gsnv
Genetic Support Network Victoria

2025 ANNUAL REPORT



Working towards access to the practical and pathways to the possible.

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Genetic Support
Network Victoria

Welcome to the Genetic Support Network of Victoria Inc.

Welcome to the Genetic Support Network of Victoria Inc. (GSNV) annual report for the period 1 January 2025 to 31 December 2025.

As we reflect on the year in review, 2025, we are pleased to highlight some of our major achievements, challenges and outcomes, including an overview of governance and financials.

The 2025 GSNV Annual Report cover photo:

The GSNV Team with Volunteers

L-R, Malavika Vasanth, Daniele Noel, Susie Roczo-Farkas, Monica Ferrie, Nicole Bester, Ashna Nimbalkar

Image credit: Susie Roczo-Farkas.



VICTORIA State Government | Department of Health

gsnv Genetic Support Network Victoria

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Acknowledgement of Country
The Genetic Support Network of Victoria (GSNV) acknowledges our First Nations Peoples as the Traditional custodians of our grasslands, waterways, and basalt plains. We recognise their connection to culture and land over thousands of years and pay our respects to all indigenous peoples.

Acknowledgement of Lived Experience
The Genetic Support Network of Victoria (GSNV) acknowledges the strength, resilience, contribution, and capacity of the genetic, diagnosed, and rare disease community and pays our respects to all living people with challenges and difficulties who are rightfully seeking to live their best lives.





2025 – BUSINESS AS USUAL (MOSTLY)

As always in the genetic, undiagnosed and rare disease (GUaRD) eco-system, this year there has been things that have moved at the speed of light and things that have moved at glacial speed.

We continued to wait for HTA reforms, welcomed new conditions to newborn screening panels, shared frustration about MSAC and PBAC decisions and the slow passage towards genetic discrimination legislation and we came together as always to tirelessly continue to find pathways to better quality of life and health outcomes for our community.

Important partnerships continued with the Dept of Health Victoria, Victorian Genetics Services across the state, diverse health professionals, industry and InGeNA (Genomics Industry Alliance), as the InGeNA Community Advisory Group was established. 2025 was also a year of endings and beginnings as we said goodbye to Australian Genomics with sadness and hello to Genomics Australia with hope in our hearts. Our community continued to support the millions of Australians living with and impacted by genetic, undiagnosed and rare conditions. Each and every day, our community continues to turn up, as individuals, families, carers, advocates, supporters, researchers, advisory groups, representatives and in their professional capacities across many sectors including health.

I would like to acknowledge the persistence, determination and solidarity of all our stakeholders and their commitment to positive change for our community. The GSNV and our community remains appreciative and grateful that you continue to stand with us as we stand with you.

As I seem to say every year, there remains much to do. Knowing we are part of a local, national, regional and international community matters. It is such a privilege to stand with our community, friends and organisational allies dedicated to the rights and agency of individuals and their families living with genetic, undiagnosed and rare disease across Victoria and Australia.



ABOUT THE GSNV

The 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 Community, Education, Advocacy and Support.

We will continue to honour the purpose for which we were created and our commitment of service to the genetic, undiagnosed and rare disease community.

The GSNV in Context

In 2025, the national and state landscape shifted across the year to feel more positive. The establishment of Genomics Australia and a consultation for a national genomics framework, COVID sitting further back in our rear-vision mirror, the prospect of a public call out to advance newborn screening, increasing and more meaningful engagement and involvement of community by stakeholders all created an environment of possibility.

Acknowledging continued pressure on health systems and resources, there was some advancement on exploring bottlenecks and possible solutions. AI became a more common discussion point, science continues to advance and the role of technologies continue to grow. Our voices continue to be needed to ensure that AI is developed and delivered to save lives as its primary function rather than a focus on saving money and increasing efficiency. As in previous years, policy is still taking a while to catch up. At the end of 2025, for us, the national agenda for the future still includes: HTA reform including faster access to therapies; genetic discrimination legislation; data interoperability progress; waiting list reductions; safety standards for the faster access to genetic test results through MyHealth record; consistent and predictable quality of health sector experience for everyone, especially our community; mental health support integration; increasing support and access for the impacts of disability, family and community supports.

We are also seeing shifting priorities across health funding and research as prevention advancements provides measurable outcomes in cancer care and some chronic illness conditions such as diabetes.

The ongoing challenge of presenting a clear evidence base for rare conditions collectively and in most cases for individual conditions remains a standout constraint in the positive advancement of health and life outcomes for people living with and impacted by rare conditions. This is of particular concern as we see increasing pressure on life-changing supports accessed through the NDIS coming under more challenge and constraints.

2025 also provided some positive global momentum, bringing together the international rare disease community as GUaRD community was boosted through the Resolution4Rare. This resolution from the World Health Assembly (WHA) mandates recognition of rare disease as a health priority across all member states – which includes Australia and the establishment of Global Action Plan for Rare Disease by the World Health Organisation. We are hoping this will highlight the ongoing challenges for our community across the globe and develop positive and implementable opportunities for change. The pace of action has been slow as the World Health Organisation has been confronted by numerous pressures throughout the year.

VISION AND MISSION



2025 was the second year of the GSNV's current strategic plan. Our plan was developed in consultation with our community and stakeholders at the end of 2023 and will continue to guide our work to the end of 2026.

We are excited that we will be developing a new strategic plan in consultation with community and stakeholders in 2026 to take us forward towards 2030.

We remain committed to patient/community led priorities and agendas, community as lived experience experts working in partnership with other key expert inputs to create positive impact.

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Genetic Support Network Victoria

Our Vision

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

Our Mission

Champion the long-term sustainability and value of support strategies and systems including genetic, undiagnosed and rare disease patient support groups.

Build stakeholder capacity to improve engagement and collaborative outcomes.

Be an enabler of a collaborative and connected support sector voice to explore issues/opportunities and co-design strategies and solutions.

Listen and learn from people living with GUaRD and their families and support groups to represent, lead and advocate for positive change.

