

genetic support network of victoria

*empowering * connecting * supporting*

**ANNUAL REPORT
2012 – 2013**



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genetic support network of victoria

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COMMITTEE AND STAFF

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

Moira Rayner	President
Katarina Rodonic	Vice President
Margherita Coppolino	Treasurer
Charlotte Stockwell	Secretary
Emma Swain	Assistant Secretary
Christine Williams	Committee
Maree Kinniburgh	Committee
Kay Timmins	Committee
Karri Carboon	Committee (18/10/12 – 10/07/13)

The Committee of the Genetic Support Network of Victoria (GSNV) operates through an Executive and general committee with delegated authority and terms of reference according to the GSNV Inc. 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, who work under an operations and line management process facilitated by the Victorian Clinical Genetics Services (VCGS).



CORPORATE GOVERNANCE

The GSNV Inc. current rules and principles of incorporation stipulate that not more than 16 Members each of whom shall be elected or appointed under Rules 65, 71, or 76 to 80 are to make up the GSNV committee.

At all times, at least two-thirds of the Members of the Committee must meet at least one of the following criteria:

- have a genetic condition;
- be a carrier of a genetic condition;
- be a sibling of a person with a genetic condition;
- be a parent of a person with a genetic condition;
- be a representative from a genetic support group;
- be a spouse of a person with a genetic condition

Representation on our committee by individuals living with and affected by genetic conditions, health professionals, researchers, educators and interested members of the community is important to us.

In the period since the previous AGM, the GSNV Executive and Committee met on the third Thursday of the month at the Murdoch Childrens Research Institute (MCRI) to discuss and manage elements of the operations of the organisation and further develop strategies to best meet our objectives, goals and priorities. Committee members participated in person or via the option of 'phone in' teleconference.

The Committee also met for special purposes throughout the year as business arising necessitated.

The current GSNV Rules can be found at:

http://www.gsnv.org.au/media/50026/ratified_constitution_as_at_2006_agm.pdf

It is noted that Current rules of the GSNV are applicable until 26th November (including this AGM) and that according to the Associations Reform Act 2012 the 'New' Model Rules apply when and where they are inconsistent with existing the GSNV Inc. existing rules. After 26 November 2013 it is recommended by the President that the Associations Reform Act 2012 new model rules automatically apply, and the incoming new Committee decides on any sub rules.

STAFF AS AT JULY 2013

Group Leader	Louisa Di Pietro
Genetic Support Coordinator	Marleen Susman
Genetic Support Assistant	Emma Swain
Administration Assistant	Catherine Beard
Administration Assistant	Emily Higgs

In the period between previous AGM and this report, the GSNV has undergone some changes in relation to staffing and operations. The GSNV currently operates with the equivalent of 2.2 full time (EFT) with all staff members classified as part time or casual. Given that the GSNV actively recruits graduates and students from the Master of Genetics Counseling Course (University of Melbourne) we have a high staff turn around. Our staff members often move on to pursue career related roles in Genetic Counselling.

The GSNV is very keen to expand the skills set of its staff force and in turn produce outcomes reflective of those skills. We are most pleased to introduce Marleen Susman as our new Genetic Support Coordinator. Marleen has completed a PhD and is MHGSA (Genetic Counselling) qualified.

Reports from the GSNV President and Group Leader here below outline the details of such changes for full transparency to our members. Regular communications and notices in relation to staffing, management and committee process are provided to the GSNV committee and line management.

The agenda for Committee meetings is prepared in conjunction with the Group Leader and the Secretary. Reports and documents are distributed to Committee members in advance of the meeting and each Committee member is free to raise agenda items and general business.

On occasion in the previous year the GSNV Committee has invited external parties to attend meetings and has sought or taken external advice, when considered appropriate.

ABOUT THE GSNV

OUR VALUES

Integrity

We are ethical, tolerant and strive to deliver

Respect

We respect diversity and promote diverse opinion and approaches

Empowerment

We strive to empower people to overcome the challenges of living with a genetic condition or caring for someone with a genetic condition and share their lived experience to inspire others

Connectedness

We are committed to fostering ongoing partnerships and relationships in support of our vision

OUR VISION

Purpose, dignity and choice for people with genetic conditions

OUR MISSION

- To influence direction and policy that empowers people, organisations and institutions that serve people touched by genetic conditions
- To develop the leadership of support services and stakeholders

To fulfill our mission we aim to:

Empower

- Empower individuals and their families to reach positive health and life outcomes
- Empower people to act as community representatives
- Represent the interests and views of individuals affected by genetic conditions to the community as well as the State and Federal governments
- Promote consumer participation and feedback
- Provide educational opportunities to individuals and their families, health professionals and the wider community
- Advocate on behalf of others

Connect

In order to support people affected by genetic conditions the GSNV aims to connect:

- Individuals/Families
- Service Providers
- Community
- Government, and
- Health Professionals

Support

The central aim of the GSNV is to provide a point of contact for individuals and families seeking information and support.

We do this by:

- Providing timely, accurate and balanced information
- Referring to support groups and other community services
- Referring to clinical services
- Facilitate peer support
- Assisting with the establishment of new support groups and the expansion of existing groups
- Providing educational opportunities such as workshops, seminars, patient information sessions and peer support training
- Supporting clinical services and the delivery of quality healthcare

WHO DO WE SERVE?

- People who are touched by genetic conditions
- Support Groups and Stakeholders who represent people who are touched by genetic conditions

WHAT DO WE NEED TO BE TO SERVE SUCCESSFULLY?

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

PRESIDENT'S REPORT

A small and energetic management committee has been very active this year, as the GSNV staff have worked through their new reporting arrangements to the VCGS.

We invited A/Prof David Amor to join the management committee as its VCGS representative and he was gracious enough to accept.

The MOU we flagged as necessary last year has in fact worked informally without it, because of the clearer understanding of our respective roles: the GSNV setting the strategic direction, and the VCGS assisting the staff to implement those views.

The Committee has now established, with the assistance of Secretary Charlotte Stockwell in particular, a very new strategic plan, simple and practical, on which the Group Leader has been able to develop an operational plan, KPIs for staff and a work plan for the year. We have also worked to a timetable for the monthly meetings of the Committee, to help us cover all bases for plans and operational activities and an action plan.

Our meetings have concentrated on strategic objectives and been short, productive and trouble free. We have benefited from a broader input of committee members, new faces and new ideas. It remains our concern that the small management committee expands its base so that more people directly affected by or supporting and servicing people with genetic conditions participate directly in working for a better deal for all Victorians.

The new line management arrangements have not been, as feared, disruptive of relationships between the committee and GSNV staff who are being line-managed by VCGS Director. The relationship with VCGS has been effective in operations management. However the financial basis for the GSNV's position is manifestly inadequate and a new emphasis is required, in 2014 and ahead, for serious fund raising. To this end we have created a Finance Sub Committee whose job it will be to develop a fundraising strategy as a matter of some urgency: we do not have a recurring grant for the on costs that were met, in 2012, by a one-off VCGS arrangement.

GSNV has done very well this year.



Moira Rayner
GSNV President



GROUP LEADER'S REPORT

As Group Leader of the GSNV it is my pleasure to report on the year that has passed.

With a great deal of energy gone into improving the GSNV's governance processes, operating procedures and strategic planning process, I am pleased to provide the following reflection and highlights with a sense of accomplishment.

