

gsnv

Genetic Support  
Network Victoria

# ANNUAL REPORT 2021

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



The 2021 GSNV Annual Report cover photo was taken at the first 'Rare Event' held at Parliament House on Feb 22nd 2022. The event marked Rare Disease Day and brought together members of Parliament, GSNV staff and representatives from the genetic, undiagnosed and rare disease community.

All persons included in this photo have given their permission for the image to be published.

*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 2021 to the financial year ended 31 December 2021.**

As we reflect on the year in review, 2021, we will highlight some of our major achievements, challenges and outcomes, including an overview of governance and financials.

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**Campus partner of** Murdoch Children's Research Institute

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# 2021 – A YEAR OF RESILIENCE AND DETERMINATION

**As I started to write this, I reflected on what I had written for our 2020 annual report and how relevant it remained for 2021. We finished 2020 with such hope.**

It would have been so easy to have become focussed on self and survival, to succumb to pandemic fatigue and simply see the year through. That's not what happened.

Again the genetic, undiagnosed and rare disease community reached out to each other, connected to the support available and was simply there, refusing to settle for where the wind would blow them and took responsibility for setting the sails. It is with deep pride and a sense of privilege that the GSNV presents our 2021 annual report.

Together with our colleagues in GUARD Collaborative Australia, (Genetic Alliance Australia – NSW, Genetic and Rare Disease Network – WA and Syndromes Without a Name – SWAN) we reached out to support our community, to connect with our national and international colleagues and community and to learn from each other. Our community, across the globe, recognised that as the pandemic unfolded, we needed to stand together, united for positive change.

This culminated in the first ever resolution passed by the general assembly of the United Nations for people living with rare disease in December 2021. The resolution states that 'It is the right of every human being, without distinction of any kind, to have access to the enjoyment of the highest attainable standard of physical and mental health and to a standard of living adequate for the health and well-being of oneself and one's family.' This forms the blueprint for our work and how we will measure our impact into the future.

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

Our vision and mission were reviewed in 2020 through 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

**2021 began with such hope and a sense of lingering fatigue as we came to terms with another year that impacted our emotional, physical and mental health. For the GSNV and our community, it wasn't simply a case of moving on.**

2020 had a residual effect, everyone was tired. Everyone was committed to 2021 being different and brought hope and excitement but the challenges of 2020 couldn't and wouldn't just be forgotten.

It didn't take long before the memories of 2020, became the reality of 2021. We went back to working from home, to endless zoom meetings, to connecting with friends and family at a distance, to cancelling holidays and focussing on what we could achieve, how we could connect and how to make a difference long distance. And again the community rallied.

We continued to focus on the Department of Health National Strategic Action Plan for Rare Diseases and to ensure that the work of the GSNV and Victoria contributed to the implementation of the plan. The pillars of Awareness and Education, Care and Support and Research and Data remain relevant and there is still much to do. We have kept the federal and state Minister for Health informed about our work and received positive support and feedback. We also continued to issue a mid-year and end of year report to all our stakeholders.

Most of the year found us working from home with a very short period in April/May where we were able to work from our office, this time we knew how hard the disconnect would be, how weeks could stretch into months and what had worked for us in 2020. Preparation didn't make it easier but it did make us able to plan and restructure our workload and also to review our expectations.

As the year progressed, we delivered projects of significance such as Genomics in Schools, our Practical Wellness month and A Day in the Life series with the Australian Psychology Society, our research into Live Well Interventions, Newborn Screening Advocacy and we also convened our mental health working group. We continued our collaborative work with patient support groups, Department of Health, genetics clinical hubs, InGeNA – the Genomics Industry Alliance, Australian Genomics and others but stepped back from projects that would put additional pressure onto patient support groups or people living with genetic, undiagnosed and rare conditions.

As in 2020, our community continued to achieve, to support and to make their voices heard. GSNV and GUARD Collaborative Australia completed many submissions and engaged in consultation and representation around the National Medicines Policy review, the Inquiry into approval processes for new drugs and novel medical technologies in Australia, Submissions to National Disability Insurance Scheme, Medical Services Advisory Committee (MSAC) applications and Pharmaceutical Benefits Advisory Committee (PBAC) applications and more.

2022 loomed with promise and expectation and again as we planned and readied for the new year, the legacy of COVID-19 and its impact on our community lingered. We made our plans underpinned by values re-confirmed as so important for our community: kindness and compassion; agility and flexibility; collaboration and cooperation. We know that collaboration is key, we know that we must all work together with all our stakeholders to ensure the translation of the UN resolution – to truly bring to reality that it is the right of every human being, without distinction of any kind, to have access to the enjoyment of the highest attainable standard of physical and mental health and to a standard of living adequate for the health and well-being of oneself and one's family.





## CEO MESSAGE

Thank you to all those who supported the work of the GSNV in 2021, to all who engage with us in conversation, exploration and genuine interest, to those who offered and provided guidance and support, to those who listened and shared, to those who attended and were generous of their time and spirit, to those who gave us feedback and ideas, who challenged and made us better. You are all part of the GSNV family and our story – we serve you all and appreciate you and all you do.

Many of you who know me, know that I am a student of history. And history has shown us over and over that no-one survives on their own, no community survives on its own.

Individuals need families and communities, communities need culture. We are a community and we create our culture. We can choose the culture we create. Culture is connection, the things that bind us together, the choices that we make. So let's choose how we go forward. Let's choose how we change the lives of 500,000 Victorians and 2,000,000 Australians, people living with genetic, undiagnosed and rare disease. Let's build a culture of equity of access and opportunity. We simply cannot tolerate anything less.

Together we are the agents of positive change. We are a community, we have patient support group leaders, we have our parliamentary representatives, we have health professionals, we have researchers, we have industry. Another lesson of history – sustainable growth is the result of webs of collaboration, networks. It's up to us. None of us can do it alone.

Everyday we don't go forward, is a day we go backwards. It is a day where lives are lost, where possibilities decline.

Thank you for being part of a new future for the genetic, undiagnosed and rare disease community.

I look forward to sharing the collaborative space with you all.



*Monica Ferrie*

**Monica Ferrie**  
GSNV Chief Executive Officer

## COMMITTEE MESSAGE

As a committee, we have been reflecting on 2021 and the impact ongoing changes have had in everyone's lives. As in earlier years, The GSNV has demonstrated adaptability and through collaborative efforts exceeded their goals for the year. This year GSNV has had significant changes in their internal structure; we have witnessed a smooth transition and can proudly say the changes haven't affected the work that GSNV does, both in quality and quantity.

The committee has also been working alongside The GSNV to maintain a strategic focus. We continued the successful structure of having themed meeting discussions which allowed us to have productive and in depth conversations where everyone is able to contribute. One of the most important topics to come out of the strategic committee discussions is the need for more people with rare conditions to be connected to relevant support groups by genetic health professionals. To do this, a focus needs to be on developing ways to convey support group information to genetic health professionals in a way they can trust is up to date and can help them assess the group that will be of benefit to the individual. Exciting ideas and discussions in this space are ongoing as a focus for the rest of 2022 and into 2023.