CEO MESSAGE



Monica Ferrie
CEO

I've been writing a CEO message for the GSNV for almost ten years now for our Annual Report. Each year I think about the enormous task at hand for ourselves, our fellow travellers in the support sector and our committed stakeholders. I marvel at what has been achieved, how the dialogue has progressed, the miracles of scientific advancement and our ability to harness learnings. We must never forget how far we've come and the role that each and every one of us has played along the way.

Everyone gives what they can, when they can and how they can, sometimes more and sometimes less but, always with the utmost gratitude for every other contributor and always with forward momentum.

There is something special about the rare community. People are generous, they give of their hearts and minds, they don't judge, they want everyone to live their best life. It's a shared heartbeat towards that common goal. The community lives on the edge but still has time for each other, to add their voice, to tell their story, co-design research or just to show support by turning up. The things our community are doing and achieving are incredible, in quiet or through in-your-face advocacy. There is no-one like us. Its humbling and exhilarating at the same time to be doing my job.

There are many things that must change for our community to truly have equity of opportunity to live their best lives. We need services that provide end-to-end holistic support alongside world class paediatric and adult diagnostics, care and treatment; we need a system that recognises us so our journey is understood, interactive and where appropriate, whole of family, whole of life; we need a health system that seeks to mitigate perceived risks acting and changing for positive impact and reflecting genomic technologies as fundamental rather than additional to mainstream health.



The GSNV and Master of Genetic Counselling Student Placements
L-R: Faustina Audrey Agatha, Malavika Vasanth, Susie Roczo-Farkas, Daniele Noel, Stella Parkinson

We need the breathtaking research and knowledge we develop to translate into implementable solutions and we need this to be how research success is measured; most of all, we need a sustainable model for support for families and individuals.

I'd like to express my gratitude for the hearts and minds that I am privileged to engage with on this journey. At the GSNV, I'd like to acknowledge the amazing team; Daniele Noel, Malavika Vasanth and Susie Roczo-Farkas, our volunteers and students who have passed by this year and had such an impact. To our amazing support groups and support group leaders, your contribution and ongoing commitment is seen, appreciated and sets an example important to everyone. A big shout out to our partner stakeholders who we have worked with on submissions and advocacy, research projects and new projects increasing inclusion and understanding across the multi-cultural community that is Victoria and Australia. I also like to add a personal thank you to my GUARD Australia colleagues, Emma Bonser at Genetic Alliance and Alison McIvor at SWAN. I know it's been a huge year for both those organisations too and working together, we have inspired, challenged and supported each other. As I've said many times this year, together we are stronger, thank you for being there for us too.

To all of you that have demonstrated increasing commitment to engaging with and listen to community voices, a big shout out. Thank you to our RareNET presenters and contributors, our CAG members who have blown stakeholders out of the park this year, our Rare Disease Day and October Wellness participants, the Human Genetics Society of Australasia (HGSA) and the Genomics Industry Alliance (InGeNA), the research community and all the health professionals who are out there committed to providing a quality experience for our community.

The To-Do list certainly doesn't get smaller as we make our small gains and take our small steps. Being on the same team sure helps.

2025 was a year of change for us. Welcoming new team members, our work becoming more focussed in key projects such as The Science Within Us and improving diverse representation while delivering our annual suite of events involved with Rare Disease Day in February and Wellness Month in October.

It's a privilege to walk the path with such dedicated and generous people, families and organisations.

Monica Ferrie

CHIEF EXECUTIVE OFFICER

PRESIDENT'S MESSAGE



Rachel Pope-Couston
PRESIDENT

As I reflect on another year as President of The GSNV Committee, I am once again so grateful to be even a small part of the initiatives, advocacy, and community connection The GSNV team have undertaken in 2025.

The GSNV has continued to speak up and advocate for investment in the rare disease community, but importantly, for investment in the ways that members of the community actually want and need – 'Nothing about us, without us' is not just a nice saying, but truly at the heart of how progress can be made for the rare disease community. I am looking forward to 2026 and seeing more of what The GSNV Team, Committee and Community can do together!

Rachel PopeCouston

PRESIDENT

OUR COMMITTEE



The GSNV began 2025 with a successful Rare Disease Day, bringing together around 40 participants for an engaging panel and meaningful discussion. Feedback highlighted the importance of connection and shared experience within our community.

Throughout the year, the GSNV, as an active member of the LINEAGE / GUARD Community Advisory Group, contributed to advancing the co-design of the 'Australian Public Perspectives on Genomic Data' survey and to national consultations on data sharing and My Health Record, advocating for informed consent and strong safeguards. We also continued to participate in key sector forums, including the Rare Disease Disability Network meeting and an EvoHealth roundtable on access to innovative medicines.

A highlight was the launch of the IMPACT series, supporting community leaders through workshops and practical resources, alongside continued engagement through RareNET sessions. We maintained our strong, ongoing collaboration with the University of Melbourne, supporting student placements and research projects each year.

This year the committee transitioned to bimonthly meetings, which appear to be working well. This rhythm has supported steady progress while allowing space for thoughtful discussion, with no shortage of ideas and initiatives being brought forward at each meeting.

On a personal note, I feel very grateful to work alongside such a dedicated and supportive committee. Our meetings not only drive this important work forward, but also creates space to connect as individuals, with members often sharing personal updates. This has helped strengthen our relationships and fosters a sense of trust and collaboration that underpins everything we do.

Thank you to our committee members and community for their continued dedication. I look forward to another year of steady progress.