I thank the incumbent GSNV Executive and Committee for their ongoing support and dedication and look forward to leading the GSNV team well into the future.

The development of a simple, practical and achievable strategic plan has been key to a successful start to 2013. With this new plan accompanied by a strong and clear business actions plan and a committee planner, the GSNV has significantly improved its efficiency, transparency and understanding of its organisational goals.

With three major documents guiding and directing how we conduct, report and measure our business operations I believe we have increased our efficiency and effectiveness.

The momentum created throughout the 2013 strategic planning process will be carried forward into the next two years with an associated revision of our Constitution/Rules and Articles of Association in relation to recent changes to the Association's and Incorporations Reform Act.

In a climate of expected increased in demand for GSNV services, and taking advantage of our unique position in being co-located with clinical services and research, our major goal during the next three years will be to ensure that our services are clear and accessible and our programs remain relevant, creative and add value to clinical and research output.

In the latter half of 2013 I report an upward trend in the demand for our input into the planning of services and support, growth in our efficiency, good relationships with our community of interest, and with those who fund and auspice our work.

The following section provides an overview of key business areas and our work over the previous year.

OPERATIONS AND MANAGEMENT PROCESSES

The GSNV has undergone a degree of assessment and continuous improvement over the last 12 months. With further reflection on our operating and management processes the development of strategic priorities and committee processes, corporate arrangements and staffing, we have once again introduced some new processes and faces.

Despite the change, the work undertaken by the GSNV team has kept our attention firmly on network activities, health policy and services, quality information, collaborative projects, advocacy for those affected by genetic conditions and ongoing support to our member organisations and groups who support the community.

Earlier in 2012 the GSNV reviewed its management practices and corporate relationship with the VCGS*, in response to some much needed clarification of corporate responsibilities, cost recovery, and liabilities. In remaining co-located within the MCRI the GSNV has for many years relied on the kind support of MCRI, the corporate services of MCRI and a loose joint projects arrangement.

The strategic planning process conducted by the GSNV committee in 2011 teased out our weaknesses in terms of this arrangement and where we might need to make change. Significant changes within the MCRI in terms of its corporate policy, pressures on accommodation options and the need for the GSNV to meet infrastructure charges as a 'Group' in the broader VCGS structure also placed a degree of pressure for review.

In March 2012 the GSNV entered a formal line management arrangement with the VCGS, with GSNV staff directly reporting to A/Prof David Amor, Director of VCGS for all operations and day to day management issues. This has been a very positive change in terms of reporting methods and day to day operations and has offered the GSNV team a supported operating environment.

With the development of a simple and practical strategic plan, a committee planner, a business actions plan and a full risk assessment, the GSNV has in the last 12 months operated with greater clarity and efficiency. The development of good business basics and a clear understanding of our organisational performance indicators and measures has strengthened our capacity.

* VCGS is a subsidiary company of MCRI

WORKFORCE PLANNING

As part of a full review of our work force planning and budget, the GSNV has undergone some staffing changes and our team currently consists of: Catherine Beard (Administration), Emily Higgs (Genetic Support and Communications), and in the near future we introduce Nancy Amin (Administration Support). In September of this year we also said goodbye to Emma Swain (Genetic Support and Communications). The GSNV currently has 2.2 EFT with a sufficient range of skills to accommodate core activities.

By June of 2014 and in accordance with formal performance review processes, the GSNV will have assessed staffing requirements and plan for any changes to EFT levels.

In support of the GSNV and in relation to a closer affiliation of the VCGS I point out that the GSNV has and will continue

to engage the advice and professional assistance of VCGS staff in delivering education and quality support services. On numerous occasions this year we have engaged VCGS staff and collaborated on projects. The GSNV has also been readily available to discuss and provide feedback on research and services provided by VCGS such as feedback on the VCGS three condition reproductive carrier screening program. This affiliation is mutually beneficial and allows the GSNV to draw on expertise and human resources as needed.

I take this opportunity to extend a formal thank you to former GSNV staff – Lynley Donoghue, Christine Chan and Emma Swain for their tireless contribution and work with the GSNV. Lynley, Christine and Emma have all contributed something special to the GSNV. I wish them all the very best for the future.

EFT Allocation as at 17 October 2013		
NAME	POSITION	EFT
Louisa Di Pietro	Group Leader	0.8
Marleen Susman	Genetic Support Coordinator	0.4
Catherine Beard	Administrative Assistant	0.3
Emily Higgs	Administrative Assistant	0.3
Nancy Amin	Administrative Assistant	0.1
TOTAL		1.9
TOTAL Budgeted EFT		2.2

GOVERNANCE

Thank you and goodbye to Kerri Carboon and Christine Williams who are both retiring from general committee. I also thank Margherita Coppolino for her contribution as Treasurer and is now moving on to pursue big things in the Disability Advocacy and Services Sector.

I thank all retiring committee members for their assistance to the GSNV team and their dedication to our important work.

I give my thanks to our Executive and committee who have worked through the challenges of changes to management and offered ongoing support of my role and work/life balance.