The committee has experienced some changes since the last report. We were sad to lose two long-term members of the GSNV Committee, Chris Richards at our 2021 AGM and Lucas Mitchell in January 2022. Chris has served the GSNV community for many years, starting as a volunteer, and joining the Committee as Treasurer in 2018. Lucas has also served the GSNV community for a long period, starting as a volunteer, joining the Committee, and taking the role of Secretary for two years. Lucas has a new role as a genetic counsellor in research. We wish Chris and Lucas all the best in their future ventures.

We also welcomed two new committee members Julie Cini, founder of SMA Australia, and Radi Breed, genetic counselling graduate involved in research. We also welcomed our new treasurer, Giorgia Maxwell and new Secretary, Marta Cifuentes Ochoa.

We would like to thank our fellow committee members for their enthusiasm and contributions to The GSNV and we look forward to another positive and productive year.



*Marta Cifuentes Ochoa*  
**Secretary**



*Rachel Pope – Coustan*  
**President**

# 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>	Rachel Pope-Couston
<b>Vice President</b>	Rebecca Purvis
<b>Treasurer</b>	Giorgina Maxwell
<b>Secretary</b>	Marta Cifuentes Ochoa
<b>Committee Members</b>	Sean Ong, Lucas Mitchell, Julie Cini, Radi Breedt, Kristiina Siiankoski, Natalie McCloughan

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.

– Being part of the GSNV Committee has enriched my understanding of the experiences and needs of patients and their families, carers and support organisations, influencing my clinical and research practice.

*Rebecca Purvis,  
Vice President*

– I am extremely grateful for the opportunity GSNV has given me to stay connected to this field I am very passionate about. It is fantastic being a part of an organisation that advocate for people, families, support networks and organisations in this field as they are usually underrepresented.

*Sean Ong  
– GSNV Committee Member*

# 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 ORGANISATION

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

In 2021, as part of our strategic plan development, we reviewed our values and these remain unchanged. This annual report reflects how we live our values.





# CORPORATE GOVERNANCE

The GSNV commenced 2021 with 8 committee members. The Committee remained committed to strengthening the Board and improving diversity.

We welcomed two new Committee members for an annual placement with our Committee. Julie Cini from SMA Australia and Radostina Breedt joined the Committee from our wonderful volunteer cohort.

As the year progressed and external pressures and opportunities impacted, we were also sad to lose a wonderful member and Secretary of the GSNV Committee, Lucas Mitchell. Lucas served the GSNV community for two years and continues to serve our community as a genetic counsellor.

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.

GSNV Committee of Management convenes all meetings to zoom and has met on the third Tuesday of each month. This will continue in 2022 although we hope to have a least one face to face meeting. 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.

## GSNV VOLUNTEER PROGRAM – REFLECTIONS

At the GSNV we maintain a strong commitment to community, collaboration and connectedness.

These values underpin much of what we do and inspires how we do it. Much of our community understands the enormous value and contribution to be made by volunteers. That ready body of 'unpaid workers' who contribute and share their skills so generously. It's no secret that helping others and contributing to one's community through positive, impactful action makes people feel good. For GSNV volunteers (predominantly made of students, post grads and training professionals), spending some time volunteering can be especially beneficial in a variety of ways.

The GSNV volunteer program provides us with strong evidence that supporting others reaps many benefits spanning across health, community and even career prospects. As GSNV volunteers make new connections and learn skills to advance their career and outlook, they invariably strengthen ties to the genetic, undiagnosed and rare diseases communities (GUARD) and broadens their own professional and support network.

Some of the advantages of volunteering with the GSNV:

### **Improve mental health and wellbeing:**

The life of students and training professionals can be very busy. As trainees learn to manage their schedule and become more independent, outside of the classroom experiences like volunteering can help improve time management skills and emotional well-being.

### **Social Good:**

One of the greatest benefits of being a GSNV volunteer is simply the rewarding act of helping others. Volunteering may also provide the opportunity to give time and talents to support a cause that's important to the volunteer or those they know.

### **Community Building and Expanding Networks:**

Networking is an important part of building a career. By volunteering and working collaboratively with others, GSNV volunteers can meet and work with people who share common interests, expanding their overall network of diverse mentors and peers.

It's these new connections — other change-makers, volunteers, employees, support groups (SG) members and SG Boards/Committees that can motivate and inspire them and even open up some professional doors in the future. GSNV volunteers may have the opportunity to do good for the GUARD community but also for their own future growth and career prospects.

### **Establish Career Goals:**

Volunteering with the GSNV is a great way to explore diverse career paths and opportunities. When it comes to choosing a field, volunteer work can help in the discovery (first-hand) if a career choice is a good fit. Despite what you think you know or want, until you actually dip your toes in, it's hard to be sure a particular career is something you will enjoy.

GSNV volunteers over the years have often found employment on campus (within RCH/VCGS/MCRI) and with our support group/advocacy networks. This has offered the opportunity to glean insight and first-hand experience in the sector and in future roles.

### **Bolster CV and Improve Job Prospects:**

GSNV volunteer work can help make finding that first entry-level job easier for students and recent graduates. Working with us helps demonstrate their career preparedness and complements an individual's academic and co-curricular path. It's been invaluable to countless volunteers over the years and we are very proud of our volunteers now working on campus or in our broader network.

### **Refine Skills:**

Volunteering provides the opportunity to practice and develop an array of social, relationship and other softer skills beneficial to career ambitions.

#### **Examples include:**

- Resourcefulness
- Collaboration
- Initiative

### **Expands Perspective:**

Volunteers get to work with many different people, groups, ethnicities, ages and socio-economic backgrounds, all of whom are invested in the same goal or cause that ties them together. Volunteers with the GSNV may benefit with a boost to their future/current professional life, in that they become more empathetic and mindful of perspectives that differ from their own foundation, through the volunteer experience.





# 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.

VOLUNTEER ORGANISATION (OR PROJECT)	VOLUNTEER MATCH	ACTIVITY
UsherKids Australia	3	Usher in Focus Webinar Series; develop social media templates
Alopecia Areata Foundation	1	Support group research and project development
AusDocc	2	NBS research, project meetings, administration and database input
Australia Sickle Cell Advocacy	1	Rare Diseases Day event
Cataract kids	1	Resource Development
Centre of Research Excellence	4	CP Achievement events, project meetings and administration
Ehler-Danlos Syndrome SG	1	ED Meetings and resources development
Genetic Support Network of Victoria	22	Survey development, events, Genomics in Schools support, report writing, volunteer workshop panels, support group grant research
GSNV project	2	Project development and delivery
Muscular Dystrophy Australia	1	Database support
NDOSS	1	Research, event support, social media supports
PCD	2	Research, meetings with prospective guest speakers, listing videos on social media
SCN2A	1	Transcription
SSPA Australia	1	Event research and support, editing and meetings
Syndromes without a name	2	Allied health database, research for interstate supports
The Aussie Hands foundation Inc	1	Administration and support

# OUR MEMBERS

Following the decision of the GSNV Committee of Management to make membership free for 2020, it was agreed to retain this moving forward.

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

As seen in 2020, we have continued to see 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, stakeholders and professional affiliates who have continued to provide support and advocacy alongside the GSNV.**

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.