Marta Cifuentes Ochoa

SECRETARY

The members of the Executive and Committee who held a position at any time during or since the 2025 AGM are:

President	Rachel Pope-Couston
Vice President	Julie Cini
Treasurer	Giorgina Maxwell
Secretary	Marta Cifuentes Ochoa
Committee Members	Keri Finlay Caitlin Howley



Julie Cini
VICE PRESIDENT



Giorgina Maxwell
TREASURER



Marta Cifuentes Ochoa
SECRETRY



Keri Finlay
GENERAL MEMBER



Caitlin Howley
GENERAL MEMBER

As a previous employee of the GNSV, I have first-hand experience of the important and varied work that the organisation carries out. As a board member, I am proud to continue to contribute to the GSNV in this small way. The GSNV plays a critical role in ensuring that the voice of the rare disease community is heard across Government, research, clinical and industry settings, allowing the people impacted the most are included in the conversation.

Keri Finlay, General Member

Being a member of the GSNV Committee for over 10 years now, I have seen how The GSNV continuously prioritises its role as a representative of the voices of the Rare Disease Community through the ups and downs of advocacy. Witnessing the work of the GSNV, and hearing the perspectives of the community it represents, makes it clear how important it is to keep advocating."

Rachel Pope-Couston, President

OUR ORGANISATION



The GSNV is an organisation underpinned by values and principles. These impact both our priorities and practice. We review our values and advocacy priorities formally during our strategic planning process and each year to determine their ongoing relevance.

This annual report reflects how we live our values.

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

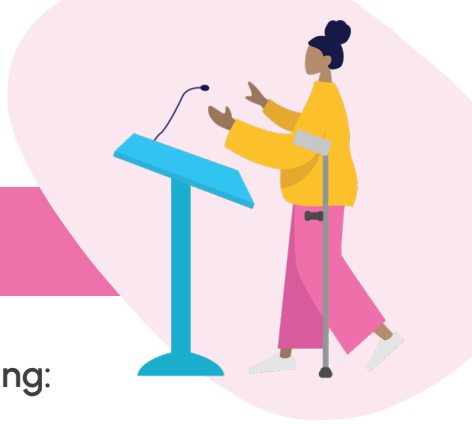
- We are ethical, tolerant and strive to deliver

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 change including:

- 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 that 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, in NDIS, of expertise, of care, of consideration, in research, in clinical trials, in treatment, in environment and in all things
- 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 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
- A national approach to consent and data collection, storage, utilisation, sharing and destruction

CORPORATE GOVERNANCE

The GSNV commenced 2025 with six committee members and completed the year with five.
We were very sorry to say goodbye to Caitlin Howley but delighted that the reason was Caitlin's new role with the Federal Government through Genomics Australia placing her unable to continue in her Board role with GSNV.

The Committee remained stable, committed to strengthening the Board and improving diversity.

Strong governance continues to remain a focus and all relevant policies were reviewed and updated accordingly as part of our annual process.

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

The GSNV Executive and Committee continued to meet via Zoom on the third Tuesday of every second month. Reporting on actions delivered and actions planned as well as deep dives into key themes is a key feature with documentation provided in advance to the Committee.



OUR TEAM

I would like to acknowledge the valued hard work, support, flexibiity, agility and support of the team Hollie Feller, Daniele Noel, Malavika Vasanth and Susie Roczo-Farkas.

The GSNV operated within our budget with a maximum of 2.0FTE. We actively recruited students and volunteers to support our work and support group projects as in the past. We were sad to farewell Hollie at the end of January with Hollie joining the RDNow Research Team at MCRI. All remaining team members were offered an increase in time allocation as a result of Hollie's departure.

The GSNV Executive and Committee and team would like to highlight the contribution of the volunteers and students over the past year. 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. It was another challenging year and the team as always embraced it.

Through our commercial arrangement with the Victorian Clinical Genetic Service (VCGS), the GSNV adopts 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. GSNV would also like to extend our gratitude to the Dr Melody Menezes Clinical Director of VCGS for their ongoing support and engagement.



Monica Ferrie
CEO



Daniele Noel
COMMUNICATIONS AND VOLUNTEER COORDINATOR



Malavika Vasanth
PROJECT AND POLICY COORDINATOR



Susie Roczo-Farkas
RESEARCH PROJECT OFFICER

EFT Allocation as at 31 December 2025			
NAME	**POSITION**	**CLASSIFICATION**	**EFT**
Monica Ferrie	Chief Executive Officer	PT	0.4
Daniele Noel	Communications and Volunteers Coordinator	PT	0.6
Malavika Vasanth	Project and Policy Coordinator	PT	0.6
TOTAL FTE as of 31 December 2025			**1.6**
TOTAL Budgeted FTE			**2.0**
Maximum FTE during 2025			**2.0**
Susie Roczo-Farkas – LINEAGE project (Research Project Officer)			**0.6**

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 2025 we engaged with a large number of organisations and committees through direct consultation, submissions, attendance at events and driving engagement alongside our essential grass-roots community engagement.

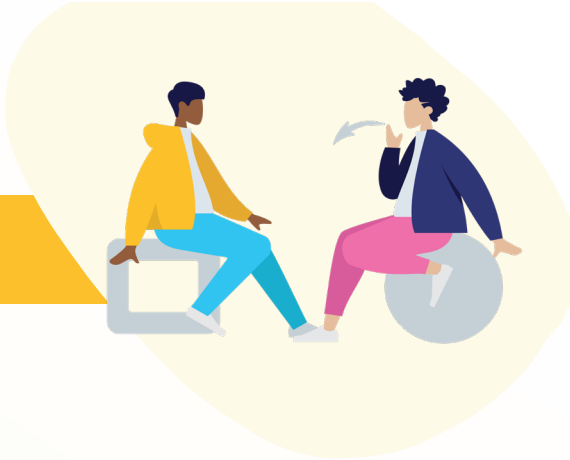
Committees and Engagement - Current

Director – Rare Disease International	
Executive Director	Asia Pacific Alliance of Rare Disease Organisations (APARDO)
Independent Director	InGeNA (Genomics Industry Alliance)
Steering Committee Member	World Dwarf Games – Australia 2027
Department of Health Victoria	Health Information Sharing Management Committee Community Member - Victorian Clinical Advisory Group
Working Group Member	HTAi Rare Disease Working Groups x 2 1. Developing a framework for rare disease in HTA 2. HTA Knowledge Mobilisation to improve HTA for rare disease
Member	GenSCAN Ethics, Legal and Social Issues (ELSI) Working Group (NBS)
Steering Committee member	HTAi Developing Countries working group
Member	RDNow Undiagnosed Disease Program – Consumer Engagement Committee
Chair	Genomics Industry Alliance (InGeNA) Community Advisory Group
Member	Patient Voice Initiative Advisory Group
Member	Deakin University Faculty of Health - Consumer and Research Network
Member	MCRI Expert Reference Group - Consumer Engagement in Research
Member	LINEAGE International Advisory Group (Genomic data usage) LINEAGE Consumer Advisory Group
Chair	Embedding Genomics in Primary Care Project Advisory Group