FIGURE 1: GSNV ORGANISATIONAL CHART

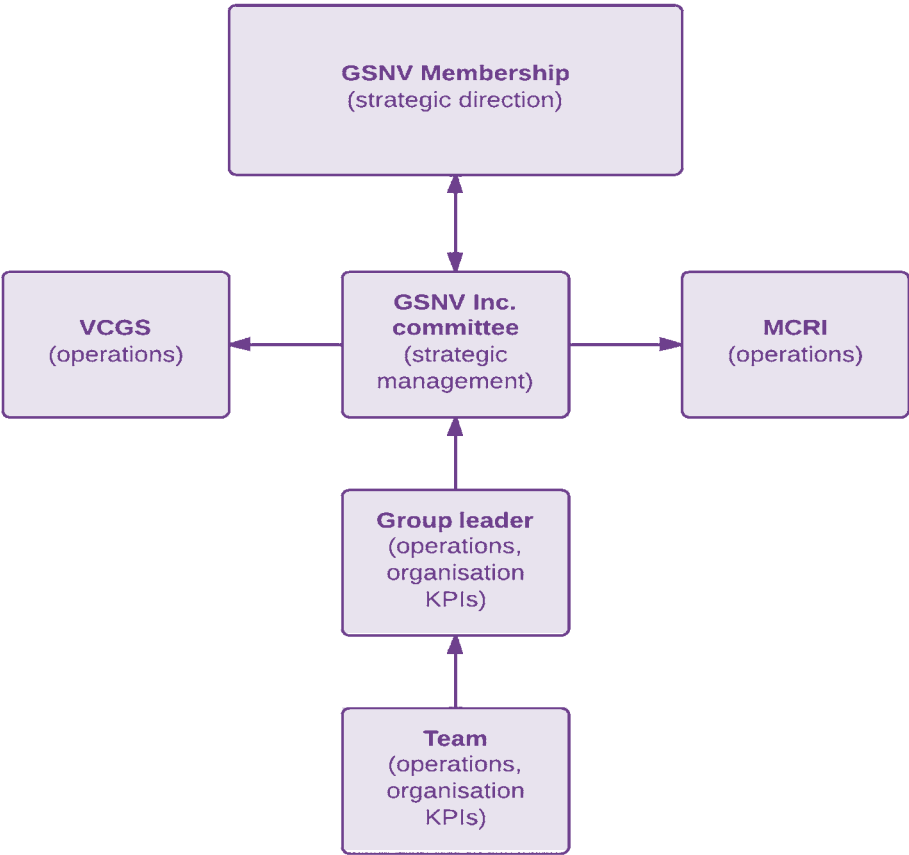
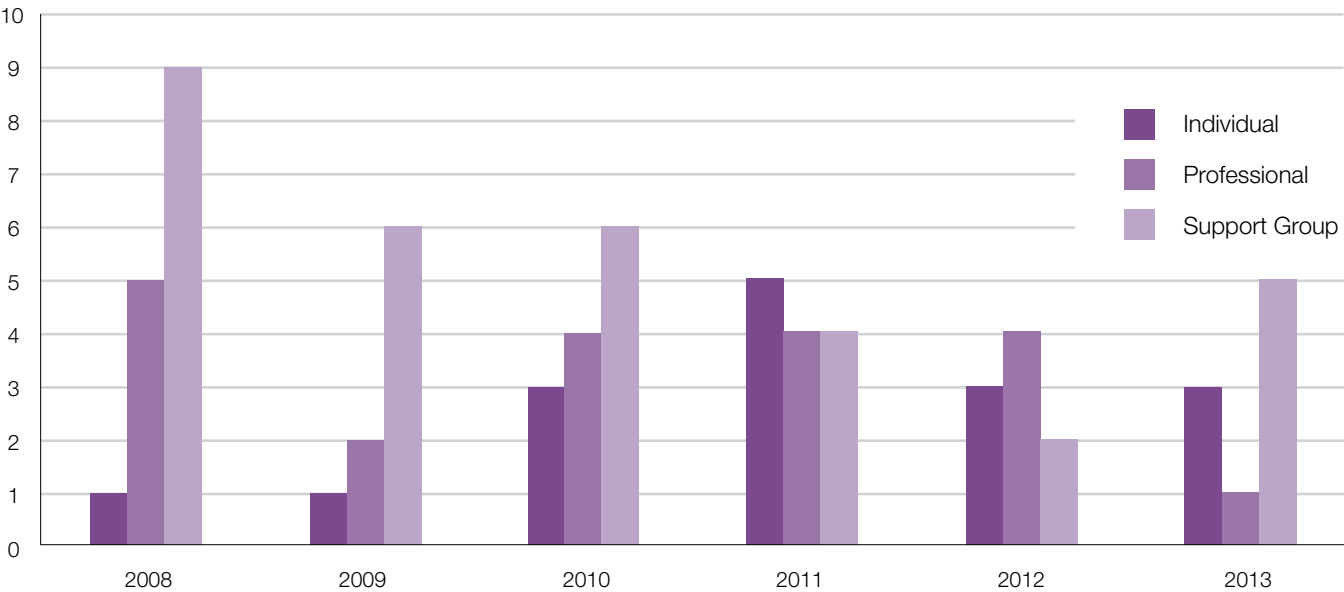


FIGURE 2: COMMITTEE COMPOSITION 2008-2013



BRANDING AND COMMUNICATIONS

The GSNV successfully completed the first stage of a branding and communications audit in 2012. This process formed part of a full services review and was designed to develop reliability, quality, recognition and a range of formats in all print and electronic communications. Brand consistency and recognition in compliment to our working partner VCGS was also a major factor in this change.

The formal launch of the GSNV website in February 2012 also entailed a large scale database and web platform integration project. With testing and tweaking the functionality for both our website and data platforms, we are pleased to report they both now speak to each other and we have great control over our throughput and generated data.

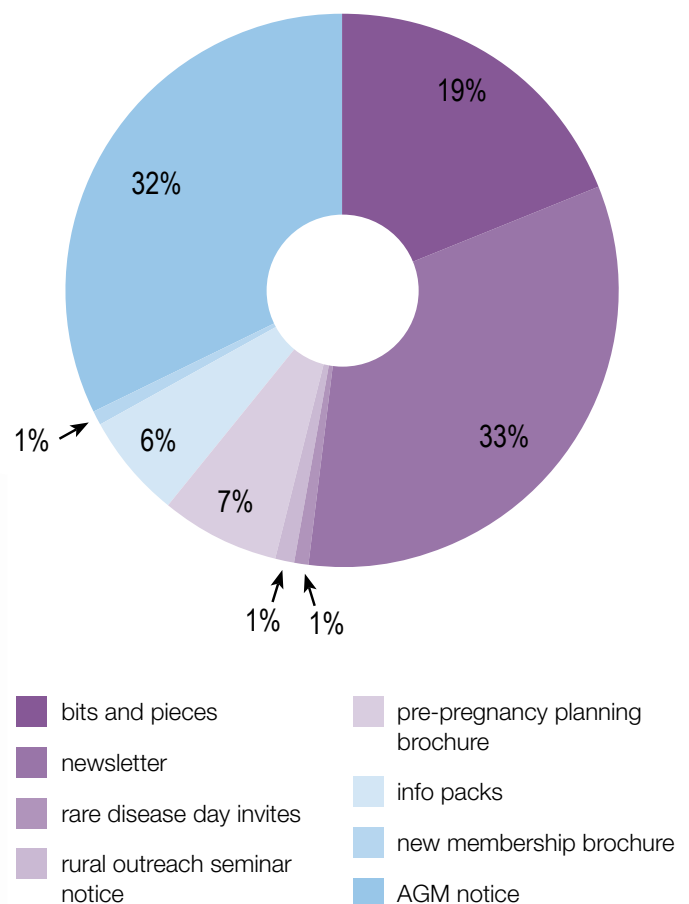
A new 'members login' function on the website was planned for late 2013 but will now be deferred to the first half of 2014. In order that we roll out this function with greater success, we are further updating our database and network information.

Once completed this functionality will allow for accurate and reliable information on support groups and allow for great efficiency in keeping our support groups list current.

Full integration of the database and web site will allow GSNV staff to accurately record, link and report all GSNV interactions and incoming/outgoing information and processes. The GSNV UMBRACO platform will allow a live and real time processing of all enquiries and further improve our efficiency.

Further improvement of the design and production of all our collateral and print material which includes brochures, newsletters, letter head, and information kits has been a priority again this year. Much of this development work depends on funding and as is often the case, it's a difficult area to meet costs. The successful acquisition of competitive funding is an important component of this work and therefore sufficient time for grant writing and applications will form a necessary part of the next year.

COMMUNICATION WITH THE COMMUNITY



NOTE: 63% of our communications have been electronically delivered via e-mail and 37% have been via post. To help save postal costs, please consider receiving your communications from the GSNV electronically by giving us your e-mail address; we appreciate your consideration.