**119**  
members

# OUR ADVOCACY FOCUS

## We are committed to advocacy that drives:

- Rare Disease to be considered as an entity in the same way that cancer is
- Engagement with lived experience community to build evidence that can be utilised broadly and purposefully including active engagement and co-design opportunities for people with genetic, undiagnosed and rare conditions in research, clinical trials and projects
- Representation means representation of the community not representation of an individual's ideas and opinions – representation must be supported
- Consumers as legitimate partners not a 'project' requirement, or 'good practice'
- 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 – for support, of information, n 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
- Recognition and action for people ageing with a genetic, undiagnosed and rare condition
- The Importance and recognition of identity and individuality in care, decision making and support – Differences are of value and inclusiveness for vulnerable populations is expected and required
- The right to knowledge, education and information for decision making and choice
- A collaborative approach from local, State, National and international organisations
- 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 Di Pietro, Hollie Feller and Kari Klein's valued support, hard work, flexibility and agility and also an outstanding year of contribution. We would also like to thank Keri Finlay who left us in 2021 for her wonderful contribution to GSNV and our Community over many years.

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 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 2021

NAME	POSITION	CLASSIFICATION	EFT
Monica Ferrie	Chief Executive Officer	PT	0.4
Louisa Di Pietro	Education and Advocacy Strategist	PT	0.25
Kari Klein	Project Officer	PT	0.3
Hollie Feller	Project Assistant	PT	0.3
Vacant	Project Coordinator	PT	0.4
EFT TOTAL			1.65
EFT TOTAL BUDGETED			2.0



# THE YEAR IN REVIEW





# YEAR IN REVIEW CONT.



## Sector and Consumer Representation

Participation, consultation and representation are critical elements of the work of the GSNV. We are committed to listening to, engaging with the genetic, undiagnosed and rare disease community and stakeholders and providing genuine representation of the diverse views, ideas, needs and expectations. In 2021, we engaged with and through the following:

- Our community; people living with genetic, undiagnosed and rare conditions and those who support them
- All Victorian Clinical Genetics Services
- Department of Health Victoria and Canberra
- 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 Industry Genomics Network Alliance
- Mackenzie's Mission Engagement Reference Group
- RDNOW Consumer Engagement Committee
- WHO Collaborative Global Network for Rare Diseases (CGN4RD)
- RCPA-HGSA Clinical Guidelines for Carrier Screening Implementation Working Group
- Rare Disease International (RDI)
- Asia Pacific Alliance of Rare Disease Organisations
- Royal College of Pathologists of Australasia 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 Australian Psychologists Society
- Centre for Consumer Directed Research
- National Patient Organisation Network



## Consultations and Submissions

- NDIS Submissions
- MSAC and PBAC Submissions, Targeted consultations and letters of support
- National Medicines Policy
- InGeNA – Industry Genomics Network Alliance
- Parliamentary Inquiry into approval processes for new drugs and novel medical technologies



## Conferences, Webinars & Global Meetings

- EURORDIS (Rare Disease Europe) Annual Meeting of Patient Organisations
- Maternal Child and Health Nurse Conference
- Asia Pacific Alliance of Rare Disease Organisations Conference and webinars
- Western Pacific Collaborative Global Network for Rare Disease Work Group
- Pinnacle events
- Health Informatics Conference
- Human Genetics Society of Australasia
- Australian Genomics Forum
- European Conference on Rare Disease
- Rare Disease International Global meetings
- Accidental Counsellor course
- Global Genes Conference
- Beacon Events
- Genetic Alliance UK discussion forums
- Consumer Health Forum Conference and Forums
- HTA Consumer Engagement Forum



# Testimonials



## Peer Support Training

Thank you for this presentation. I've already recommended it to the community I represent!



## The Accidental Counsellor Workshops

The course provided me with information and new insights that I will take with me into my workplace and into my private life (a bonus!)



## Dismystifying grief and loss

The theories of grief gave me insights and the contemporary updates gave me better understanding.

# Practical Wellness Month Evaluation

By Hollie Feller

Supporting Mental Health Awareness Month in 2021, the GSNV held a series of workshops over the month of October to build capacity in our members in relation to their practical wellness skills.

This year we hosted our partners from the previous year Cystic Fibrosis Community Care with their well regarded Peer Support Training and Women with Disabilities Victoria presented their Right to Safety Workshop after its introduction last year.

We were delighted to introduce a new collaboration with counsellors Melanie Schroder and Sandra Willie from Calm Conversations with their workshop on the Accidental Counsellor.

Very Special Kids was invited to share some of their content which forms part of their volunteer training modules. This workshop presented the latest theories on grief and loss a subject that emerges often in the life-course of rare disease patients and their families. Close to 100% of participants reported that attending the workshops would make a difference to their rare disease communities and could apply their new skills to real world setting.

Many of the resources and videos are still uploaded to our website; Resources can be found on the GSNV website

[www.gsnv.org.au/events/practical-wellness-series-october-2021/](http://www.gsnv.org.au/events/practical-wellness-series-october-2021/)

# Genomics In Schools Launch

By Hollie Feller

## The Project:

In increasing the awareness of the social implications of genomic technologies, we believe it is important to begin the education process from a young age. The GSNV educates the general community on genomics and its implications. In collaboration with an experienced steering committee, the GSNV have developed a genomics education program for high school aged students.

After a small successful pilot program in 2019, the GSNV launched its program of resources to teachers during 2021. The resources were created to align with the VCE biology study design, using the power of story-telling. Through case study examples, the resources for teachers and students bring to life the connection between the science concepts and personal experience, to give a greater perspective of the roles of the experts and the impacts of the practice on real people.

## The program consists of:

- Teachers guide & teacher education sessions
- Creative program with guided activities worksheets and props
- Case studies with lived experience videos
- Short career interview videos identifying potential career pathways in genomic health

## The delivery:

The program was advertised to teachers to register their interest for the resources via social media platforms:

- VCE Biology Teachers groups on Facebook
- Victorian Teachers online community
- LinkedIn, Instagram, GSNV community newsletter & socials
- GTAC website/GTAC newsletter (September 2021)
- Article published in Labtalk Science Publication Volume 65, 2021

## Registrations:

A portal was created on the GSNV resource website The Genetic Link to register interest and a link was emailed to teachers to download the files at no cost to use in the classroom.

- 158 registrations from individual teachers across Victoria
- 33 Teachers registered from rural schools in Victoria, 125 metro and greater Melbourne

## Use of the Content:

- 115 teachers will use the content for VCE classes
- 38 teachers will use the content for Year 10 science/biology
- 33 teachers will use the content for Year 7-10 science/biology

## Evaluation:

The registered teachers have been asked to complete a short evaluation survey of the content and how it was applied and received in the classroom. A separate survey for their students was also sent out.

Initial feedback suggests most teachers will use the content for the 2022 study design when the GSNV plans to revisit the evaluation of the content.

**IT IS ESTIMATED THE USE OF THESE RESOURCES WILL REACH A MASSIVE 44, 000 CHILDREN STUDYING SCIENCE IN HIGH SCHOOL**

## Next Steps:

Feedback from the Steering Committee indicated that no further case studies were required to extend these resources.

- Focus will be on further distribution channels of the resources, including the use as an accredited professional development resource
- Presentation at the 2022 STAV Biology Conference
- Further educational events to showcase the GSNV educational component will be sought through 2022.
- Inclusion in the 2022 Victorian Middle Years Science Challenges project

## GSNV Research: a longitudinal study

### GSNV Research Summary

By **Stephanie Best**

#### Summary Authors:

**Stephanie Best** Australian Genomics  
**Malia Byun** Californian Lutheran University  
**Inez Beadell** Master of Genomic Health  
**Monica Ferrie** CEO GSNV  
**Hollie Feller** Project Assistant GSNV

The GSNV, in collaboration with Australian Genomics continued their work on the longitudinal study of the impact of COVID-19 on the GUaRD community through the study of monthly journals submitted across a 12 monthly period in 2020-21.

