We have deliberately sought to strengthen these relationships both nationally, regionally and globally. This is consistent with our commitment to reduce duplication of work, learn from others and connect our community in every way possible.

Our 2020 work program was reshaped to ensure that our community was supported and connected. The support sector was challenged like never before. An even more uncertain and isolating environment, an even less accessible health and support services system and always an anxiety about catching and sharing the virus. We are always amazed and grateful to the support sector for the amazing work they do and inspired by the resilience, courage and kindness of our community.

We focussed more on connection to strengthen and support our community establishing a Thursday Chatroom on zoom and developing our 2021-2023 Strategic Plan through extensive on-line consultation. We also focussed on connection for ourselves – strengthening our relationships with the health and research sectors, building new relationships with industry, collaborating wherever possible and connecting to support through submissions, representation, advocacy to Government, Government agencies such as NDIS, MSAC, PBAC and Joint Standing Committees and Royal Commissions.

While the global environment is yet to settle and recover, we are fortunate to envisage a more stable path ahead.



## CEO MESSAGE

Thank you to all those who supported the work of the GSNV in 2020.

It was a year that challenged us all but never have I been more inspired by the community that I work with, more proud of my team and more grateful to know and share my life with the people that I do.

As the year progressed, it felt like we were all working harder, the never-ending zoom meetings merged into one another and kept us trapped in chairs for hours on end. Sometimes it felt like Groundhog Day! It could not go on – but it did and so did we.

It was a year of the same and yet a year of different. We welcomed Hollie Feller to our team, said hello face to face and then didn't physically meet for almost a year. Not the usual GSNV welcome but the team was outstanding in it's support for each other and commitment to our community. We farewelled Keri for a year as she started a new chapter with her partner with the birth of Otis in January 2021.

The GSNV acted quickly to keep our community connected and to ensure that no-one was left behind. We removed our membership fee and have kept membership free so no-one was disadvantaged, we created opportunities for conversation, we facilitated connection and shared support through our Thursday Chatroom and projects like the C19 Journals project.

It was a rewarding year and when we reflected to plan our 2021, we were amazed at all our achievements. Whilst we focussed on connection, we did it purposefully collaborating with our GUARD colleagues to implement the Patient Pathways Program for people living with genetic, undiagnosed and rare conditions funded by the Australian Government and administered by the Centre for Consumer Directed Research. This program provides direct support to connect people to health and support services, to information and to the navigation pathways that can be so confusing.

We advocated for our community in the health, mental health and disability portfolios, we participated as representatives on the Mackenzies Mission Engagement Reference Group, the RDNOW project, The InGeNA Genomic Industry Alliance, the Victorian Clinical

Advisory Committee and the COVID-19 National Clinical Guidelines Taskforce Consumer Panel to name a few. We also represent Australia as part of the Asia Pacific Alliance of Rare Disease Organisations Board of Directors and as part of the Collaborative Global Network for Rare Diseases Panel of Experts. These national and international relationships are critical to achieve our goal of not duplicating work that is already going on and also to learn lessons from the work of others so we can optimise our resources across the sector.

In 2021, we will focus on implementing some exciting new programs aimed at alleviating some of the burden continually placed on support organisations. These will include: Share for Rare which will create a skills and resource bank for support groups at different stages of their lifecycle, Care for Rare which will focus on support and activities including mental health, NDIS and Ageing. We will continue to provide practical support with our amazing volunteer cohort who averaged more than 100 hours a month with support groups during 2020. They are an outstanding group of people who contribute generously with quality outputs and project support.

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. 2021 will see us continue to move forward and build on this strong foundation.

I'm looking forward to doing that together.



**Monica Ferrie**  
GSNV Chief Executive Officer

## COMMITTEE MESSAGE

As we all know, 2020 has been full of challenges and changes in the workplace. Despite all of this, the GSNV has demonstrated strength and adaptability by achieving so much this year.

The committee has been in full support of the GSNV staff and their incredible work. This year, we attempted a new approach by discussing different themes at each meeting. We had excellent discussions, informing future strategic planning and gaining valuable learning opportunities through sharing ideas and experiences.

Some highlights this year included a revamp of the GSNV website, My Genes and Me campaign, and hosting webinars for the Australian Society of Genetic Counsellors (ASGC) and the Australian Psychology Society (APS). We also welcomed four new committee members Giorgina Maxwell, Sean Ong, Kristiina Siiankoski and Natalie McCloughan.

I would like to thank my fellow committee members for their enthusiasm and contributions to the GSNV. On behalf of the committee,

I would also like to thank our valued members for their unwavering support.

Genetic healthcare is constantly evolving, bringing exciting opportunities. Now is the time for the GSNV to reflect, thinking to the future and how we can create positive change. We hope to see a genetic healthcare system that is equitable, providing support to those in need.



**Lucas Mitchell**  
GSNV Secretary

## WHO WE ARE

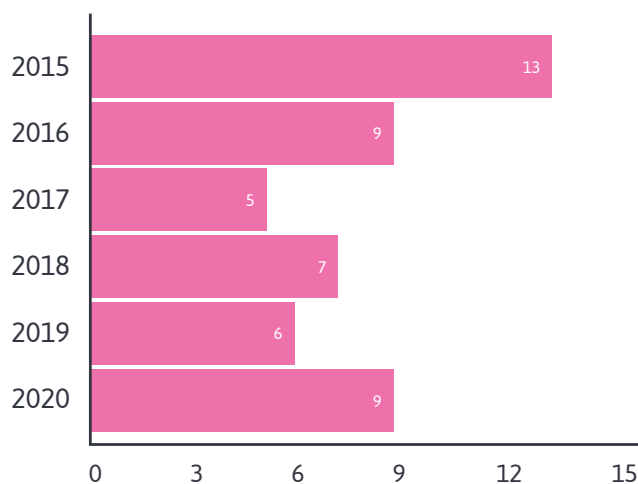
The members of the Executive and Committee who held a position at any time during or since the previous AGM are:

<b>President</b>	<b>Rachael Pope-Couston</b>
<b>Vice President</b>	<b>Rebecca Purvis</b>
<b>Treasurer</b>	<b>Chris Richards</b>
<b>Secretary</b>	<b>Lucas Mitchell</b>
<b>Committee Member</b>	<b>Marta Cifuentes-Ochoa</b>

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 NUMBERS 2015 – 2020

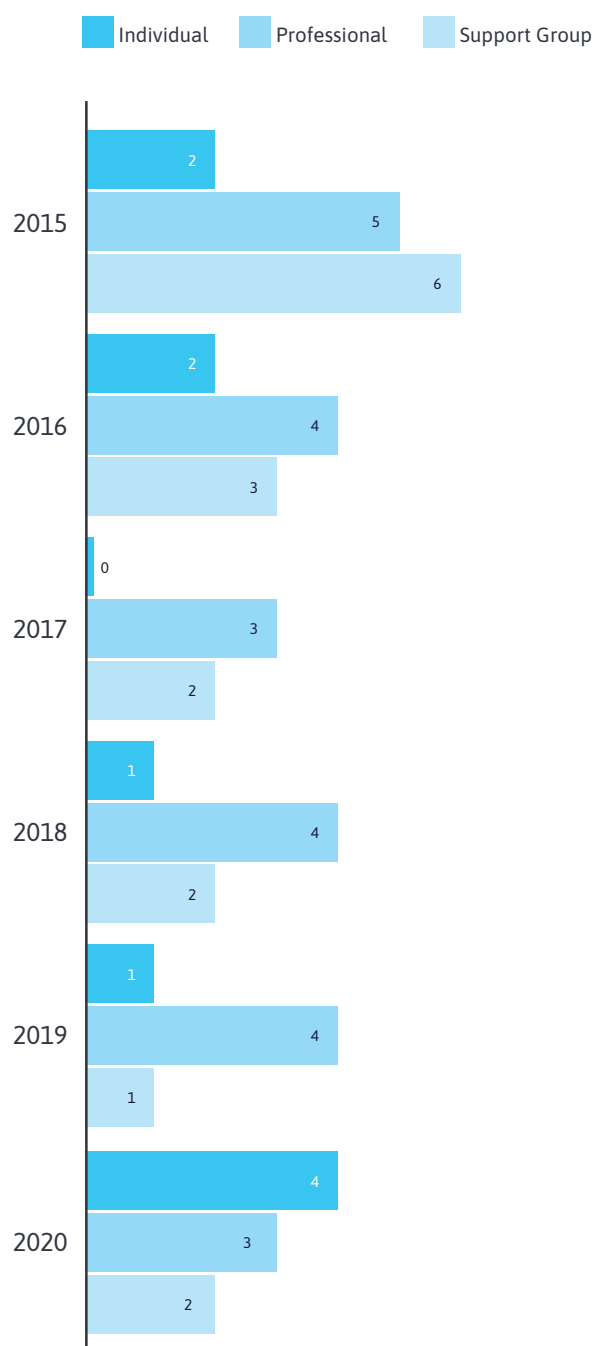


Being a committee member this year has made me acutely aware of the importance of “supporting the supporters”, especially during the difficult year our community has experienced. I hope we have been a supportive platform for the GSNV to continue delivering diverse activities with relevant stakeholders to make a difference in the everyday lives of people with genetic or rare conditions and their community.



The GSNV Committee includes thoughtful, enthusiastic and altruistic people who are genuinely invested in the community.

## COMMITTEE COMPOSITION 2015 – 2020



## OUR ORGANISATION

The GSNV is an organisation underpinned by values and principles. These impact both our priorities and practice. In 2020, as part of our strategic plan development, we reviewed our values and these remain unchanged.



## 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.

### Integrity

- We are ethical, tolerant and strive to deliver.

### 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.

### 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 FOCUS

We are committed to advocacy that drives:

- 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, in NDIS, of expertise, of care, of consideration, in research, in clinical trials, in treatment, in environment and in all things – with particular focus on disadvantaged communities including rural and regional Victoria, Indigenous, multi-cultural and refugee communities.
- Recognition and action to build mental strength for people with genetic, undiagnosed and rare 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 from local, State, National and international organisations.
- Active engagement and co-design opportunities for people with genetic, undiagnosed and rare conditions in policy, systems, research, clinical trials and projects.
- Our place as the Victorian peak support organisation for people with genetic, rare and undiagnosed conditions and those who support them.

These values and principles are also evidenced in the individuals who make up the GSNV team.

## THE GSNV TEAM

I would like to thank Louisa DiPietro, Keri Finlay, Kari Klein and Hollie Feller for their valued support, hard work, flexibility and agility and also an outstanding year of contribution.

The GSNV operated within our budget with a maximum of 2.0EFT (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 highlight the contribution of the volunteers over the past year.

They have been outstanding. The Committee would also like to recognise 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 his ongoing support and engagement.

### EFT ALLOCATION AS AT 31 DECEMBER 2020

NAME	POSITION	CLASSIFICATION	EFT
Monica Ferrie	Chief Executive Officer	PT	0.4
Louisa DiPietro	Education and Advocacy Strategist	PT	0.25
Keri Finlay	Genetic Support Coordinator	PT	0.4
Kari Klein	Project Assistant	PT	0.3
Hollie Feller	Administrative Assistant	PT	0.3
<b>TOTAL:</b>	<b>1.65</b>		
<b>TOTAL Budgeted EFT:</b>	<b>2.0</b>		

## OUR MEMBERS

In 2020, a year of increased hardship for some of our members and their communities the GSNV Committee of Management, together with the GSNV made a decision to make membership free for 2020 and to review in 2021. We wanted to ensure that everyone who wanted to, could access our resources, join our discussions and connect in whatever way they needed.