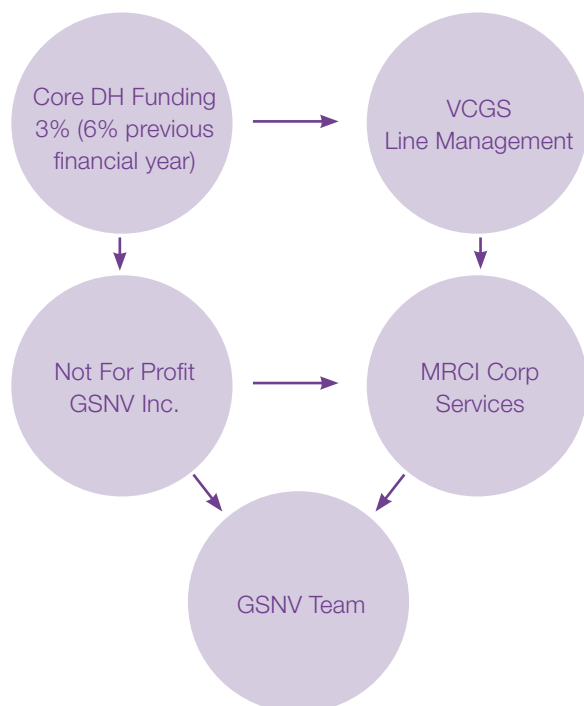
STAKEHOLDERS

The GSNV team has continued to work closely with the Murdoch Childrens Research Institute (MCRI) and the Victorian Clinical Genetics Services (VCGS) and the Department of Health (DOH) Victoria to create open, transparent and effective corporate relationships that are mutually beneficial.

We work very hard to secure sufficient and sustainable funding to meet our commercial obligations and expand our work after 2013. This is a particular challenge in the coming years as our work has become increasingly more expansive to run and the demand on our services has expanded exponentially.

As the Group Leader of the GSNV all operations and management processes are coordinated by me and I acknowledge the support and encouragement I receive by all stakeholders to continue to grow and expand our work.

The management support offered to me by A/Prof David Amor is particularly invaluable and I acknowledge that I enjoy very much, working with David and receiving daily operations support.



ACTIVITIES

A full discussion of the GSNV education and support activities is covered in a later section of this report.

I am pleased to point out however that we have continued to support, educate and advocate at every opportunity.

The GSNV has written letters in support of research, individual advocacy and systemic advocacy and contributed to processes designed to inform practice outcomes.

The GSNV team and I have set ourselves the task of maintaining an influential position within the genetic support and services landscape. Our desire to support research, provide a consumer voice and empower support in the community is reflected in our tireless work to position the GSNV as a leading and national voice and respected opinion.

Promoting participation in research studies, for example:

- Experiences of parents raising a child with an undiagnosed medical condition
- Fragile X 'FREE FX' study
- HIRC Forum on Person Centred Care

CONSULTATION

Health Innovation and Reform Council (HIRC)

Human Genetics Society of Australasia (HGSA)

HGSA Ethical and Social Issues Committee (ESIC)

Consumer Health Forum

Chronic Illness Alliance Special Interest Group

HGSA Victorian Branch

Health Issues Centre Surveys

GSNV ADVOCACY

Date	Event	Key advocacy message
12 March 2013	University of Melbourne PCP small group session	GSNV input into 'what makes a good doctor'
1 May 2013	Carer Support Forum	
4 June 2013	PCD training session	Facilitated workshop
13 June 2013	Australian Disorders of the Corpus Collosum – training session	Facilitated workshop to empower support group independence
10 July 2013	Meeting with Rare Voices Aus	Confirming working relationship
12 July 2013	Meeting with Department of Health	Annual review
6 September 2013	Master of Genetic Counselling Accreditation	GSNV input as a community placement site and in providing Masters research supervision
8 September 2013	HHT Information Session	Establishing a HHT Registry in Australia – Stakeholder input
24 September 2013	EMPAG planning meeting	Ethical, Legal and Social aspects of next-generation methodologies, with particular reference to prenatal testing
8 October 2013	Combined support group meeting	Raise awareness about carrier screening
16 October 2013	Health Innovation and Reform Council stakeholder forum on person-centred Care	Stakeholder input on opportunities to improve person centred care, in the last 12 months of life

PROFESSIONAL DEVELOPMENT

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

Staff Member	Program
Louisa Di Pietro	DNA Management
Marleen Susman	Tips and Techniques of Effective Speakers This seminar teaches the skills and techniques to ensure those who attend are able to improve their public speaking skills, as well as ensuring that their oral presentations use thoughtful and effective communication techniques.
Catherine Beard	Chronic Illness Alliance (CIA) presentation on the National Disability Insurance Scheme (NDIS) This informative session drew together representatives from a wide variety of peak bodies and support groups, whose members will be affected by the introduction of the NDIS. Throughout the seminar, much discussion was had around the implications of the NDIS for those with chronic illness, as well as those affected by a genetic condition.
Emily Higgs	Grand Rounds Grand Rounds is a weekly seminar held at the Royal Children's Hospital. It is a flagship educational meeting designed to be informative and dynamic, with weekly guest speakers from around the world.
Marleen Susman, Catherine Beard & Emily Higgs	VCGS Friday Seminars + Clinical Laboratory Interface Meetings Fortnightly seminars are organised through the Victorian Clinical Genetics Services, aimed at the clinicians and laboratories who work within the genetics sector. The meetings raise thought and discussion around particular cases, new research, new approaches as well as community issues.

Successful completion of all MCRI compliance training modules under the i-manage and i-know systems; all staff.



HUMAN GENETICS SOCIETY OF AUSTRALASIA (HGSA) CONFERENCE

After the success of the 36th HGSA conference in Canberra 2012 and the many conversations I had with HGSA committee members, I was inspired to apply for a position on the Ethics and Social Issues Committee (ESIC) of HGSA. My application was accepted and this year, was given the opportunity to contribute to the discussion and review of some key issues and frameworks including:

- A review of the HGSA Guidelines on a Clinical Genetics Services Standards Framework in Australia
- Drafting of a response to the American College of Medical Genetics and Genomics (ACMG) recommendations Reporting of Incidental Findings in Clinical Exome and Genome Sequencing
- Genetic Advisory Committee of the College of Pathologists/HGSA – ESIC Joint position statement on Direct to Consumer Genetic Testing

The Ethics and Social Issues Committee (ESIC) of the Human Genetics Society of Australasia, is a key committee of the HGSA, is responsible for offering expert opinion to Council and Executive, and developing and reviewing HGSA policy and position statements on a wide range of ethical issues.

The 37th Human Genetics Society of Australasia (HGSA) Annual Scientific Meeting was once again an important professional development exercise for the GSNV team. The HGSA represents the most important professional conference for genetics professionals in Australasia.

The programme for the meeting this year included current advances in gene technology and genetic research, and an array of Special Interest Group (SIG) sessions. GSNV representatives at the conference were particularly interested in the Australasian Society of Genetic Counsellors (ASGC) SIG sessions and the presentation of interesting cases from genetic counsellors.

The GSNV has been directly involved in three research projects presented at HGSA this year:

“Parental experiences of living without a diagnosis for children with unexplained syndromes” (Oral presentation, won ASGC award for best presentation) Justine Elliot, Alison Archibald, Louisa Di Pietro, Susan White

“Exploring experiences of establishing a genetic support group in Victoria” (Poster presentation) Emma Swain, Margaret Sahhar, Dr Laura Forrest, Louisa Di Pietro.

“Exploring experiences of the Victorian Clinical Genetic Services Reproductive Genetic Carrier Screening Program” (3 minute thesis presentation) Catherine Beard, David Amor, Alison Archibald, Louisa Di Pietro.

The GSNV was also directly involved in the 4th Australia-New Zealand Roundtable on Genomics as the GSNV sits on the Ethics and Social Issues Committee (ESIC). This year’s Roundtable focused on Ethical, Legal and Social aspects of next-generation methodologies, with particular reference to prenatal testing, general issues about managing incidental findings and current issues in research involving Maori.