We received on average 10 journals a month. Data analysis, using a Resilience Framework, identified three key time related areas of support that would be of benefit for many in the Genetic Undiagnosed and Rare Disease community. We have referred to these findings as waves of support as they were identified at different points in the pandemic.

#### 1st wave:

##### Facilitate finding a framework to structure day-to-day life:

This support was found in journals right from the start as people's lives were turned upside by the pandemic and with lockdowns. We did not see it later on as people got into their stride.

#### 2nd wave:

##### Consistency of communication of health information:

This finding came in a little later and the topic of the health information varied though towards the end of our study.

#### 3rd wave:

##### Support for mental wellbeing:

This finding came in later in our data collection period. We found a need for mental wellbeing support across all age groups which is different to previous studies.

We have subsequently written up the findings and submitted them to an academic journal where it was published in October 2021. (Byun, H. Feller, M.Ferrie, M. Best, S Living with a Genetic, Undiagnosed or Rare Disease: a longitudinal journaling study through the COVID-19 pandemic Health Expectations [www.onlinelibrary.wiley.com/doi/full/10.1111/hex.13405](https://www.onlinelibrary.wiley.com/doi/full/10.1111/hex.13405)).

From the C-19 journals study we could see many members of the Genetic Undiagnosed and Rare Disease community had a range of strategies to help them in their day to day lives whether during a global pandemic or not.

We were curious to investigate these strategies further. As a result, the Interventions to 'Live Well' study was started. We re-analyzed the journals to identify these strategies and grouped them by:

- Support for individuals with GUaRD – including mental wellbeing
- Support for carers of people with GUaRD – including mental wellbeing
- Education/Employment – support for people with GUaRD to find education and employment
- Transition – transitioning to adulthood/out of NDIS

We held three focus groups with 13 people from the Genetic Undiagnosed and Rare Disease community in September 2021 to <sup>1</sup> discuss benefits and challenges of the strategies found in the journals and <sup>2</sup> see if there were further approaches we should consider. The findings from these vibrant discussions have been fully transcribed and data analysis has been submitted to be published in relevant peer reviewed journals. Successful publication of the findings will be shared with the community once we have been notified

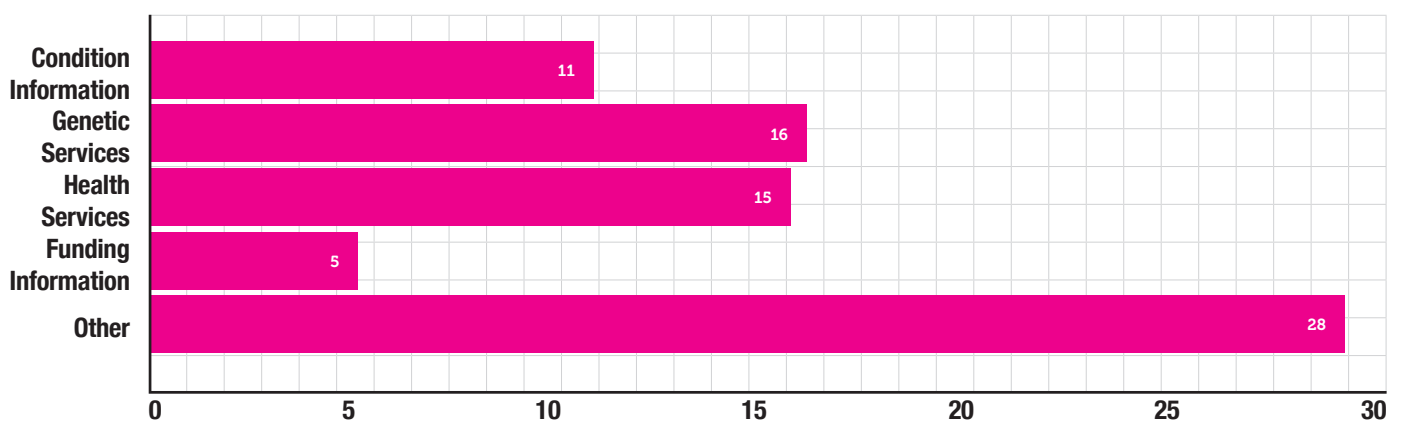
All information relating to GSNV Research projects can be found on our website.



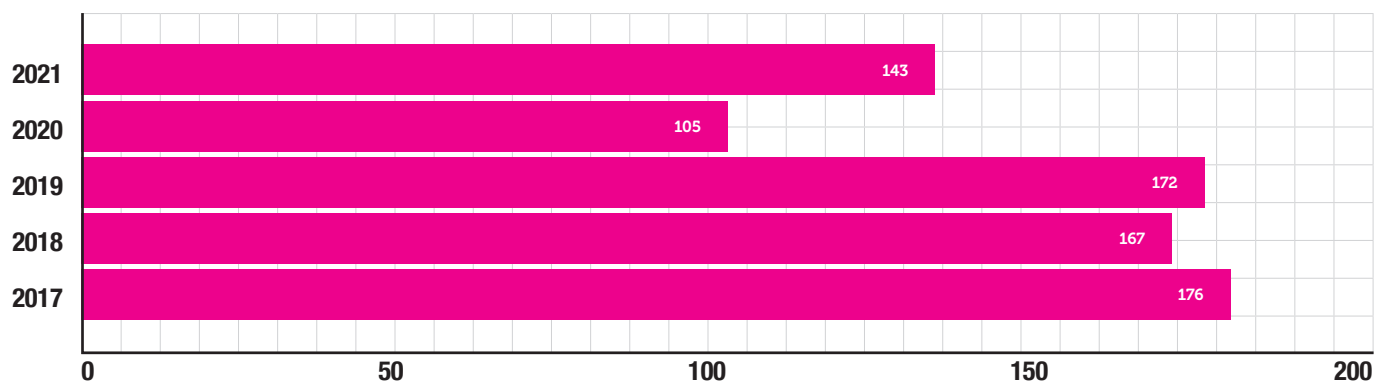


## 2021 GSNV ENQUIRIES

### Types Of Enquiries



### Annual Enquiries



# HIGHLIGHTS FROM A PRODUCTIVE YEAR



## National Strategic Action Plan for Rare Diseases

GSNV continued to implement the National Strategic Action Plan for Rare Diseases, reporting both to the Federal and Victorian Governments mid-year and with a 2021 annual review. The GSNV continues to be linked with this important Department of Health plan to action the work outlined by our community as national and state priorities. Our reports can be found on the GSNV website.



## Rare Disease Day

February 28th was international Rare Disease Day and again we delivered virtual events where we focussed on "Who's on Your Team?" Knowing that collaboration and working together is the only way to create positive change, our Rare Disease Day event focussed on identifying the key players our individuals and communities need to be on their team to be able to access their best lives. We concentrated on how to identify and build your team and how to bring all the players together for a common outcome. We also re-iterated that the GSNV is always a collaborative and supportive team member for all our patient support groups and identified practical ways that we can assist.