Research – Within 2 years

Associate Investigator	Australian Genomics, Involve Australia
Associate Investigator	Exploring the lived experiences and needs of peer support providers for couples and/or individuals who have received a prenatal variation in sex characteristics test result.
Chief Investigator	Ethical governance for clinical and genomic datasets. (LINEAGE)
Associate Investigator	"The Epi-Genetics Newborn screening (EpiGNs) Program
Chief Investigator	Embedding Genomics in Primary Care
Chief Investigator	Enabling inclusive population-scale genomics through culturally appropriate participant information, innovation in language translation, and workforce development.
Chief Investigator	Improving Access and Community Trust in Perinatal Genomics for Culturally and Linguistically Diverse Communities: The ImpACT-PG project

RESEARCH AND PROJECTS





Malavika Vasanth

Creating Accessible and Practical Resources for Support Groups

One of the challenges we kept coming back to last year was this: research is only useful if people can actually use it. Through our partnership with the Melbourne Disability Institute and the University of Melbourne, we were part of the *Benchmarking Communities of Support* research project. The findings were thoughtful, detailed, and grounded in lived experience but like most research, it wasn't immediately accessible to the people who could benefit from it most: support group leaders and community members.

As part of this project, I led the development of a plain language resource called *'Creating and Growing Online Support Communities: A Practical Resource for Support Groups'.* The goal wasn't just to simplify the research, but to translate it into something practical and usable for groups navigating the realities of running online communities, often with limited time, capacity, and support.

Throughout the process, what stood out was the complexity behind something that can often look simple from the outside. Online communities can be lifelines. They offer connection, understanding, and a sense of belonging especially for people living with genetic, undiagnosed, and rare conditions who may not find that support elsewhere. At the same time, they rely heavily on the emotional and often invisible labour of moderators and community leaders.

Capturing both sides of that experience felt important. The resource intentionally acknowledges not just what works, but what's challenging: moderation pressures, misinformation, burnout, and sustainability. Rather than positioning these as barriers, it offers practical ways to navigate them, alongside tools, templates, and prompts that groups can adapt to their own context.

This work came to life during our first IMPACT Workshop, where the resource was used as a starting point for discussion rather than a final product. Participants engaged with the content in a hands-on way reflecting on their own communities, sharing challenges, and exploring how the tools could be applied in practice.

Feedback from the workshop reinforced the value of this approach. Participants shared that having the research translated into clear, practical guidance made it feel more relevant and less overwhelming. The flexibility of the resource, being able to "pick and choose" sections based on their needs, was particularly appreciated, as was the focus on real-world challenges faced by moderators and community leaders.

Looking back, this work reinforced that accessibility isn't just about simplifying language. It highlights the importance of slowing down and asking how information is shared, who it is for, and whether it is genuinely usable. It also reinforced the value of co-design and continuous feedback, ensuring that what we create is shaped not just by evidence, but by the people it is intended to support.

Research Involvement

Over the past year, I served as primary supervisor on Ella Sanders' Master of Genetic Counselling research project, which explored genetic healthcare professionals' attitudes and experiences towards online genetic support groups, an area not previously examined in the literature.

My role spanned the full research lifecycle. I contributed to the development of the ethics application and worked closely with Ella to shape the qualitative methodology, including the design of semi-structured interviews and recruitment of practicing clinicians. A key area of my involvement was in the data analysis phase, where I participated in thematic coding and interpretation of interview transcripts.

The study identified an overarching theme of clinician "protectiveness," with genetic healthcare professionals balancing recognition of the benefits of peer support, such as connection and shared experience, with concerns around misinformation, emotional overwhelm, and variability in support group quality. The project highlighted the complexity of how clinicians engage with patient-led support systems, and the influence these attitudes have on referral practices and patient experiences.

Highlights

GSNV's IMPACT Series launched

Last year, the GSNV launched its IMPACT Series workshops, moving beyond research and into real conversations with the people doing the work.

The first session, *Creating and Growing Your Online Support Groups*, unpacked what it actually takes to build strong, safe, and sustainable communities. The second, *Caring for Carers*, shifted the focus inward, giving leaders space to recognise burnout, share challenges, and learn practical ways to protect their own wellbeing.

Both sessions were highly interactive, creating space for connection, shared experience, and practical learning. The series was met with enthusiastic feedback and strong interest in future workshops, highlighting its relevance and ongoing impact.

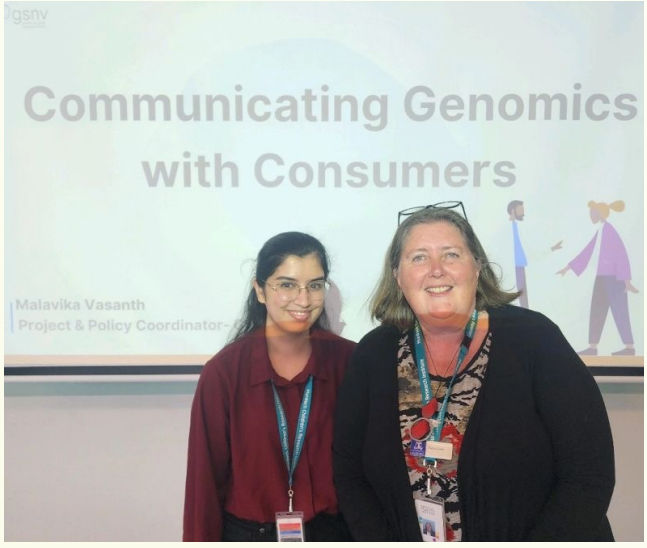


Supporting Inclusive and Accessible Genomic Communication

Malavika delivered a tutorial for Master of Genomic Health students at University of Melbourne on *Communicating Genomics with Consumers*. The session focused on building practical skills in clear, empathetic, and inclusive communication, using real-world scenarios to explore how communication can break down and how to improve it.