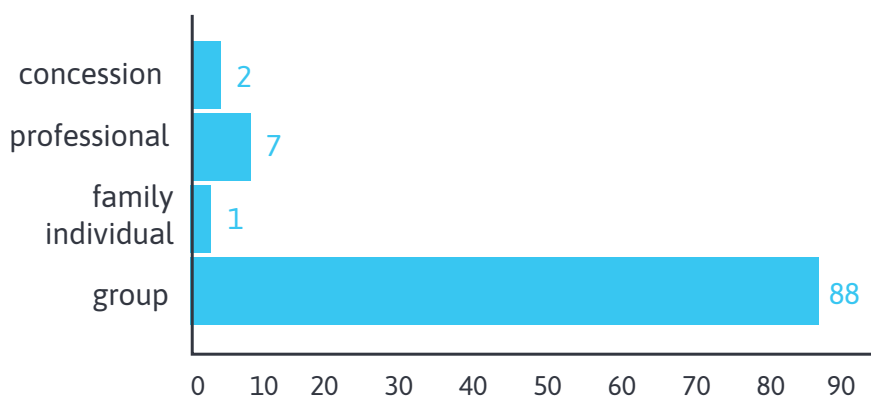
As a result, we experienced an increase in membership and ongoing engagement with groups not previously connected to us. We are thrilled to have been able to support more broadly and to be learning from and engaging with both new and previous GSNV members.

The GSNV would like to say a huge thank you to all members, consumers, stakeholders and professional affiliates.

GSNV membership offers the opportunity to gain access to the Genetic Link, a portal holding resources, information and access to skills for families, communities, health professionals and support organisations. Membership also ensures engagement and representation in areas that are important to our community and access to our GSNV Volunteer Program.

**The GSNV  
currently has 98  
members and 531  
individuals on our  
mailing list**

## ACTIVE MEMBERS COMPOSITION 2020



## OUR VOLUNTEERS

Our volunteer 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, project assistance and more.

## THE GSNV VOLUNTEER PROGRAM

We currently have **46 volunteers** and approximately **16 support groups** that have been assisted by volunteers. 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 2020 were:

VOLUNTEER ORGANISATION (OR PROJECT)	VOLUNTEER MATCH	ACTIVITY
UsherKids Australia	3	Usher in Focus Webinar Series; develop social media templates
Spinal Muscular Atrophy Australia	1	Updating patient experiences booklets
SCN2A Australia	2	Help write information packs for families and clinicians
Leukodystrophy Australia	2	Helping edit new website
EHE Rare Cancer Foundation	1	Assist with genomic collection study
Syndromes Without A Name	2	Create a Maternal Health and interstate, special school and ECIS database
Australian Sickle Cell Advocacy Inc.	2	Help plan for Sickle Cell Awareness month

“

The opportunity to continue work for support groups remotely has been fantastic for allowing flexibility in volunteering during the craziness of 2020. If I had one hope for the future, (post-coronavirus restrictions), it would be allowing that kind of work to continue so that people who live further outside of Melbourne could lend helping hands more easily.

”

“

It is good to have the option of things which can be completed remotely from home, like my current volunteer role with SWAN as I can balance this with my part time job and not have to worry about travel and coming in.

”

“

I understand the difficulty of coordinating a volunteer program with a pandemic going on, but GSNV has done an absolutely incredible job keeping the program going in whatever capacity is possible.

”

“

I love the personal attention and support given by the GSNV staff to every volunteer and their project!

”

“

Well organised, flexible and understanding. Great program and can't wait to volunteer more in the future.

”

“

It's been wonderful so far! Such a supportive community, it's been really enjoyable and great to meet so many inspiring people and help out here and there.

”



## CORPORATE GOVERNANCE

The GSNV commenced 2020 with 5 committee members. We were absolutely delighted to welcome Marta Cifuentes Ochoa, (a volunteer with GSNV) to the Committee in January 2020. The Committee remained committed to strengthening the Board and improving diversity. To welcome new people to the Committee, a plan was endorsed to invite a Support Group representative and a volunteer representative to strengthen our pool of potential Committee members and also to model good Committee governance.

As the level of interest was strong, we welcomed four new Committee members for an annual placement with our Committee. Natalie McCloughan from the Childrens Tumour Foundation, Kristiina Siiankoski from MRKH Australia joined our Committee and Giorgina Maxwell and Sean Ong joined the Committee from our wonderful volunteer cohort. This has been a really successful initiative and will be continued in 2021.

At our Annual General Meeting, we were also sad to lose a long-term member of the GSNV Committee, Anna Jarmolowicz. Anna served the GSNV community for many years and continues to serve our community as a genetic counsellor. We also welcomed a new President, Rachel Pope-Couston and a new Secretary, Lucas Mitchell.

Strong governance continues to remain a focus and all relevant policies were reviewed and updated accordingly.

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

In 2020, the GSNV Committee of Management moved all meetings to zoom and has met on the third Tuesday of each month. This will continue in 2021. 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.

**2020 saw 4  
new Committee  
members join  
from our wider  
community  
bringing diversity  
from support  
groups and  
volunteers**





in 2020.  
we wanted  
to ensure  
that everyone  
who wanted to,  
could access our  
resources, join our  
discussions and connect  
in whatever way they  
needed.