## Fit for Practice

We are extremely grateful to 5 patient support organisations who hosted Masters in Genetic Counselling students for the Fit for 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 2021. 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.



## GUARD Community Advisory Group

It's always been so important to listen to our community, we continually advocate for health professionals to listen to lived experience and to treat people living with genetic, undiagnosed and rare disease as the experts in their condition and its impact. It's the same with patient support organisations, they hold the expertise and knowledge around what their communities need. To ensure this drives the advocacy, submissions, understanding and the work program of GUARD Collaborative Australia (GSNV, Genetic Alliance Australia (GAA NSW) and Syndromes Without a Name (SWAN) Australia) we convened the GUARD Community Advisory Group.

This group consists of a diverse range of support group leaders and individuals living with genetic, undiagnosed and rare conditions. Our focus in 2021 has been on understanding the environment and the areas for collaborative focus – this has included jointly working on the National Medicines Policy Submission and developing a work plan.

I'd like to take the opportunity to thank all the GUARD CAG members for joining us to focus on national representation, collaboration, submissions and opportunities.



## Carrier Screening

The GSNV continued to be actively engaged in projects and Committees championing access to carrier screening. The GSNV chairs the Mackenzie's Mission Engagement Reference Group, ensuring that our community is part of the discussion and development of information and processes around the largest carrier screening project in Australia and in 2022 will play a role in research translation. We are also active members of the Carrier Screening Reference Group and we were delighted with the successful MSAC submission for the inclusion of carrier screening for Spinal Muscular Atrophy (SMA), Fragile X and Cystic Fibrosis onto the Medical Benefits Scheme. There are many people working tirelessly to expand carrier screening access, to ensure implementation of carrier screening programs are patient centred and guidelines are clear and universal. We thank everyone involved in these efforts and for continuing to support the inclusion of the patient voice in design and implementation.



## NewBorn Screening

Throughout 2021 and continuing into 2022, the GSNV have had the pleasure of leading a project investigating Newborn Screening (NBS) in Australia. With two amazing volunteers, we have sought to assess the current process and recent changes to the NBS applications process. We have investigated how the GUaRD community can advocate for a significant shift to deliver a more robust system effectively, equitably and efficiently in the future. Our work is not finished, but we have established the basis for a GUaRD collective approach, to this vital screening service.

The work conducted by GSNV volunteers and staff could not have been possible without the research and input of our student researcher on placement from Deakin University (Faculty of Science, Engineering and Build Environment, School of Life and Environmental Sciences – Professional Practice in Bioscience).

Together, our student placement and volunteers put a great deal of effort into looking at the current NBS landscape and how the recent change has impacted this screening program and its future use in Australia. Everyone worked to investigate NBS in Australia vs the UK model and the UK rare diseases advocacy approach, which sets up a terrific model for a uniquely Australian GUaRD approach to NBS as a public health priority program.



## Margaret Sahhar Grant

In 2021, the Margaret Sahhar Grant was awarded to SWAN Australia. The grant was awarded to support the development of a SWAN Advocacy Resource Kit. This advocacy kit will be a valuable resource for the undiagnosed community and also be available on the GSNV website to assist the entire genetic, undiagnosed and rare disease community.



## International, National and Local Networking

### INTERNATIONAL NEWS

December 2021 delivered an amazing result, led by Rare Disease International and EURORDIS and supported by patient support groups around the world seeking adoption of a resolution by the United Nations General Assembly - Addressing the challenges of persons living with a rare disease and their families

The resolution was adopted in December. The patient voice was critical throughout this journey, as many support groups joined with the GSNV seeking Australian support to adopt this resolution.

#### The resolution calls upon all countries and is focussed on:

- Reaffirming the right of every human being, without distinction of any kind, to the enjoyment of the highest attainable standard of physical and mental health and to a standard of living adequate for the health and well-being of oneself and one's family, including adequate food, safe drinking water, clothing and housing, and to the continuous improvement of living conditions, with particular attention to the alarming situation of millions of people for whom access to health-care services and medicines remains a distant goal, owing to a number of different barriers, in particular people who are in vulnerable situations, including those in developing countries,
- Recognizing the need to promote and protect the human rights of all persons, including the estimated 300 million persons living with a rare disease worldwide, many of whom are children, by ensuring equal opportunities to achieve their optimal potential development and to fully, equally and meaningfully participate in society,
- Recognizing that some persons living with a rare disease have disabilities and impairments, and may face attitudinal and environmental barriers as persons with disabilities,
- Reaffirming that health is a precondition for and an outcome and indicator of the social, economic and environmental dimensions of sustainable development and the implementation of the 2030 Agenda for Sustainable Development, and acknowledging the reciprocal benefits between the attainment of Sustainable Development Goal 3 and the achievement of all other Goals,
- Recognizing the fundamental importance of equity, social justice and social protection mechanisms as well as the elimination of the root causes of discrimination and stigma in health-care settings to ensure universal and equitable access to quality health services without financial hardship for all people, particularly for those who are in vulnerable situations, including those living with a rare disease,
- Recognizing also that persons living with a rare disease and their families should have access to social protection and assistance that enables them to contribute towards the full and equal enjoyment of their rights and to ensure a safe and supportive family environment,
- Recognizing that persons living with a rare disease and their families may be psychologically, socially and economically vulnerable throughout their life course, facing specific challenges in several areas, including but not limited to health, education, employment and leisure.
- The principles outlined in this resolution will inform our work in 2022 and beyond. It is so important to have our community front and centre in the United Nations family and part of the acknowledged delivery of the UN Sustainable Development Goals.



## Collaborative Global Network for Rare Disease (CGN4RD)

This project involves representation across the globe and is led by Rare Disease International (RDI), with the GSNV contributing to discussions that focus on the Western Asia-Pacific region. To inform the proposal to develop a collaborative global network for rare disease and ensure that persons living with a rare disease, no matter where they live, can reach a network of expertise to access diagnosis and care, RDI conducted an extensive global Population Needs Assessment Study. This study identified ten common areas of need impacting the diagnosis, care and treatment of the rare disease community globally.

#### The ten common areas are not surprising and include:

1. Social and cultural acceptance, equality, and inclusion of Persons Living with a Rare Disease (PLWRD)
2. Systematic, standardised data collection and data sharing
3. Political recognition and dedicated policy framework and budget for rare diseases
4. Availability, affordability, and coverage of rare disease tests and medicines
5. Focus on prevention and screening
6. Widespread availability of expertise, specialised services, and standards of care
7. Coordination of care across devolved or fragmented healthcare systems
8. Geographical and cultural considerations
9. Supporting technology infrastructure and use of telemedicine
10. Empowerment of patients and families to self-care and advocate

These areas are consistent with the Australian Department of Health National Strategic Action Plan for Rare Diseases and will further inform the GSNV in 2022.

The CGN4RD project will continue to develop and unfold with the GSNV actively engaged.



## General

We continued building relationships at all levels in 2021. In the international arena, we are active members of Rare Disease International (RDI), 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, Pinnacle and Asia Pacific Economic Cooperation webinars and workshops.

In Victoria, we continued to work with Australian Genomics, Melbourne Genomics, Genetic Alliance Australia in NSW, Syndromes Without a Name (SWAN) Australia through our national collaboration – GUARD Collaborative Australia. We also broadened our relationships and representation as part of the genomics industry alliance InGeNA, Join Us Registry and many others.