Students were introduced to practical tools such as plain language approaches, visual communication, and digital accessibility strategies, alongside the role of organisations like the GSNV in advocacy and peer support.

A central theme was "ask, don't assume," reinforcing the importance of engaging with consumers to ensure information is accessible, respectful, and meaningful. The session was highly engaging, with strong student interest in consumer-centred approaches to genomics.



Malavika Vasanth pictured with A/Prof. Sharon Lewis

COMMUNICATIONS & ENGAGEMENT



Daniele Noel

Communications Impact Report – Growth, Engagement and Strategic Alignment

In 2025, GSNV's communications function delivered a purposeful shift to better align strategy, content, and engagement with organisational priorities. Driving community engagement, communication strategies and tactics demonstrated a cohesive and intentional approach to strengthening trust, improved consistency, and amplify the voices and needs of the genetic, undiagnosed and rare disease community.

Communications activity continues to strongly align with GSNV's strategic priorities, with clear, consistent messaging that centres lived experience, diversity of perspectives, and community-first principles. This has strengthened GSNV's credibility and sector influence, evidenced by increased engagement across all channels and growing attendance at our online and in-person forums and events. Flagship initiatives such as **RareNET, Rare Disease Day**, and **October Practical Wellness Month** have become trusted platforms for connection, learning, and capacity building, attracting diverse audiences including people living with rare disease, support group leaders, clinicians, researchers, and students.

Digital Engagement

Digital engagement continues to grow through purposeful content shared consistently via social media, eNews, and the website.

Social Media

~1.4k	Total Followers
718	Total Followers
674	Total Followers

Care for Rare eNews

650 SUBSCRIBERS

Care for Rare eNews reached ~650 subscribers in 2025, with strong engagement (50–57% open rates) and high delivery performance.

The newsletter remains GSNV's most effective digital communication channel for reaching community, sector and policy audiences.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Genetic Support Network Victoria
Care for Rare
information, resources and updates for support groups of individuals and their networks living with genetic, undiagnosed and rare diseases (GUaRD)
Issue: February 2026
Instagram | Facebook | LinkedIn
CEO Message
Hello,
GSNV Rare Disease Day 2026
Friday 27 February

Collectively, these outcomes demonstrate communications as a key enabler of GSNV's impact, building visibility, strengthening sector relationships, and supporting advocacy and community capacity.

RARE DISEASE DAY

February 28th, 2025

"More than you can imagine"

The Genetic Support Network of Victoria (GSNV) marked Rare Disease Day (RDD) 2025 with a thought provoking and well attended event, bringing together our community members, people living with rare disease, clinicians, researchers and sector partners to reflect on the past, present and future of rare disease care. Hosted at the Larwill Hotel and generously sponsored by Alexion, the event welcomed more than 40 attendees, creating a rich and inclusive forum for dialogue, reflection and connection.

Aligning with the 2025 international Rare Disease Day theme, "More than you can imagine", GSNV explored this concept through a unique lens: where the rare disease community imagined it would be at the turn of the century, compared with where we now find ourselves nearly a quarter of the way through it. Participants were invited to consider whether progress has delivered more than expected, or whether it has unfolded differently to what was once imagined.



The event concluded with thoughtful questions and contributions from the audience focused on future priorities, urgency, and collective impact. This highlighted both the immense potential ahead and the need for sustained, coordinated action to ensure advances translate into equitable access, improved care and meaningful outcomes for people living with rare diseases in Australia.

ALEXION®
AstraZeneca Rare Disease

At a Glance

Genomics must be future-ready:
Reanalysis and retesting are essential to improving diagnoses. Stronger links between research and diagnostics are needed.

Collaboration drives impact:
Partnerships increase visibility, funding opportunities, and advocacy strength for small and ultra-rare communities.

Support groups are under strain:
Volunteer-led organisations, often run by people with lived experience, face burnout and financial pressure despite being central to education, advocacy, and policy change.

Lived experience is expertise:
Advocates hold deep, valuable knowledge that must be respected and financially recognised to ensure sustainability and prevent burnout

National coordination is needed:
Improved, ethical data connectivity and a coordinated national hub would strengthen access to research, trials, support, and networks across Australia.

Rare Disease Day 2025
Top L-R: *Daniele Noel, Agnes Nsofwa, Mel Anderson, Monica Ferrie, Joshua Schultz,*
Bottom L-R: *Dr. Melody Menezes, Prof. Zornitza Stark, Louisa Di Pietro, Dr. Erin Evans, Libby Noble*

GSNV extends sincere thanks to our dedicated volunteers and to all panellists and speakers who shared their expertise and lived experience so generously. Their diverse insights underscored a shared commitment to driving hope, progress and a more inclusive future for rare disease care across Australia.

OCTOBER PRACTICAL WELLNESS MONTH



Supporting our Community's Mental Health and Wellbeing

In 2025, GSNV delivered October Practical Wellness Month workshops acknowledging the critical role Support Group leaders play as online community leaders and lived experience experts.

Through the newly developed **IMPACT** series, the September workshop on building online communities was intentionally paired with a follow up mental health session in October focused on the emotional demands of community leadership.