1



GSNV SMALL  
GRANT AWARDED

2



SUPPORTING THE  
SUPPORTERS  
EVENTS HELD

531



GSNV NEWSLETTER  
SUBSCRIBERS

46



GSNV VOLUNTEERS

41



WEEKLY VIRTUAL  
COMMUNITY OPENLINE  
AND CO-WORKING  
SESSIONS

10



GENETIC HUB  
BULLETINS SENT OUT

500



ENQUIRIES

1000



HOURS OF  
VOLUNTEER  
ASSISTANCE

98



GSNV MEMBERS

1,560



MINUTES OF ENQUIRY SUPPORT

822



FACEBOOK LIKES

609



TWITTER  
FOLLOWERS

214



INSTAGRAM  
FOLLOWERS

6,502



YOUTUBE VIEWS

21



LINKEDIN PAGE  
VIEWS

# YEAR IN REVIEW

A snapshot of what our year included:



## Sector and Consumer Representation

- Our community; people living with genetic, undiagnosed and rare conditions and those who support them
- All Victorian Clinical Genetics Services
- Department of Health and Human Services
- GUARD Collaborative Australia
- Genomics Clinical Advisory Group - Victoria
- Australasian Institute for Digital Health – Precision Healthcare Steering Committee
- Human Genetics Society of Australasia
- Australian Genomics
- Melbourne Genomics
- InGeNA- Genomics Industry Genomics Alliance
- Mackenzie's Mission Engagement Reference Group
- RDNOW Consumer Engagement Committee
- National COVID-19 Clinical Guidelines Taskforce – Consumer Panel
- WHO Collaborative Global Network for Rare Diseases (CGN4RD)
- Rare Disease International (RDI)
- Asia Pacific Alliance of Rare Disease Organisations (APARDO)
- Royal College of Pathologists Lay Committee (RCPA) Lay Committee
- Carrier Screening Reference Group
- Health Navigation Hub
- Deakin University Faculty of Health - Consumer and Research Network
- Research Australia
- Consumer Health Forum
- Rare Voices Australia
- Victorian Council of Social Services
- Women With Disabilities Victoria
- The George Institute – Join Us Project
- Rehabilitation Psychology for Injury, Chronic Illness and Pain Interest Group
- Centre for Consumer Directed Research



## Consultations

- GSNV Strategic Plan for 2021- 2023
- NSW Genomics Framework Consultation
- Direct to Consumer Genetic Testing Consultation
- National Consent Form Consultation



## Submissions

- Parliamentary Inquiry into approval processes for new drugs and novel medical technologies in Australia
- MSAC guidelines review and PBS submissions and letters of support
- Submission to Victorian Parliamentary inquiry on Impact of Covid - 19



## Conferences & Webinars

- EURORDIS (Rare Disease Europe) Annual Meeting of Patient Organisations
- Asia Pacific Alliance of Rare Disease Organisations Annual Meeting
- Health Informatics Conference
- Human Genetics Society of Australasia
- Australian Genomics Forum
- European Conference on Rare Disease
- Rare Disease International Global meetings
- Women with Disabilities webinar “Right to safety”
- Global Genes Conference
- Social prescribing webinar
- Consumer Health Forum Conference
- Assessing Rare Disease Awareness and Management in Asia-Pacific”
- Australian Institute of Digital Health (AIDH) Digital Health Live : Living and learning during a pandemic a consumer perspective
- Aged Care Industry Information Technology forum on national healthcare

# HIGHLIGHTS FROM A PRODUCTIVE YEAR



## National Strategic Action Plan for Rare Diseases

GSNV was part of the steering committee for the development of the Department of Health National Strategic Action Plan for Rare Diseases. This plan was launched in February at Parliament House and provides a policy framework and recommendations for the sector to implement. The GSNV has provided a report card to the Federal Minister for Health and Victorian Minister for Health on our 2020 progress with the recommendations.



## Genomics in Schools

Our Genomics in Schools project advanced in 2020 but was then put on hold with the ongoing uncertainty faced by our education system. We presented a number of schools who have expressed an interest in engaging their students in this program. Two case studies were completed in 2020 ready for roll out in 2021.



## Genomics in Practice

We are extremely grateful to 5 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. This unit was delivered virtually in 2020, vastly different than in previous years. Both organisations and students found this to be an incredibly valuable experience with overwhelmingly positive feedback. We were thrilled to hear in student presentations that many felt that their practice would be positively impacted by what they had learnt. Students also completed an additional project reflecting on the impact of the pandemic on the organisations of their placement.



## International, National and Local Networking

We continued building relationships at all levels in 2020. In the international arena, we are active members of Rare Disease International, the European Rare Disease Organisations network (EURORDIS) and sit on the Board of Directors of the Asia Pacific Alliance of Rare Disease Organisations (APARDO). We are also active in international projects such as the Collaborative Global Network for Rare Disease (CGN4RD) and participated in World Economic Forum and Asia Pacific Economic Cooperation webinars and workshops. In Melbourne, we continued to work with Australian Genomics, Melbourne Genomics, Genetic Alliance Australia in NSW, Genetic and Rare Disease Network in WA, Syndromes Without a Name (SWAN) through our national collaboration – GUARD Collaborative Australia. We also broadened our relationships and representation as part of the genomics industry alliance InGeNA, the National COVID-19 Clinical Guidelines Taskforce Consumer Panel and Join Us Registry. We continued to chair the Mackenzie's Mission Engagement Reference Group and actively engage in project advisory committees such as RDNOW and steering committees such as the Australasian Digital Health Agency Precision Healthcare Steering Committee.



## Wellness Week

In such a strange year, we remained concerned with the impact of the pandemic and isolation, 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, in 2019, this training was expanded to a group of 16 support group leaders. In 2020 we supported another 12 organisations to attend virtually as part of our wellness week in November.

Wellness Week also included Peer Support Training, a Right to Safety workshop facilitated by Women with Disabilities Victoria, the launch of the Mental Health Working Group and Psychologists database and an NDIS workshop. All events were well attended and we received excellent feedback.



## Rare Disease Day

February 28th was international Rare Disease Day and we hosted a great event focussed on activating and empowering the genetic, undiagnosed and rare disease community to be effective advocates to deliver fair and equitable access to testing, treatment, research and/or clinical trials. We also launched the RDNOW program and showcased the Mackenzie's Mission Carrier Screening Research project.