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.



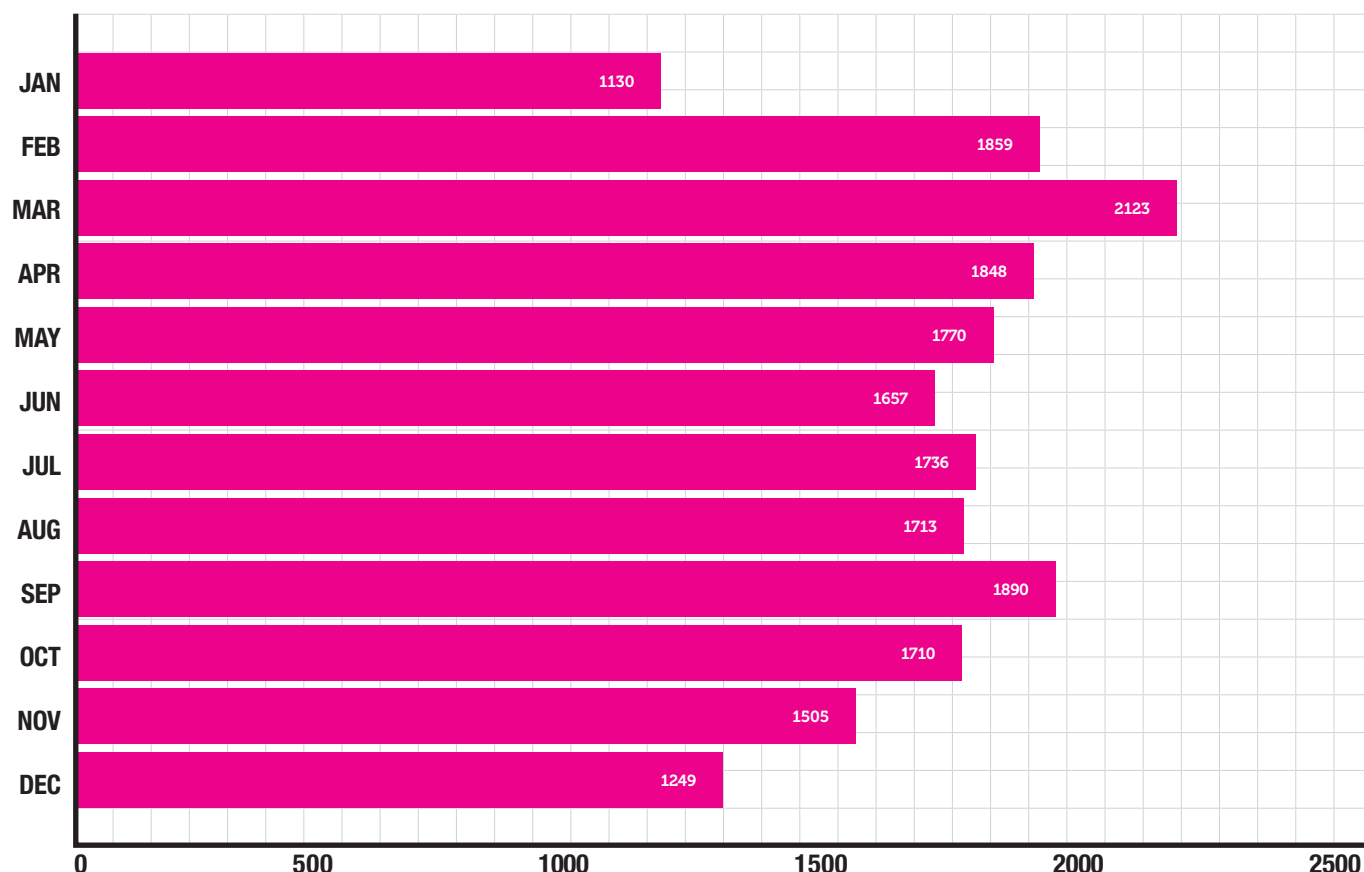
# WEBSITE, DATABASE AND SOCIAL MEDIA

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 2021 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 Instagram and LinkedIn. The GSNV seeks to follow trend on social media and subscribes to over 2,000 pages on Twitter and has over

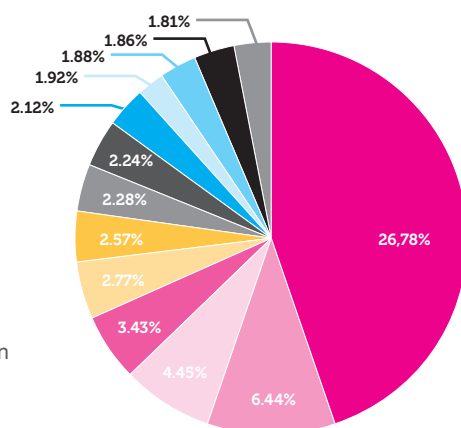
1020 followers on Facebook, which is over 150 more than in 2020. It is anticipated that social media will require further time and resources in the future as the GSNV has launched an Instagram account to support the support groups who are regularly engaged with the GSNV and members by advertising events as well as publishing live video stories.

## Number Of Website Views By Month 2021



## Website Page Views 2021

- home page
- find a genetics service
- volunteer
- our team
- support groups
- contact us
- practical wellness
- support group direct
- membership
- how can we help you
- resources for families
- genetic health information
- community



## Number Of Website Views

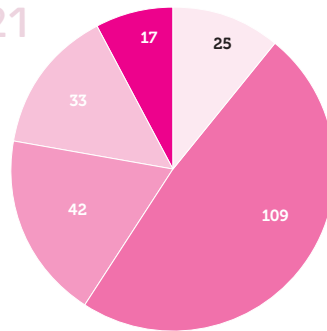


23,067
2017
22,996
2018
19,741
2019
15,694
2020
20,190
2021



## Types of Facebook Posts 2021

- survey/research
- GSNV events and announcements
- community events and webinars
- supporting group info/shout outs/awareness days
- advocacy/position statements