Led by Melbourne University Lecturer Dr Jennifer Beckett and Venessa Paech, the workshop explored compassion fatigue, boundary setting, and sustainable coping strategies for those managing online support groups in a 24/7 environment. Strong attendance and engagement reflected the relevance of mental health supports for leaders navigating complex and often isolating roles.

This focus continued in RareNET, where Leukodystrophy Australia's Family Advocate and Social Worker Claire Kingsley, alongside lived experience parent Joel Taggart, joined the forum to explore rare specific mental health needs. Facilitated by Genetic Alliance Australia CEO Emma Bonser, the discussion highlighted intersectional experiences across rare, ultra rare and undiagnosed communities, gendered caregiving impacts, and the importance of culturally and psychologically safe care. The session reinforced GSNV's commitment to compassionate, community led approaches to mental health advocacy.





RARENET COMMUNITY FORUM



RareNET Community Forum – Building Connection, Capacity and Collective Voice

In 2025, RareNET strengthened its role as the GSNV's and its strategic relationship with Syndromes Without A Name (SWAN) and Genetic Alliance Australia (GAA), known as the GUARD Collaborative, to become a flagship community engagement forum.

Providing a trusted space for connection, shared learning and sector dialogue, RareNET brought together people living with rare disease, support group leaders, clinicians, researchers and advocates to explore issues that matter most to the community, grounded in lived experience and collective knowledge.

Throughout the year, consistently strong attendance demonstrated RareNET's value as a responsive and relevant platform, supporting peer connection, reducing isolation and strengthening sector relationships.

With purposeful curation of topics and speakers, RareNET reinforced the GSNV's strategic commitment to community led engagement, trust building and visibility, ensuring diverse voices are heard and supported while positioning the GSNV as a convenor and connector across the rare disease ecosystem.

RareNET Program Highlights for 2025 include:

MARCH

Speaker:
Sharon Lewis

Unlocking Research for Change

Partnering with Students to Drive Advocacy Impact

JULY

Speaker:
Monica Ferrie

#Resolution4Rare

What does it mean, and how does it affect us?

OCTOBER

Speaker:
Matilda Haas

RareNET Spotlight:

Matilda Haas – Director, Community Impact and Partnerships, Genomics Australia

NOVEMBER

Speaker:
Julia Mansour

RareNET Spotlight:

Julia Mansour, CEO Human Genetics Society of Australasia (HGSA)

GENETIC UNDIAGNOSED AND RARE DISEASE

gsnv Genetic Support Network Victoria

genetic alliance australia

Syndromes Without A Name



VOLUNTEER AND STUDENT CONTRIBUTIONS

Thanks to the dedication and support of our volunteers and University of Melbourne Masters of Genetic Counselling and Masters in Genetic Health student partners, GSNV delivered a wide range of projects and activities that strengthened our community engagement priorities throughout 2025.

Our volunteers played a vital role in the successful delivery of key initiatives, including Rare Disease Day. Their support spanned event promotion, in person assistance on the day, and thoughtful engagement with guests and speakers, helping to create a welcoming and well coordinated experience for our community.

Volunteers also contributed to our communications activities, supporting the delivery of consistent, high quality social media content and our monthly eNews in alignment with GSNV's brand and stakeholder messaging. Through this involvement, volunteers gained greater insight into GSNV's strategic priorities and a deeper understanding of our working environment.

This year, we were also pleased to partner with the University of Melbourne's Master of Genetic Counselling Fit for Practice program. Across the support group network, students were attached to organisations to gain experience and understanding of community needs and expectations and support group roles, capabilities and capacity in supporting their community. Post placement presentations demonstrated the value of these placements to students and support groups. The students commonly acknowledged a practice changing and thought provoking experience. At GSNV, students supported key organisational projects, including website updates and the establishment of our IMPACT workshops. Working alongside enthusiastic first year students, the GSNV team provided mentoring and coaching across our advocacy initiatives, helping future genetic counsellors build awareness of the challenges and opportunities faced by the genetic, rare, and undiagnosed disease community.

We are deeply grateful to all our volunteers and student partners for their generosity, commitment, and ongoing contributions to improving the lives of people living with genetic conditions, undiagnosed conditions, and rare diseases.



Malavika Vasanth with Rare Disease Day volunteers Nicole Bester, Ashna Nimbalkar

RESEARCH INVOLVEMENT





Susie Roczo-Farkas

Research continues to play a vital role in shaping the health journeys of people living with genetic, undiagnosed, and rare conditions.

In 2025, GSNV strengthened its commitment to meaningful research involvement through national initiatives such as LINEAGE, alongside creating opportunities to support emerging researchers. We recognise that impactful research begins with, and belongs to, the communities it aims to serve.

In partnership with the University of Melbourne, GSNV contributed to the development of student-led research projects within the Master of Genetic Counselling and Master of Genomics and Health programs. Two projects initiated in 2025 explore neurodivergent experiences of genetic services and hospital discharge experiences for families of children with complex care needs, reflecting shared priorities across the sector.

This work reflects a commitment to co-learning, bringing together students, researchers, clinicians, and community perspectives, and strengthening research as a tool for partnership, shared learning, and meaningful system change.

Project: LINEAGE Study

Community Perspectives on Genomic Data Governance

(Funded by Medical Research Future Fund [MRFF] [2022-2027])

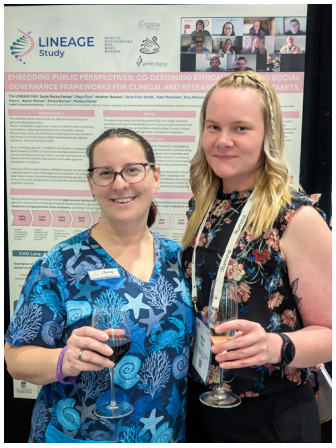
Building on the establishment of the LINEAGE–GUARD Community Advisory Group (CAG) in 2024, 2025 marked a transition from establishing the CAG to demonstrating its impact in shaping research and national discussions.