## Lived Experience Interviews

In 2019, we broadened our Lived Experience Series. This connected us to some amazing individuals to whom we are very grateful. These wonderful people 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. These videos have been used by the GSNV at events and in 2020 has expanded into the Putting Patients at the Centre Project which will launch in June 2021.



## Margaret Sahhar Grant

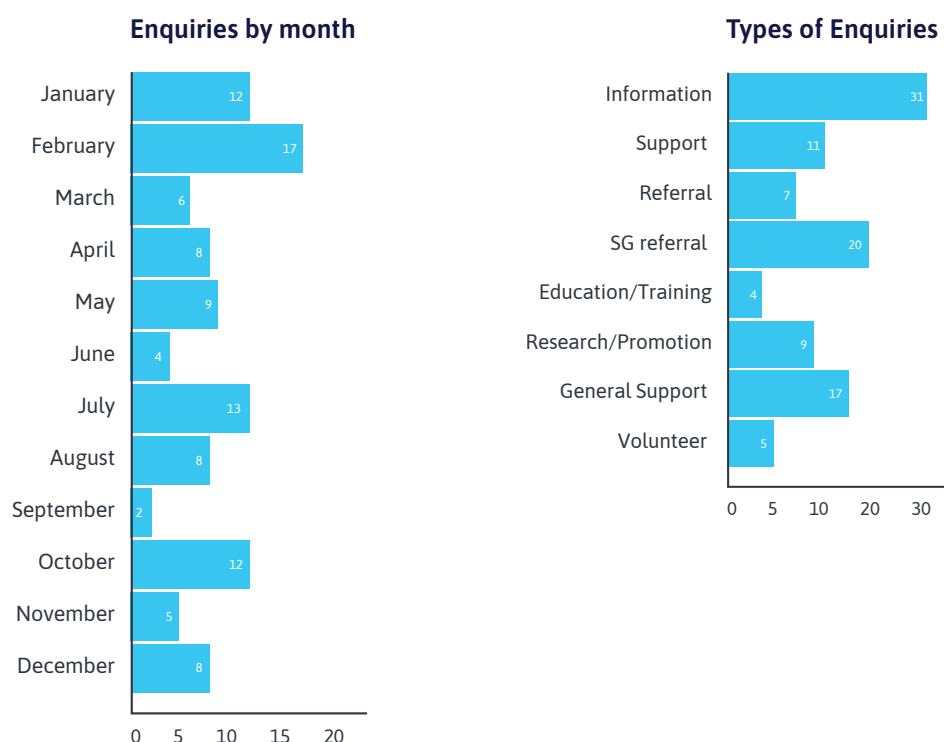
In 2020, the Margaret Sahhar Grant was awarded to PCD Australia Inc. The grant was awarded to support PCD's 'Making Pictures' project. We hope to be able to share both the process undertaken by PCD and the end result as this would be a valuable resource for other support groups.



## 2021-2023 STRATEGIC PLAN DEVELOPMENT

The development of the strategic plan occurred over 6 months. More than 30 meetings were held with stakeholders around key topic areas. We were thrilled with the level of engagement and the depth of discussion at each meeting. We could not have developed our new plan without this engagement and are grateful to all those who participated. We have a really strong and clear direction to guide our work over the next three years.

### 2020 Enquiry Breakdown



### 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 have assisted a number of groups including the following:

- Children's Tumour Foundation
- Muscular Dystrophy Australia
- Leukodystrophy Australia
- Ovarian Cancer Australia
- Syndromes Without A Name
- The Aussie Hands Foundation Inc.
- SMA Association of Australia
- UsherKids Australia
- Australian Alopecia Areata Foundation
- Australian Sickle Cell Advocacy Inc
- Fanconi Anaemia Support Australasia
- Fragile X Association of Australia
- PCD Australia
- SCN2A Australia
- EHE Rare Cancer Foundation
- Fanconi Anaemia

## EDUCATION

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

**Professional | Community | Students**



### Professional

#### MCHN Conferences

In 2020 the State-wide Maternal Child Health Nurse conferences were pivoted to take place as a virtual exhibit in October 2020. The GSNV was represented through the inclusion of flyers and information brochures covering the services offered by our organisation. A summary flyer was distributed through the exhibition website to advise nurses how the GSNV could assist them with supporting their families with genetic conditions.



### Community

#### Wellness Week (GSNV 5 Days to Wellness Event) November, 2020

Over the course of 2020 the need for connection as a human condition became ever more so apparent- we all sought it and needed it. Wellness Week sought to bring this connection to our community virtually in the form of education. It heralded the launch of our 'Care for Rare' initiative. The week-long event provided the community with Peer Support Training, a Right to Safety workshop facilitated by Women with Disabilities Victoria, the launch of the Mental Health Working Group and Psychologists database and an NDIS workshop. The positive feedback and participation rates have encouraged us to look at a version for 2021.



### 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:

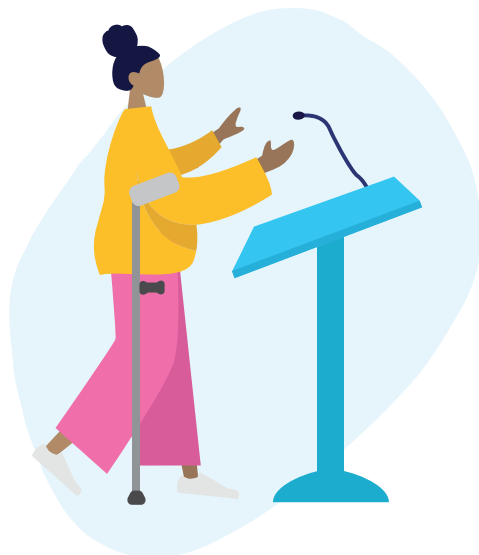
- Develop an understanding of the multidisciplinary nature of health care
- Demonstrate an understanding of how support organisations can be incorporated into genetic health care
- Demonstrate an understanding of the impact of disability on an individual and their family

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 groups of four. This year the placements were undertaken virtually with each support group having the autonomy to direct the placement and communication with the students in the most practical way for their organisation. The feedback from both students and support groups was extremely positive given the new circumstances and proved to be a successful interpretation of the previous years.