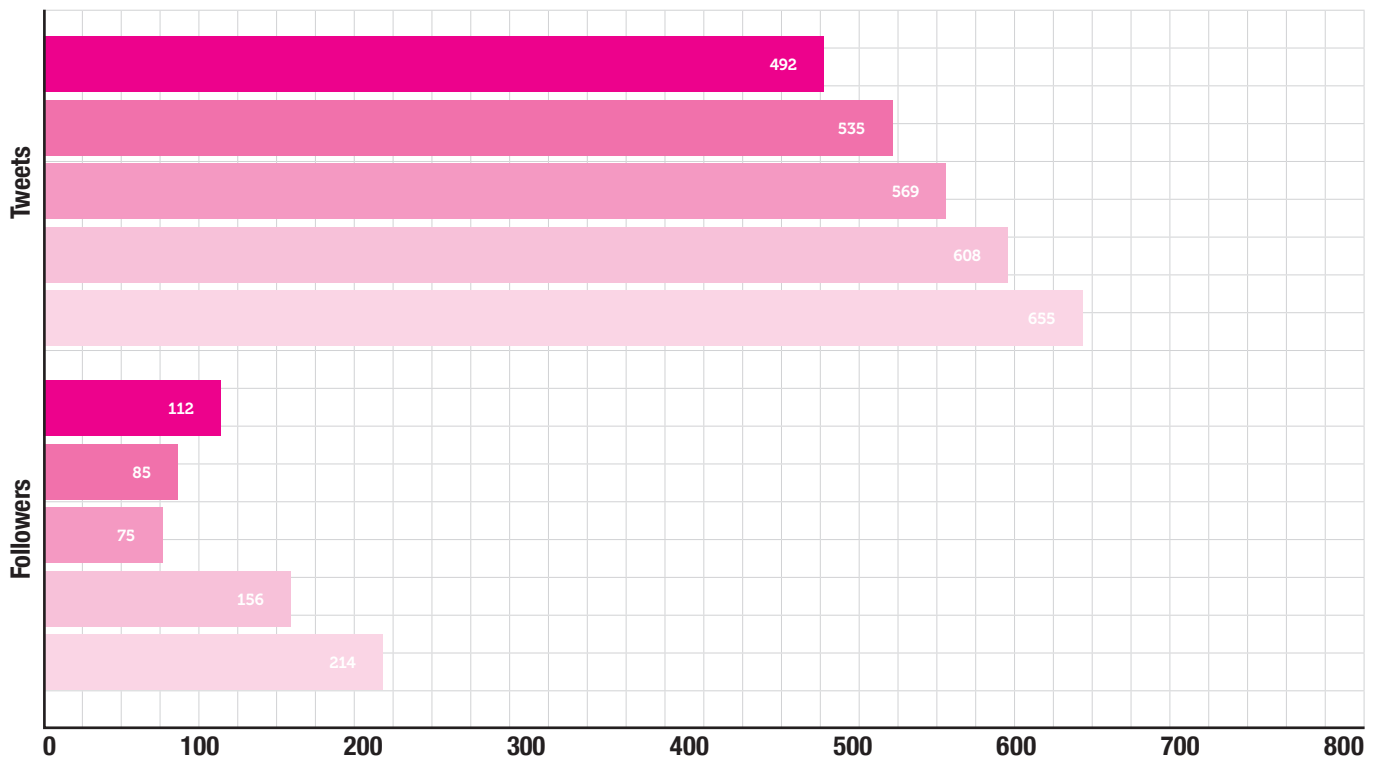


# WHO ARE WE REACHING ON FACEBOOK AND TWITTER?



## Twitter Reach

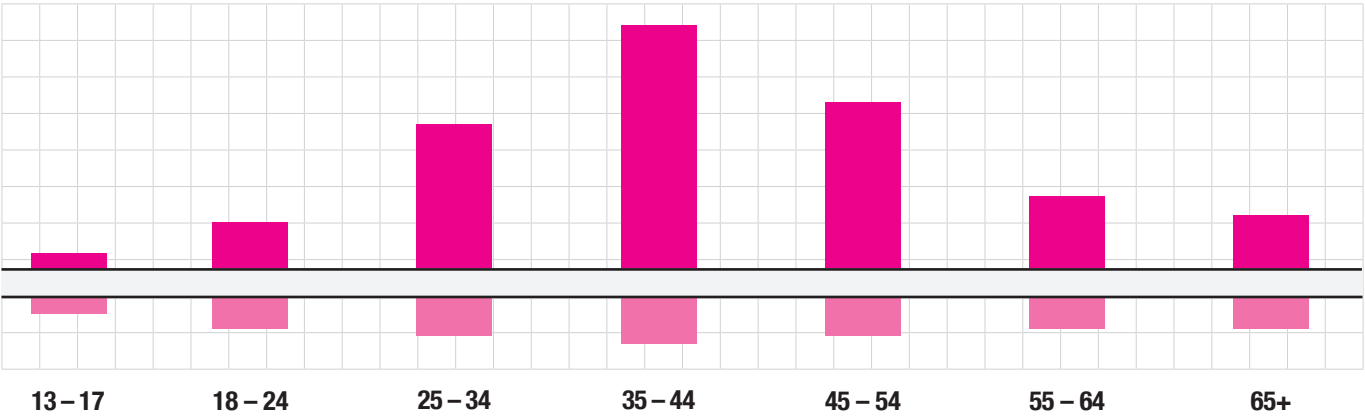
■ 2017 ■ 2018 ■ 2019 ■ 2020 ■ 2021



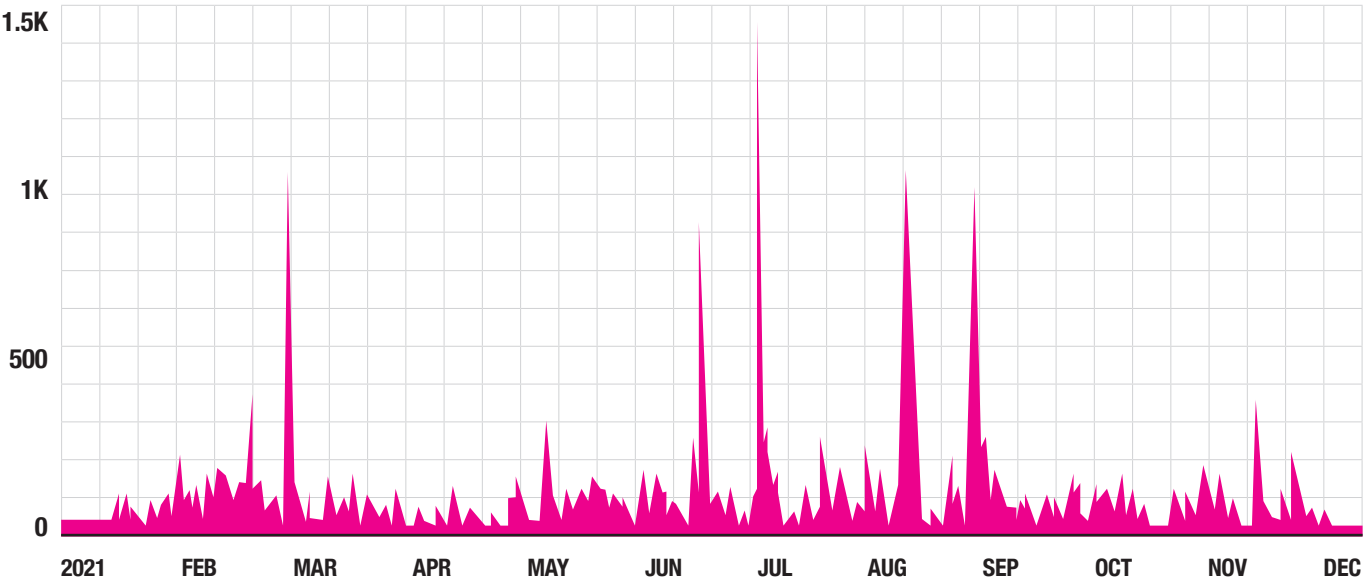


# Gender and Age of Facebook Audience

Female 87% Male 13%



## Facebook Post Reach 2021 • People Reached 11,272





# MACKENZIE'S MISSION

As we come to the close of 2021, it has been an amazing year for the Mackenzie's Mission carrier screening research project and the Mackenzie's Mission Engagement Reference Group (MMERG).

Over the past year, the MMERG has added the consumer voice and perspective to recruitment strategies, to communication pieces, to inclusiveness and accessibility, to research processes and information gathering, and supporting the Mackenzie's Mission project team as appropriate.