Under the leadership of Monica Ferrie (Chief Investigator) and Susie Roczo-Farkas (Project Lead) at GSNV, the CAG made a significant contribution to shaping key elements of the LINEAGE Study through ongoing co-design, discussion, and knowledge exchange. Through a series of structured meetings and workshops, members explored key issues including trust, consent, data access, transparency, and control. This work heightened awareness among consortium members, prompting critical reflection on the implications and significance of their work. The CAG's insights reinforced the importance of getting the framework as right as practically possible, highlighting that decisions in genomic data governance have real and enduring consequences for the people they affect.

Delivering Real-World Impact Through National Engagement – HGSA 2025

A key highlight of the year was strong representation at the HGSA Conference, where the CAG presented their conference poster and led a dedicated workshop segment, alongside engagement with the broader LINEAGE consortium.

The poster demonstrated how lived experience was embedded within the LINEAGE Study, showing how community input shaped research design and challenged traditional assumptions. Building on this, the workshop translated these insights into practice. Using real-world and future-focused scenarios, it prompted clinicians, researchers, and other stakeholders to reconsider routine approaches to consent, data use, and decision-making.



These discussions resonated strongly and continue to be referenced in ongoing sector conversations.

The role-play format, grounded in lived experience, surfaced insights that traditional academic presentations often overlook. Attendees reflected on the unintended impacts of routine clinical and research practices, recognising how patients and families experience them. This created space for honest dialogue, critical reflection, and a clear willingness to rethink practice.

Reshaping Research Through Lived Experience

The CAG demonstrated that embedding lived experience strengthens both the quality and relevance of research. Community contributions ensured that key research outputs, including the national survey, were designed through a lived-experience lens, shifting the focus from academic constructs to what genuinely matters to people and families. This approach was recognised in sector discussions as a novel, community-driven contribution to genomic research.

Engagement with the CAG also challenged assumptions, exposed previously unrecognised risks, and connected theoretical concepts such as trust and consent to real-life implications. This led to research that is more grounded, relevant, and responsive to the community's needs and expectations.

Moving Beyond Engagement to Influence

The CAG's role went beyond mere influence. Their input shaped key project outputs, including the co-designed national survey on public trust, communication, and the use of genomic data. CAG perspectives also informed broader sector discussions, including consideration of direct patient access to genetic test results via My Health Record. These discussions highlighted the ethical, emotional, and practical implications of unsupervised access to complex results, reinforcing the need for safeguards and patient-centred communication.

Across this work, the CAG brought forward community-defined priorities including autonomy, ownership, fairness, transparency, and safety, reinforcing that governance frameworks must reflect what matters to the people whose data is being used.

Leading a Shift in Research Practice

This work reflects a clear shift from consultation to partnership. Community members are not only informing research but actively shaping its direction, challenging assumptions, and influencing its outputs.

Through the LINEAGE–GUARD CAG, GSNV demonstrates that embedding lived experience strengthens research design, improves relevance, and builds trust. It also shows that governance frameworks must extend beyond technical design and remain grounded in the realities of the people they are intended to serve.



Useful links:

Further details about the CAG and its activities:
https://guard.org.au/lineage-project-guard-consumer-advisory-group-cag/

More information on LINEAGE: https://lineagestudy.org.au/



Project: Embedding Genomics into Primary Care

The project is part of the Embedding Genomics in Primary Care research program and has a direct focus on Developing resources for people considering reproductive genetic carrier screening (RGCS) in Australia.

This project aims to:

Generate evidence-based resources (which may include information sources and/or a decision aid) to equip the public for further discussion with their general practitioner (GP), obstetrician or other healthcare provider about Reproductive Genetic Carrier Screening (RGCS). These resources will enable people considering reproductive carrier screening to have the knowledge base and value-alignment needed to make value-consistent decisions about whether to undertake RGCS. People living in Australia who are planning a pregnancy or in pregnancy can access a range of RGCS options through a Medicare provider, such as their local GP.

This study has generated evidence about the views, attitudes, opinions and beliefs of potential consumers regarding how they want to receive information needed to make decisions related to RGCS. This evidence will inform practice of healthcare professionals discussing RGCS with patients and the resources developed may support users' decision-making about RGCS. This project is being led by researchers at the Murdoch Children's Research Institute in Melbourne and Macquarie University in Sydney. The Project Advisory Group is chaired by the GSNV CEO.

Project: Epi-Genomic Newborn Screening (EpiGNs) Program

EpiGNs is examining if conditions linked to intellectual disability, autism, severe obesity and seizures can be identified as part of the heel prick test performed in the first year of life of 100,000 infants in Victoria. Detecting these conditions from birth can lead to life-altering effective treatment and care pathways which are not possible without early diagnosis. The EpiGNs program is using a new screening approach to identifychanges in the activity of genes. This is helping to detect developmental conditions including Fragile X, Prada Willi, Angelman Syndrome, Dup15q, Turner, XXY, XXXY, XXYY Syndromes. The project has published a number of important papers to date, presented globally and has taken a global leadership role.

The project stakeholder group is convened by GSNV CEO.

Publications

1. Downie L, Godler DE, et al. Gold NB. (2026) Operationalizing the Wilson-Jungner principles for the genomics era: Consensus recommendations from the International Consortium on Newborn Sequencing. Genet Med. 28(1):101618. doi: 10.1016/j.gim.2025.101618.

2. Godler DE, Ling L, Gamage D, Bui M, Field MJ, Amor DJ. (2025) Extended newborn screening using DNA methylation testing for fragile X syndrome in 17 107 infants. Genet Med. (Accepted 18 December 2025)

Rare Diseases Now (RDNow)

RDNow is an exciting initiative that provides genomic diagnoses and personalised care to children at The Royal Children's Hospital (RCH).