Given that the conference is broken up into SIGs, the programme covers genetic advances, research translation, ethical issues, genetic counselling practice and the assessment/improvement of professional standards of all Society members.

In recognition of the contribution that the GSNV makes to research and consumer participation, future HGSA Scientific Meetings are on the GSNV radar. The HGSA Annual Scientific Meeting is always a highlight for the GSNV and provides an incredible learning environment for all staff involved.

OUR MEMBERS

At every opportunity the GSNV communicates directly with its members and networks and seeks feedback on what we are doing and how well we meet the needs of those we serve. Feedback from our members is vital and from time to time we offer small incentives to encourage ongoing feedback and comment.

This has proven to be a great success and sample responses include:

"I enthusiastically read each addition of the GSNV newsletter.

I just wanted to sincerely thank everyone that contributes to this important publication. It's such a vital service that is being provided and I'm truly grateful. I love learning about the latest research being conducted and services and support available. It makes a huge difference to families like mine and provides us with hope and a feeling of being more in control and able to handle our daughter's condition."

*A parent in response to
Winter/Spring 2013 Newsletter*

"Your service is so valuable and important. If I can provide any support in any way to help the continuation of your service, I would be happy to do so."

*Early Intervention
Team Worker*

"One of the strengths of the GSNV is its effective, empathetic, collaborative approach, which is often lacking in other medical/health organisations."

Anon

"I always find the GSNV newsletter has really important bits of information or advice relevant to my situation. It's very user friendly and broadly informative."

Anon

THE ANNUAL GSNV SMALL GRANTS SCHEME

Every year the GSNV offers Small Grants to members for projects that assist the work of support groups. Small grants are usually awarded to financial members of the GSNV as memberships provide the pool of funding for the grants scheme.

In 2012 however, the GSNV called an amnesty on membership fees in lieu of a review of its memberships policy. The GSNV has not issued membership renewals for the financial year 2012-2013. Consequently, we opened the small grant applications process to all support groups who are listed on the GSNV support group directory, regardless of financial membership status.

Information regarding the GSNV Small Grants Scheme 2013 will be announced before December 2013 (will coincide with the new memberships scheme). GSNV membership fees are returned to our members via the Small Grants Scheme and are not used for operations.

Small Grants may be used for a once-off project or activity that your group or persons your group wish to undertake and deem as a benefit to the community. Examples from past years include printing brochures, venue hire, event organisation, event catering, and purchase of resource material and library books to contribute to a program.

Small Grants are not awarded for the purchase of aids and equipment. This funding is designed to provide once-off financial assistance to support groups who find it difficult to obtain funding via other grants schemes. GSNV grants may also be used towards administration costs for unfunded agencies.

GSNV staff will build up this feedback and draw on some of the suggestions and comments for future planning.

A MESSAGE FROM THE WILLIAMS SYNDROME FAMILY SUPPORT GROUP:

African drumming a hit!

This year's camp activity was a little more sedate (although noisy) than other years which was great as it was raining most of the day! All ages and abilities gathered for instruction and fun, making music. I admit to being fairly rhythmically challenged so I gave it a go but was definitely outshone by young talent like Ruby, Maya and Zoe.

New to our group, dad Matt dazzled with a solo and both he and mum Cassie looked on in amazement as baby Isabella (WS) recovered from her sensitive hearing reaction to bang on her 'drum chair' in the window. The star of the show though had to have been little Heidi Aldous, whose enthusiasm had everyone cheering.



We would like to acknowledge the assistance with gratitude from the Genetic Support Network of Victoria (GSNV) – Small Grants Scheme 2012 which provided a small grant to help fund this activity.”

Reproduced with permission from the Williams Syndrome Family Support Group Newsletter Issue No. 3 December 2012

VOLUNTEERISM

The GSNV launched the Volunteer Program in May 2013. This program is an opportunity for support groups to source suitable volunteers to help them with various small tasks. Volunteers are students in the Masters of Genetic Counselling program (University of Melbourne), or students interesting in applying for the Masters and seeking some hands-on experience in the genetic health and support community.

We currently have 11 volunteers and 9 support groups involved. Potential volunteers apply through the GSNV website and are then invited for an orientation at the GSNV. Volunteers are then matched with a support group based on mutual skills and interests. Some examples of volunteer-support group matches are:

Volunteer organisation	Volunteer match	Activity
Australian Leukodystrophy Society	1	Assistance with newsletter
Friends of Sammy Joe Foundation	1	Assistance with database
Muscular Dystrophy Association	1	One day on-site
Niemann-Pick C Disease Foundation	1	Writing condition-specific information to provide health professionals
CleftPals	1	Assistance with mail-out
Syndromes Without a Name	1	Assistance with mail-out
Australian Alopecia Areata Foundation	1	Promoting awareness in hairdressers
Aus. Gorlin Mutual Support Group	1	Website design
PKU	1	Assistance with fundraising

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





HUGS

Haemoglobinopathies Unit Giving Support

P.O. Box 2031 Templestowe Heights 3107

August 2013

To the President

Genetic Support Network of Victoria
Murdoch Childrens Research Institute
Parkville VIC 3052

Dear Ms Moira Rayner,

It is with great pleasure that the Haemoglobinopathies Unit Giving Support (HUGS) provides a cheque donation to the Genetic Support Network of Victoria (GSNV). HUGS is aware of the important work of the GSNV through Miss Louisa Di Pietro and would like to contribute to your programs, as they are identified to be consistent with the HUGS vision.

Please accept this cheque as a once off donation to be used by the GSNV for any projects or programs that are deemed to have a direct benefit to Victorian families affected by genetic conditions. We offer up this donation in order to assist the GSNV in achieving some of its goals. At your convenience please provide HUGS with an official receipt for our records.

Thank you to Miss Louisa Di Pietro for introducing the GSNV to HUGS and we wish your group well in providing important services to the community.

Kind Regards,

Mrs Nancy Moltisanti
(President HUGS)



FUNDRAISING

Thank you to HUGS Auxiliary! The GSNV was thrilled to receive an injection of funding of \$3,000 for our rural/regional trip to Albury in 2013. The GSNV specifically thanks Mr and Mrs Molitsanti and family for their recognition of the work of the GSNV and the generosity of this spontaneous donation.

Acquiring competitive funding and attracting philanthropic support is forever a challenge for the GSNV as we remain in competition with some very big and well run fundraising machineries and brands. However, our work is unique and the GSNV will continue to identify and seek every opportunity to broaden our budget and development fund in order that we can do more for the community and continually expand and improve our work.

Over the closing months of 2013 and until the next GSNV Annual General Meeting in 2014 I look forward to continuing my work as Group Leader and striving to meet all of the strategic and operations objectives delegated within my remit.