Mackenzie's Mission is now operational in all states on Australia, making carrier screening accessible for couples considering pregnancy and in the early stages of pregnancy. Knowledge and evidence gained through the project have already informed an application to the Medical Services Advisory Committee (MSAC) for expanded carrier screening carrier screening to be covered by Medicare. This is in the first stages of moving through the MSAC process and will take some time to progress through the system.

Mackenzie's Mission currently has all states meeting their recruitment targets and on-track to complete enrolment into the study by 31 March 2022.

The research study will then move into the research analysis phase where the project will move from benefits to couples enrolled in the study through to understanding the population benefits of informed choice around carrier screening, the impact of carrier screening uptake on the health system, the decision making influences on couples, the information which is most valuable and many other areas.

The MMERG will work with the Mackenzie's Mission project team through the post-enrolment phase of the project to continue the critical role of bringing the consumer voice and perspective.



# INVOLVE AUSTRALIA



The GSNV is delighted to be involved in the Australian Genomics led initiative Involve Australia.

Involve Australia aims to promote the effective involvement of consumers in genomic research. The primary objective is to develop guidelines to be used by genomic researchers to involve the public, consumers of health technology, patients, and other people affected by genomics research. This will involve partnering with patient support and advocacy groups, members of Indigenous communities, patients and carers, interested members of the public with a representative distribution, and members of the genomic research and clinical community.

Involve Australia will build its guidelines from the perspective of non-researchers. This will allow patients and carers, as the end users of healthcare research, to highlight what they need if they are to maintain their involvement in research. Ultimately, Involve Australia aims to ensure that everyone's needs are built into genomic researchers' consumer involvement strategies before projects begin, and set the standard for involvement in other areas of healthcare research.

We are not seeking to re-invent or duplicate existing resources and we value work already completed, but the importance of clear guidelines co-created with consumers has never been more critical. The drive for genuine, tangible (not tokenistic) involvement is at an all-time high across all levels of research. It will be very easy for the research community to unintentionally increase the burden on people who's lived experience already ensures challenging lives, requiring extraordinary resilience just to get through each day. For many, there is the desire to engage but simply no accessibility.

The Involve Australia project team has convened a specialist multidisciplinary working group. This group includes: John Cannings OAM, Monica Ferrie (Project Lead), Anne McKenzie AM (Project Lead), Sean Murray (Project Lead), Jack Nunn, Gregory Pratt and Fiona Russo and supporting the project from Australian Genomics is Tiffany Boughtwood, Isabella Sherburn and Keri Finlay. The Involve Australia team is very focused on ensuring that community voices who don't often have the opportunity to contribute and are under-represented in our research have the opportunity to have their voices heard.

Involve Australia is committed to engagement that translates to improved lives. The project will unfold over the next two years, and provide opportunities for broader engagement and involvement so watch this space.

# MENTAL HEALTH WORKING GROUP

Mental health and wellbeing have been a focus for many stakeholders over the past year.

The GSNV, patient support groups, people living with genetic, undiagnosed and rare conditions and the general community have been impacted substantially by the challenges of 2020 and 2021 as COVID-19 has cast a persistent shadow.

The Mental Health Working Group formed to understand the mental health support environment, to bring together expertise and experience and explore how to serve our community in this space.

Our group has reviewed the current environment and supports, informed projects and events delivered by the GSNV such as our Day in the Life Series for the Australian Psychologists Society and Practical Wellness months events such as The Accidental Counsellor, Right to Safety Workshop, Peer Support and our Grief and Loss webinar. We have also learned much about what exists and where the gaps are for our community. 2022 will action projects and activities to help fill these gaps, establish relationships with key mental health service providers and help us to more fully understand the mental health and wellbeing needs for our community. These will extend beyond the supports in the health system and explore community and other support mechanisms.

My appreciation and gratitude to all our contributors; Julie Cini, Sarah O'Neil, Nikki Dean, Bianca Comfort, Emma Palmer, Rachel Pope-Couston, Clare Stuart, Nicole Bester, Hollie Feller, Heather Renton and Jan Mumford

# THANK YOU

Over a very challenging couple of years, knowing we have such wonderful support has never been more important.

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, Victoria 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 and patient support groups, clinical services, researchers, universities, industry and so many others. A special mention to Professor Martin Delatycki for his ongoing support and generous time.



# FINANCIAL REPORT 2021

On behalf of the executive and committee of the GSNV I am pleased to report the financial details for the financial year 1 January 2021 – 31 December 2021.

The GSNV continues to manage its budget well and will carry forward a surplus into 2022. 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, 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 31/12/2021

70680 GENETIC SUPPORT NETWORK (V)

	CURRENT MONTH			CURRENT MONTH			FULL YEAR BUDGET
	Budget	Actual	Variance	Budget	Actual	Variance	
INCOME							
DHS Grant	18,818.23	-8,206.50	-27,024.73	224,026.55	221,091.86	-2,934.69	224,026.55
Other Income	750.00	0.00	-750.00	9,000.00	5,045.00	-3,955.00	9,000.00
TOTAL	19,568.23	-8,206.50	-27,774.73	223,026.55	226,136.86		233,026.55
EXPENDITURE SALARIES & WAGES							
Gross Salaries	8,221.57	12,728.49	-4,506.92	97,774.20	92,774.20	4,681.53	97,455.73
Other Employment Costs	0.00	0.00	0.00	0.00	420.00	-420.00	0.00
Provn of Employee Entitlements	1,502.10	4,593.93	-3,091.83	4,519.68	8,244.73	-3,725.05	4,519.68
Superannuation	794.35	1,202.32	-407.97	9,183.52	9,008.71	174.81	9,183.52
Work Cover	55.60	63.64	-8.04	659.12	511.79	147.33	659.12
TOTAL	10,573.62	18,588.38	-8,014.76	111,818.05	110,959.43	858.62	11,181.05
CONSUMABLES							
Administrative Expenses	9,470.98	12,743.75	-3,272.77	113,950.31	111,936.02	2,014.29	113,950.31
Infrastructure Costs	154.45	154.45	0.00	1,853.36	1,853.36	0.00	1,853.36
Computer Expenses	166.67	328.50	-161.83	2,100.00	668.05	1,431.95	2,100.00
TOTAL	9,792.10	13,226.70	-3,434.60	117,903.67	114,457.43	3,446.24	117,903.67
TRAINING & TRAVEL EXPENSES							
Travelling Expenses	250.00	0.00	250.00	3,000.00	720.00	2,280.00	3,000.00
TOTAL	250.00	0.00	250.00	3,000.00	720.00	2,280.00	3,000.00
TOTAL EXPENDITURE	20,615.72	31,815.08	-11,199.36	232,721.72	226,136.86	6,584.86	232,721.72
ACCOUNTING SURPLUS/(DEFICIT)	-1,047.49	-40,021.58	-38,974.09	304.83	0.00	-304.83	304.83





Victorian Clinical Genetics Services  
Murdoch Children's Research Institute  
Flemington Road, Parkville VIC 3052 Australia  
P +61 1300 11 8247 F +61 3 8341 6366  
W [vcgs.org.au](http://vcgs.org.au) ABN 51 007 032 760

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### 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 2021 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







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

**genetic support** network of victoria

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