The Community Placement program offers an opportunity for the support sector to plug into professional 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.





**“My virtual remote internship with the GSNV has been one of the positives that has come from the pandemic period. This internship has allowed me to gain experience and enhance the skills that I will need in the future. I am extremely thankful for this opportunity and could not have worked with a better organization!”**

## POST GRADUATE INTERNSHIPS

In 2020 the GSNV entered into partnership with International Studies Abroad to bring a Postgraduate student to work on research related projects at the GSNV. With the onset of the global pandemic the students were unable to come to Australia for this internship and we took a virtual placement to provide assignments within the students field of study.

Malia Buyan from the Lutheran Catholic University in California joined the team in May 2020 as the research assistant on a collaborative project with Australian Genomics - Covid-19 and the lived experience of the Genetic, Undiagnosed and Rare Disease Community. The placement was extended to run for 12 months in total so she could see the research through to its evaluation and conclusion in May 2021.

# WEBSITE, DATABASE AND SOCIAL MEDIA

Social media was pivotal in 2020 to connect communities together in a time of lockdown and isolation during the height of the pandemic.

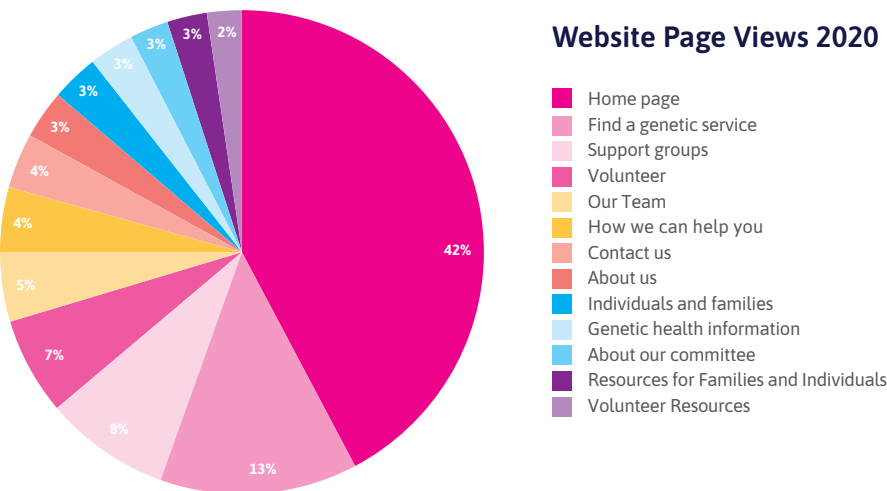
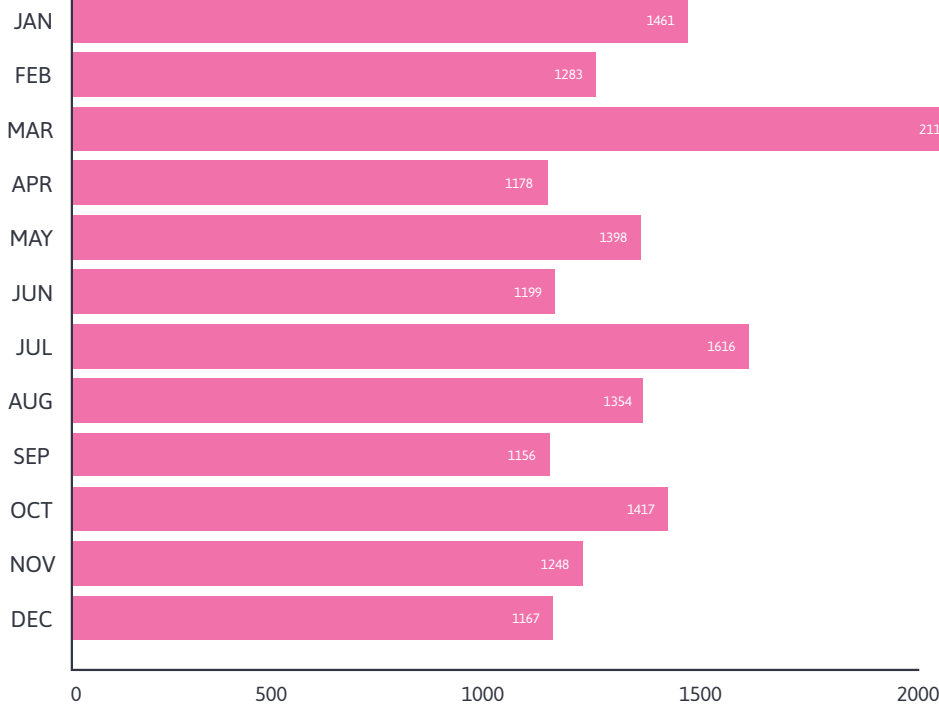
It was used as an important tool in reaching our community with what is in the media in regards to news, research, events and sharing what information is within our network.

In 2020 the GSNV used social media to advise on public health messages relating to Covid- 19 restrictions locally in Victoria, highlight our community events and information. Facebook was the most significant platform during this time with the ability to link our community with national and international surveys and webinars throughout the year.

Social media has been incorporated into the GSNV communications policy, using the most influential platforms of Facebook, Twitter, Instagram and YouTube. The GSNV seeks to follow trends on social media and has over 600 followers on twitter and nearly 1000 followers on Facebook, which is 200 more than in 2019.