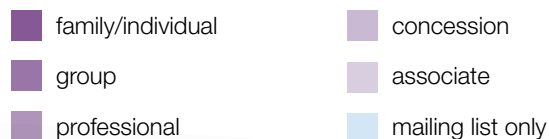
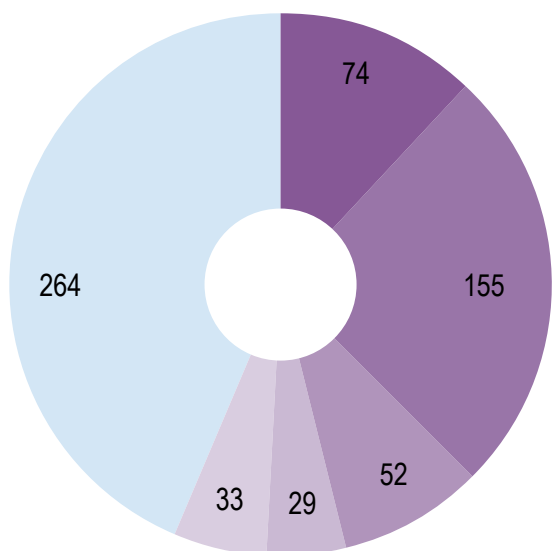
Working on clearly identifiable and measurable KPI's to assist the GSNV team in achieving outcomes is high on my agenda and overall, I am excited to look toward greater outcomes in the coming years.

Like most not for profits, the GSNV does not operate without its challenges. However, with a commitment, consensus and sound partnership between the GSNV team, committee, and stakeholders our core function and value to the community, we are in good stead to achieve our best and remain strongly placed in the genetic health and support services landscape in Victoria and nationally.

Louisa Di Pietro
Group Leader

MEMBERS AND CONSUMERS

FIGURE 3:
MEMBERS COMPOSITION 2013



*empowering * connecting * supporting*

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

GENETIC AND ALLIED HEALTH

- Clinical Geneticists
- GPs
- Researchers
- Social workers
- Genetic counsellors
- Allied Health Professionals

GOVERNMENT BODIES

- Victorian Health Department (DoH)
- Public Hospitals
- Local Councils
- General Practice Divisions
- Funding Bodies
- DHS

COMMUNITY

- Individuals
- Families
- Carers
- Students
- Community groups
- Maternal Health Centres
- Early Intervention Education
- Corporate business
- Charitable Organisations
- Philanthropic societies
- Culturally and linguistically diverse groups

NETWORKS

- Not for Profit Organisations
- Support and Advocacy Groups
- International Advocates and Alliances
- Health Networks and Organisations

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

The GSNV currently has 623 members.

EDUCATION AND SUPPORT

EDUCATION

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

- Community awareness and support
- Clinical/Genetic Health Professional knowledge of GSNV and genetic awareness
- Education and awareness of genetic health to schools, early childhood development centres, maternal health
- Stake Holder communication with influential groups
- Medical
- Nursing
- Health training and education

PRE-PREGNANCY PRESENTATIONS

The GSNV was approached earlier this year by the Epworth Hospital to participate in a 'Pre-Pregnancy Planning' pilot program. Over two hundred people registered for the first night which was held on July 25th. Show bags were provided that contained brochures and information relevant to the presentations that were given on the evening.

The presentations were grouped into three themes: preparing your body, preparing your finances, and preparing the medical.

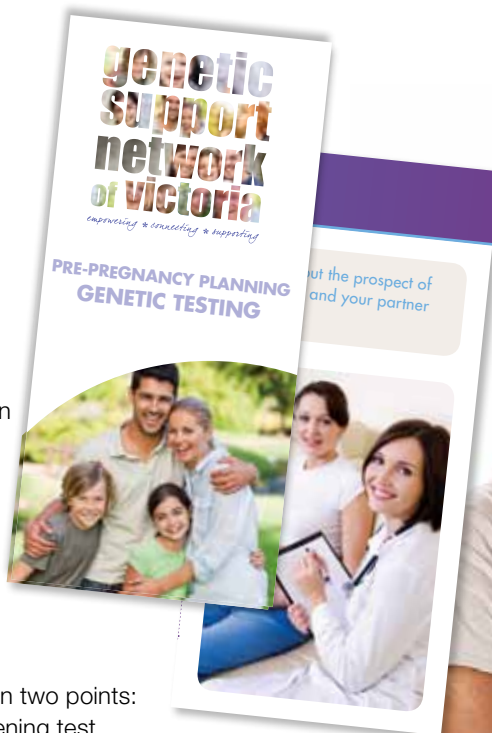
The GSNV's presentation focused on two points: the new pre-pregnancy carrier screening test offered by the VCGS for cystic fibrosis, spinal muscular atrophy, and fragile X and the importance of couples having discussions, in advance of their pregnancy, about prenatal testing for Down syndrome.

Feedback from the evening was very positive and a second 'Pre-Pregnancy Planning' evening is being held on October 17th. The Epworth plan to make this a regular event offering two to three evenings per year.

MONASH PRESENTATION

The GSNV was invited by Monash University to host a guest lecture as part of the Bachelor of Biomedical Science. The theme of this lecture will be 'Genomics from a Consumer Perspective'.

The GSNV will inform students about current genomic technology and translation of genomic research to clinical practice, and provide a valuable overview of health outcomes and psychosocial impact from the consumer's perspective.



RURAL OUTREACH SEMINAR

In conjunction with the Association of Genetic Support of Australasia (AGSA) the GSNV ran a rural outreach seminar designed to bring together families, health professionals and service providers on the Albury/Wodonga border. The seminar aimed to broach some of the issues and/or gaps in servicing regional areas. Below is some feedback received from those who attended.

WHO ATTENDED:

Demographics:

	<18	18-25	25-35	35-50	50-60	>60
Which age bracket do you fall into?			1 (5%)	7 (37%)	6 (32%)	5 (26%)

	Male	Female
Are you male/female?	3 (16%)	16 (84%)

	NSW	Vic
In which state/territory do you reside?	9 (75%)	3 (25%)

Feedback:

Level of Satisfaction	Least satisfied 1	2	3	4	Most satisfied 5
Topics covered today			2 (11%)	4 (22%)	12 (67%)

Many thanks for the info and the beautiful luncheon, morning and afternoon teas.

I think more families would have come along if perhaps more description was given on speakers i.e. Tony Tinlin was on behaviour – not actually on the Service Aspire. And just not on genetics. Really pleased I attended – something from every speaker. Thank you.

Extremely informative seminar. Thank you kindly. NDIS was my main concern for this seminar.

Was great to get some solid information and things explained in a non rushed environment. Would have been good to see Centrelink here or getting some more information on financial assistance. Great job on organising today and ongoing support. Look forward to the next seminar.

Thank you – very enlightening and great speakers.

Great to attend a seminar having such great presenters on various topics. Found it very interesting and learnt so much, thanks to everyone for making this seminar possible.

Great seminar – well done and thanks for organising this.

Some more of these events would be wonderful and many thanks for a most interesting day.

Would like to see more of these events in Albury and other rural areas. Congratulations, a lovely informative day.

I would like the opportunity to attend more of these workshops. Being the parent of disabled children for over 30 years, I'm probably more interested in protracted care and how to ensure my child will be ok if I die rather than diagnosis and genetic counselling. P.S. Keep up the good work.

SOURCE: AGSA Evaluation Report 2013

THE UNIVERSITY OF MELBOURNE – PRINCIPLES OF CLINICAL PRACTICE

This unique program offered by the University to first year medical science students provides a timely discussion on 'what makes a good health professional' and what do consumers have to say about that.

The GSNV has for four years now provided our consumer perspective on the patient/doctor relationship, supported self management, health communication, health literacy and complexities of primary health care for those with rare and complex conditions with multiple co-morbidities.

This session is a highlight on the GSNV education calendar and provides a fantastic opportunity for student and presenters alike to debate and explore how we improve health delivery by the professional and health outcomes from the patient.