About RDNow

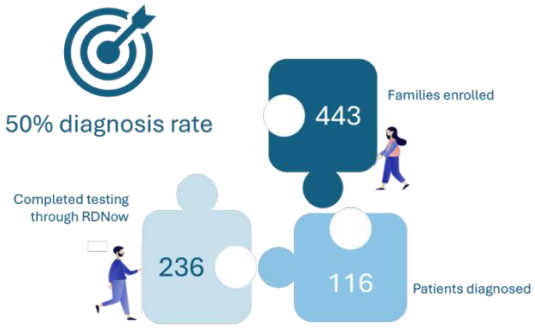
In 2025 RDNow helped children and their families by providing a pathway to look for a diagnosis for those who remain undiagnosed after clinical genomic tests. RDNow used advanced analysis tools to re-analyse genomic information (exome and/or genome sequencing data). It provided access to specialised testing such as long-read genome sequencing, RNA sequencing and proteomics. This gave the children enrolled in the project the best chance of receiving a diagnosis which could lead to access to the latest clinical trials and treatments, and supports. RDNow actively engaged with the rare disease community to produce a suite of educational resources that included two documents listing links to existing, patient/family-facing information explaining genetics, genomics and multi-omics testing, and three guides that explained technologies used in the RDNow program. RDNow's Consumer Engagement Committee, that included representation from GSNV, provided advice and guidance to the RDNow Executive team to ensure the project's goals were aligned with consumer need.

RDNow at a glance

Since it began in 2020 the RDNow project has recruited over 440 families through referrals from the RCH.

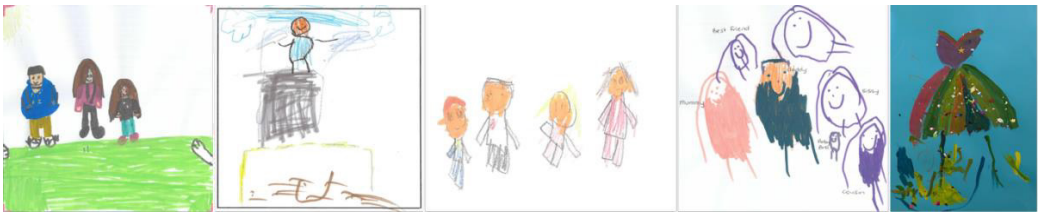
As of the end of December 2025:

- Testing and analysis were complete for 236 participants.
- 116 participants had received a diagnosis through the RDNow program.



- 120 patients remained undiagnosed after completing RDNow testing.
    - The data of undiagnosed patients will continue to be analysed as new gene discoveries and technologies become available.

For more information about the RDNow project please see our website - https://www.mcri.edu.au/research/projects/rdnow



Drawings provided by RDNow families and used with permission

The Royal Children's Hospital, 50 Flemington Road
Parkville, Victoria 3052 Australia
E rarediseasecoordinator@mcri.edu.au
P 03 8341 6358

RARE DISEASES NOW
is a collaboration between
Murdoch Children's Research Institute
and Victorian Clinical Genetics Services

gsnv
Genetic Support
Network Victoria

THANK YOU

The GSNV continues to appreciate and value our community's gifts of lived experience, time, perspective, talent, expertise and knowledge. We thank those who have donated and those that continue to offer support to our organisation, our community and each other.

We are especially grateful for the ongoing support of the Department of Health (DoH), who continue to provide funding and support for our important work. We thank in particular Marianne Griffin and Sonia Caruana for an ongoing supportive relationship with the GSNV and their wisdom and counsel.

We are thankful for the professional relationships including support and advice from all our stakeholders including people with genetic conditions, clinical services, universities, support groups, industry, researchers and so many others. A special mention to Melody Menezes for her ongoing support and generous time.



VICTORIA State Government | Department of Health

FINANCIAL REPORTS

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W vcgs.org.au ABN 51 007 032 760

30 April 2026

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 Grant Thornton who are our External Auditors. The accounts for 2025 have been audited by Grant Thornton in accordance with this practice.

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

Kind regards,

Deb Sullivan

Chief Financial Officer

Murdoch Children's Research Institute /

Victorian Clinical Genetics Services

Profit & Loss Statement - Genetic Support Network of Victoria

December-2025

Profit & Loss Statement - Genetic Support Network of Victoria ($000's)				
	Year To Date		Annual	
Description	Budget	Variance	Budget	Forecast
Turnover	**$373.0**	**($40.1)**	**$373.0**	**$332.9**
Government grants and funding	**$373.0**	**($40.1)**	**$373.0**	**$332.9**
DHHS grants	$250.0	($0.0)	$250.0	$250.0
* Other grants	$123.0	($40.1)	$123.0	$82.9
Operating costs	**$373.0**	**$92.5**	**$373.0**	**$280.5**
Salaries and Wages	**$198.4**	**$22.8**	**$198.4**	**$175.6**
Employee Entitlement expense	$11.8	$20.6	$11.8	($8.8)
Gross Salaries	$187.0	$22.1	$187.0	$164.9
Other Employment Costs	($22.7)	($22.8)	($22.7)	$0.1
Superannuation	$22.3	$2.9	$22.3	$19.3
Consumables	**-**	**($0.1)**	**-**	**$0.1**
Consumable Costs	-	($0.1)	-	$0.1
Travel expense	**$2.0**	**($2.5)**	**$2.0**	**$4.5**
Travel	$2.0	($2.5)	$2.0	$4.5
Other expenses	**$172.7**	**$71.3**	**$172.7**	**$101.4**
Computer Software & Expenses	$0.9	($0.6)	$0.9	$1.5
Insurance	$1.5	$0.3	$1.5	$1.2
Memberships	$0.3	($0.5)	$0.3	$0.7
Other administrative costs	$164.5	$66.7	$164.5	$97.8
Staff Training & Conferences	$5.5	$5.5	$5.5	-
Telephone	-	($0.2)	-	$0.2
Impairment loss	**-**	**$1.1**	**-**	**($1.1)**
Bad Debts	-	$1.1	-	($1.1)
EBICDA	**-**	**$52.4**	**-**	**$52.4**
Operating Result	**-**	**$52.4**	**-**	**$52.4**

Run Date: 14/05/2026