For 2021 a scheduling app will be implemented to coordinate the posts for all social media and increase the frequency with which we post and reach our audience. The increase in exposure and content on our Youtube channel will be a focus for 2021 as well.

Number of Website Views By Month 2020



Number of Website Views

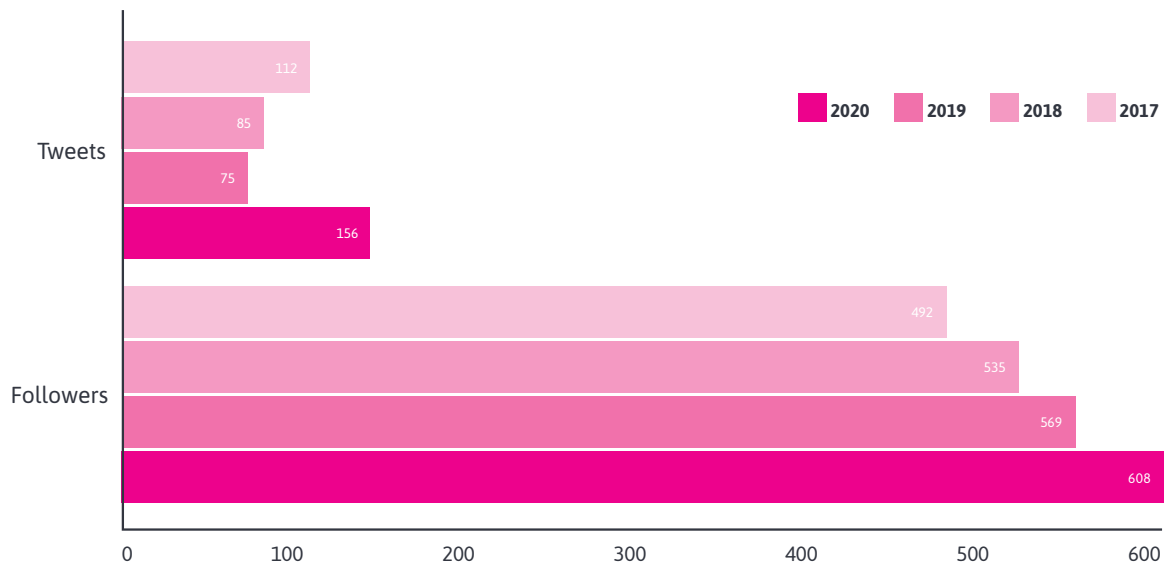
19,124	17,093
2016	2017
22,996	19,741
2018	2019
15,694	
2020	



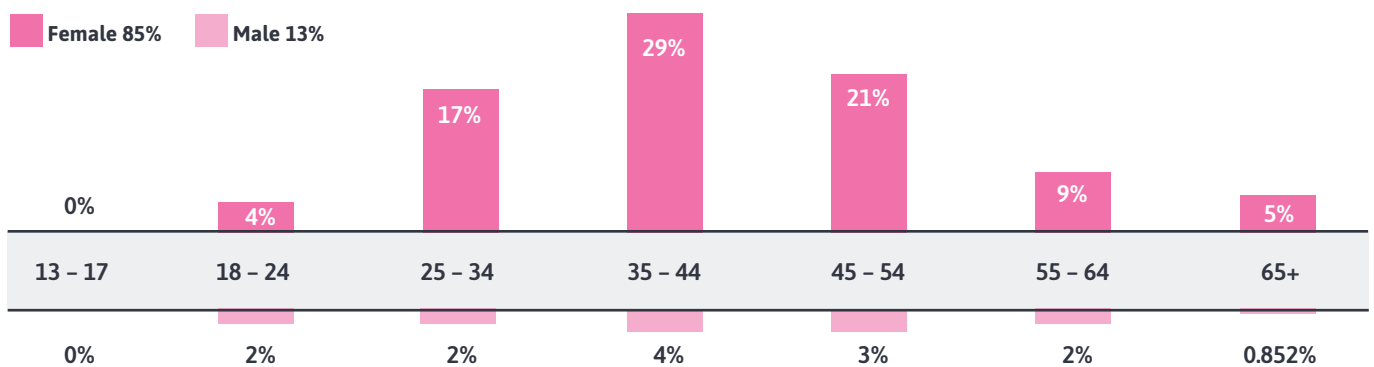
# WHO ARE WE REACHING ON FACEBOOK & TWITTER?