THE UNIVERSITY OF MELBOURNE – MASTER OF GENETIC COUNSELLING

The GSNV supports the University of Melbourne Master of Genetic Counselling program each year and has established a synergetic relationship with the course coordinators and student population. Each year we conduct a three hour tutorial and use the opportunity to provide students with the unique GSNV perspective on elements of their training.

In 2013 we explored 'Genetic Counselling in the Community' and provided an in depth analysis on definitions of community. We explored how to harness community spirit to instigate change provide input into genetic health. Students discussed the importance of professional recognition of the role played by this important stakeholder group.

The students explored the relationships between clinical service providers and consumer groups and the strength/opportunity in that partnership. Students were mentored on the transitioning of support groups from an idea to the boardroom and the evolution of community interest and common goals around genetic health that has led to local, national and international championing.

THE UNIVERSITY OF MELBOURNE – PUBLIC HEALTH GENOMICS

The GSNV participated in the University of Melbourne Public Health Genomics course 2013. With a focus on 'Public Health Genomics': the course explored genetics vs genomics, clinical genetics vs public health genetics, genomic technologies, government and public health, law and public policy, and consumer expectations.

The GSNV provided an overall assessment of consumer expectations in a genomics era and the realities of the slow processes in research translation. Advanced genetic technologies are giving consumers the opportunity to glean more information, but not necessarily provided the answers they are looking for by way of confirmed diagnosis or advances in clinical care.

VCGS FRIDAY SEMINAR SERIES

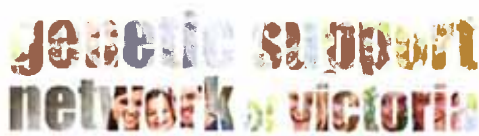
In 2013 the GSNV hosted and co-presented in three Victorian Clinical Genetics Services (VCGS) Friday seminars:

- Breaking bad news: Parents' perspectives, presented by SWAN
- Supporting Australia's MD community, presented by MDA
- Partnerships in screening program development: offering population-based carrier screening for Cystic Fibrosis (CF)

These sessions provide valuable insight and narrative offered by a range of speakers, but importantly provide VCGS clinical and training staff with 'real life' perspectives and stories from consumers, support providers and carers. In 2014 the GSNV will aim to provide a range of topic for Friday seminar that cover areas not previously explored in this forum.

GSNV INFORMATION PACKS

The GSNV is committed to providing useful, practical and up to date information. The GSNV provide generic information packs for health professionals, disability professionals, and for the community. The packs include a range of information sheets and brochures about genetic testing, pathways to genetic diagnosis, and access to services. These packs have played an essential role in raising the profile of the GSNV as a peak support organisation.



Genetic Support Network of Victoria

9th Floor, South Building, Murdoch Childrens Research Institute
Flemington Rd, Parkville, VIC 3052
Ph: (03) 8341 6315 Fax: (03) 8341 6399
Email: info@gsnv.org.au Web: www.gsnv.org.au

Dear community member,

Thank you for your interest in the services of the Genetic Support Network of Victoria (GSNV). The GSNV is a vibrant and active organisation that aims to maintain a network committed to promoting the interests and well-being of individuals and families who are having investigations into a genetic diagnosis, or who have had a genetic diagnoses, who are living with a genetic condition or who are caring for someone with a genetic condition. The GSNV assists individuals and families with the 'human', non-clinical side of genetic diagnoses through establishing fully supportive, ongoing and enduring relationships with those impacted by a genetic condition.

Our vision: Purpose, dignity and choice for people with genetic conditions.

Our philosophy: The GSNV believes that *collaboration* between individuals, families, support groups, professionals and genetic health service providers is the essential basis for achieving the best outcomes in health and wellbeing and service delivery.

The GSNV can assist you or your family by offering the following:

- Assisting you to navigate clinical pathways so you are supported during periods of no clinical interaction
- Providing you with the opportunity to have an in-depth, empathetic and confidential conversation with a genetic support professional working outside of the regular clinical genetics service. GSNV Genetic Support professionals are MHGSA (Genetic Counselling) qualified.
- Putting you in contact with others with shared experiences through our Peer Support program
- Providing appropriate, current and accurate information about genetic health
- Assisting you to identify specific services, funding opportunities, government and community supports on an ongoing basis and in response to changing needs
- Assisting you with locating and connecting to an existing support group, or establishing a new support group where none exists
- Assisting with carer, respite and family support
- Advocating for individuals and groups on issues important to them, e.g. PGD, life saving drugs, funding for testing etc.

You can access our services by contacting us by phone: 03 8341 6315, email: info@gsnv.org.au or through our website: www.gsnv.org.au. You may also ask your healthcare professional to make a referral to us, and we will initiate contact with you.

Kind regards,

Louisa Di Pietro
Group Leader

We are in the process of developing two brochures, one for consumers and one for health professionals, which explain the role of the GSNV in each context respectively. In the future, these will be used to promote the GSNV as a peak body and to attract new members.

In 2013, the GSNV has responded to individual enquiries with a comprehensive individualised response. Initial enquiries are usually by telephone or via the GSNV website, but more often than not the follow up communication is via email. Using email allows for appropriate web site addresses to be provided via a direct hyperlink. This is in addition to other information relevant to the enquiry.

SUPPORT

GSNV offers supports to individuals, families and groups in a number of ways:

- Support, information and assistance to an average of 19 people from the general community per month
- Includes linking people "in the same boat"
- Referring people to specialised services/organisations
- Health professional enquiries
- Service enquiries
- Network enquiries

Through the work of our genetic support team we aim to provide a point of contact for families and individuals affected by a genetic condition to find the most appropriate support group, ensure they are supported in all areas including ongoing development, have appropriate support and information available to them immediately to reduce feelings of isolation and confusion and facilitate the mechanics of lobbying to address specific issues.

Support for support groups is also a big part of what we do and includes:

- Assisting new groups in setting up
- Incorporation
- Finances
- Communications
- Corporate Governance
- Peer Support
- Information dissemination

Recent support group assistance includes:

- AusDoCC – Training workshop October 2012
- PCD Support Group – facilitated meeting February 2013
- PCD Support Group – Training workshop June 2013
- SWAN Support Group Meeting – facilitated June 2013
- AusDOCC – facilitated meeting June 2013

- PCD Support Group – facilitated meeting September 2013
- Fragile x, SMA and CF Facilitated session on reproductive carrier screening.

SUPPORTING WITH A CUP OF TEA

In late 2012 the GSNV hosted its own 'DisabiliTEA', supporting a nationwide tea party to support the Every Australian Counts campaign in calling for the National Disability Insurance Scheme (NDIS). The GSNV is proud to have been part of the strong community support involved in getting the NDIS off the ground. Following the national introduction of DisabilityCare (NDIS), the GSNV has produced a Fact Sheet explaining the scheme and how it will affect our members, which is now available on the GSNV website.

PEER SUPPORT

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

The GSNV runs an annual half day workshop aimed to help individuals feel empowered to listen and talk to others who are facing genetic challenges, and to share their wisdom and experience. Upon completion attendees receive a certificate as well as a Peer Support contract with the Genetic Support Network of Victoria.

This year's Peer Support Training Day will be held in December.