## Twitter Reach & Followers



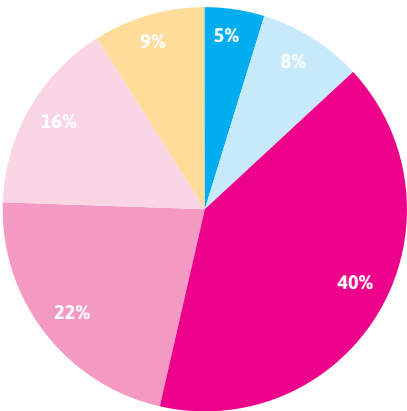
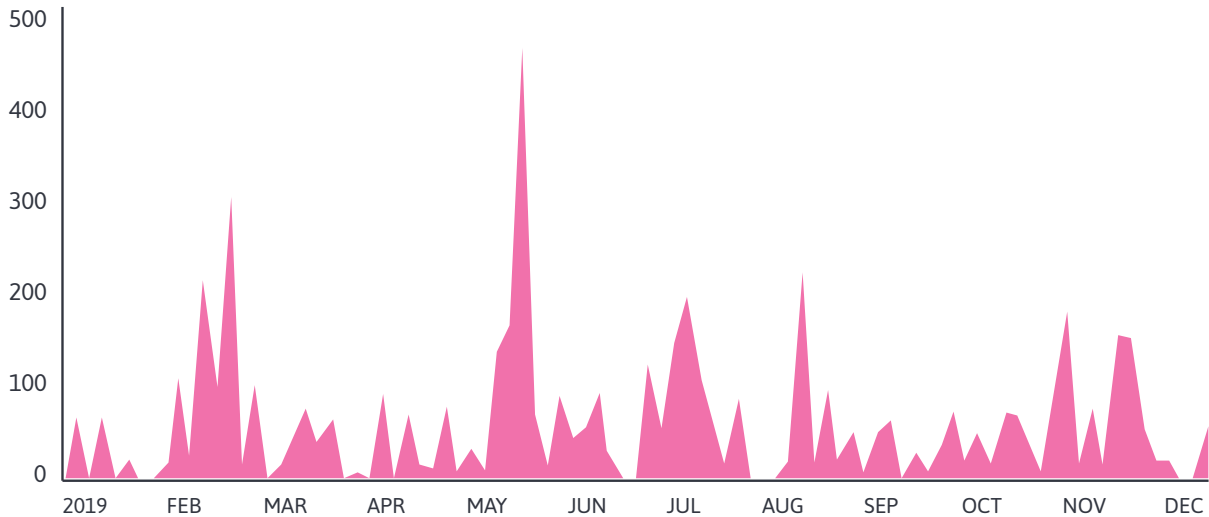
## Facebook Audience Gender and Age Breakdown



# FACEBOOK AUDIENCE AND REACH cont.



Facebook Post Reach 2020



## Types of Facebook Posts

- GSNV events and announcements
- Surveys
- Covid 19 - health announcements
- Community Events and webinars
- Support group info / Shoutouts / Awareness days
- Mental health Support

Performance for Your Post

948

People Reached

43

Likes, Comments & Shares

29

Likes

5

On Post

24

On Shares

4

Comments

0

On Post

4

On Shares

10

Shares

9

On Post

1

On Shares

26

Post Clicks

0

Photo Views

9

Link Clicks

17

Other Clicks

NEGATIVE FEEDBACK

0

Hide Post

0

Hide All Posts

0

Report as Spam

0

Unlike Page

Reported stats may be delayed from what appears on posts




# THANK YOU

We appreciate and value your gifts of time, perspective, talent, expertise and knowledge. We thank those who have donated and those that continue to offer support to us, our community and each other.

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.





**We remain  
extremely grateful  
for the continued  
grant funding from the  
Department of Health and  
Human Services, which allows  
us to continue our great  
work.**

# FINANCIAL REPORT

On behalf of the executive and committee of the GSNV I am pleased to report the financial details for the financial year 1 January 2020 – 31 December 2020. The GSNV continues to manage its budget well and will carry forward a surplus into 2021. Despite the many challenges presented by the pandemic, the GSNV was able to continue delivering on their business plan, and savings were realised accordingly through reduced traveling and other expenses.

As part of our agreement with VCGS our accounts are audited by KPMG who are the external auditors for VCGS. The report findings can be found below and concluded that the GSNV accounts were in order.

We remain extremely grateful for the continued grant funding from the Department of Health and Human Services, which allows us to continue our great work. The GSNV continues to responsibly manage its finances under guidance from the committee, which places us in an excellent position to support those we serve in the coming year.





# STATEMENT OF INCOME AND EXPENSES

STATEMENT OF INCOME & EXPENSES FOR THE MONTH ENDED 31/12/2020

70680 GENETIC SUPPORT NETWORK (V)

	Budget	Year To Date Actual	Variance
<b>INCOME</b>			
DHS GRANT	219,302.40	226,598.91	7,296.51
OTHER INCOME	11,000.04	9,753.77	-1,246.27
<b>TOTAL INCOME</b>	<b>230,302.44</b>	<b>236,352.68</b>	<b>6,050.24</b>
<b>EXPENDITURE SALARIES &amp; WAGES</b>			
Gross Salaries	230,302.44	236,352.68	6,050.24
Other Employment Costs	0.00	84.50	-84.50
Provn of Employee Entitlements	5,055.60	1,635.53	3,420.07
Superannuation	9,605.52	9,230.39	375.13
Work Cover	1,011.12	0.00	1,011.12
<b>TOTAL</b>	<b>119,333.40</b>	<b>104,627.54</b>	<b>14,705.86</b>
<b>CONSUMABLES</b>			
Administrative Expenses	102,306.46	99,632.63	2,673.83
Telephone Expenses	0.00	355.13	-355.13
Laboratory Expenses	0.00	394.10	-394.10
Infrastructure Costs	2,109.36	2,109.36	0.00
Computer Expenses	500.04	253.55	246.49
<b>TOTAL</b>	<b>104,915.86</b>	<b>102,744.77</b>	<b>2,171.09</b>
<b>TRAINING &amp; TRAVEL EXPENSEES</b>			
Travelling Expenses	6,000.00	1,096.48	4,903.52
Staff Training	0.00	180.84	-180.84
<b>TOTAL</b>	<b>6,000.00</b>	<b>1,277.32</b>	<b>4,722.68</b>
<b>TOTAL EXPENDITURE</b>	<b>230,249.26</b>	<b>208,649.63</b>	<b>21,599.63</b>
<b>ACCOUNTING SURPLUS/(DEFICIT)</b>	<b>53.18</b>	<b>27,703.05</b>	<b>27,649.87</b>



### **Audit Statement**

I confirm that the funds belonging to Genetic Support Network of Victoria are being held by the Victorian Clinical Genetics Services (VCGS).

The accounts of the VCGS are audited annually by KPMG who are our External Auditors. The accounts for 2020 have been audited by KPMG in accordance with this practice.

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

Kind regards,



**David Mylonas CPA, CGA**

VCGS Finance Manager

Murdoch Children's Research Institute /

Victorian Clinical Genetics Services





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