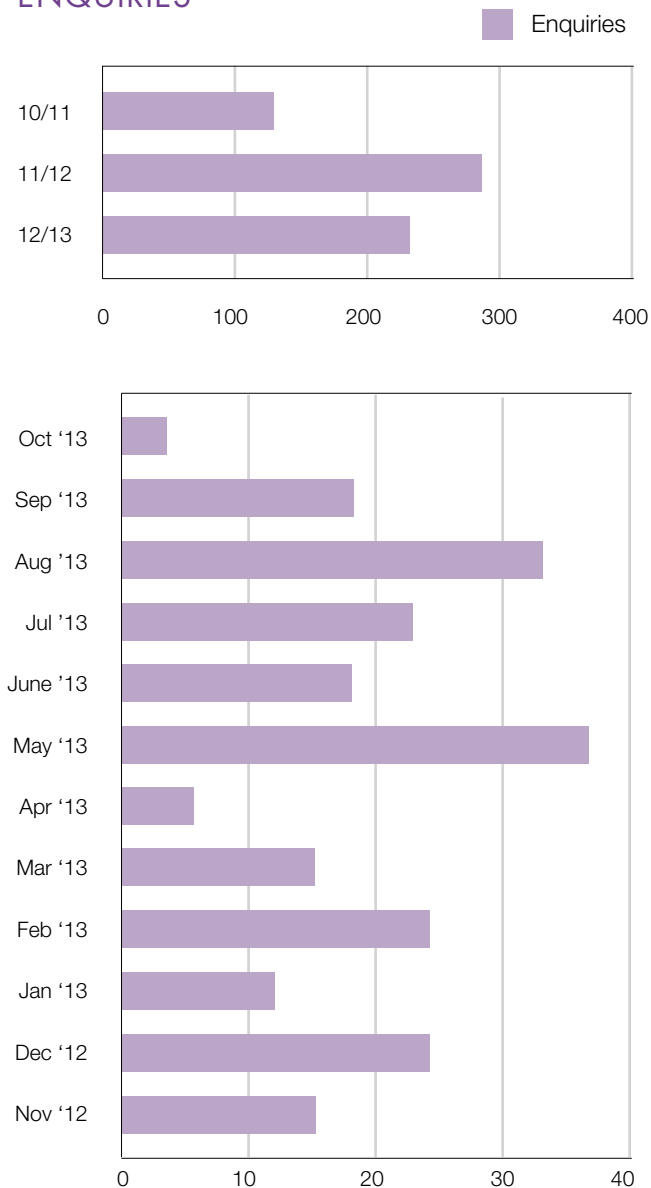
OTHER ACTIVITIES

In recognition of the Sixth Annual Rare Disease Day, the GSNV hosted a seminar and morning tea at the Royal Children's Hospital.

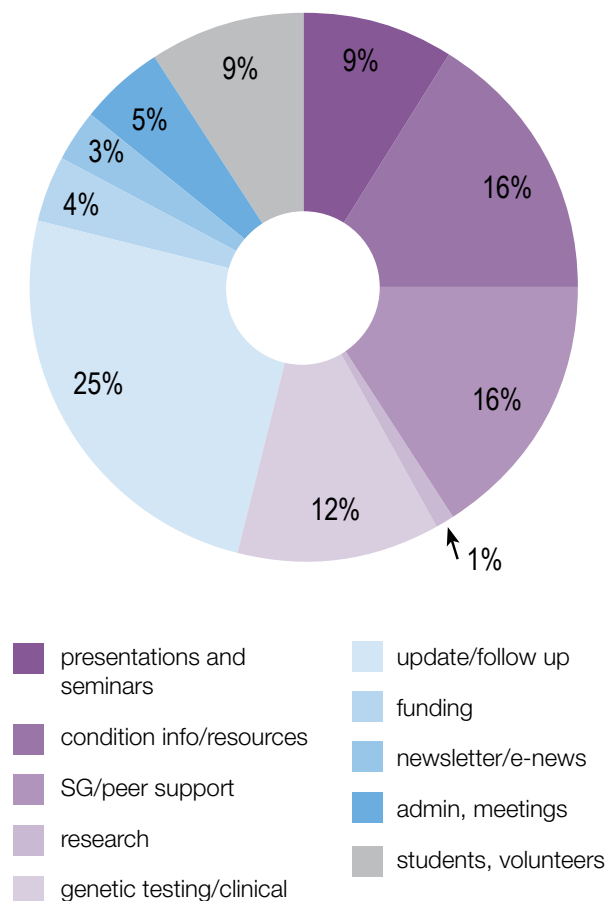
Bringing together support groups, families, clinicians, researchers and those living with rare conditions, the morning also focussed on celebrating the contributions made by many and the various rare disease research activities supported by the Murdoch Childrens Research Institute (MCRI) and the Victorian Clinical Genetics Services (VCGS).

INFORMATION REQUESTS

ENQUIRIES



TYPES OF ENQUIRIES RECEIVED BY GSNV NOVEMBER 2012 – OCTOBER 2013



The GSNV handles many enquiries per day. Requests come from individuals, families, groups and health professionals.

Enquiries cover a range of topics including information about genetic conditions and support groups, peer matching, disclosure, accessing genetic testing and other genetic health and community services, and support group issues such as establishing and maintaining a support group, fundraising and compliance.

Depending on the nature of the request, they are responded to in different ways. It is important to note that the data below reflects only the limited information we are currently able to obtain from our database.

The enquiries record reflects only the original interaction between the GSNV and callers and does not reflect the multiple transactions that follow an enquiry. Staff have also been utilising our GSNV information packs which have been met with great enthusiasm from both individuals and health professionals alike.

ADVOCACY

The GSNV actively seeks opportunities to provide a voice for, and representation of, individuals and families affected by genetic conditions.

In providing consumer feedback, comment and position statements on a wide range of issues including access, equity, health reform, management, support and systemic reform, our aim is to represent the genetic perspective in the overall approach to health, health delivery and the quality of life of those living with genetic conditions.

Advocacy involves:

- Representing the interests and views of people and their families affected by a genetic condition to the community, State and Federal Government
- Providing “arms length” representation when needed
- Empowering GSNV existing members and the general community
- Raising issues and providing feedback on a range of topics

Please refer to table on page 9 for examples of our advocacy work in 2013.

NATIONAL DISABILITY INSURANCE SCHEME

Ongoing communication and participation in feedback, following the debate and reporting to our members. The GSNV formally submitted to the Productivity Commission in 2010 has continued to lobby State and Federal politicians who have championed this important change in Australia.

In support of the ‘Every Australian Counts’ campaign, the GSNV hosted a DisabiliTEA, Friday 26 October 2012 and encouraged all VCGS and MCRI staff to join us and raise awareness of the need for the National Disability Insurance Scheme (NDIS) and to call on the Federal Government to introduce the scheme without further delay...and so we are on our way!

INFORMING MEMBERS’ OF OPPORTUNITIES

E.g. National Disability Insurance Scheme, Australian Charter of Human Rights and Victorian Charter of Patient Rights.

RARE DISEASES

Following the approaches to a national strategy and continuing to be a peak representative and collaborator with our national counterparts.

ADVOCACY AND REPRESENTATION

The GSNV represents people affected by genetic conditions and their support networks in a range of forums including the following committees:

Chronic Illness Alliance (CIA)

- Peer Support Network
- Chronic Disease Self Management Special Interest Group
- Multiple Conditions Working Party
- Former Committee of Management members
- Network Partner
- Network Participant

Consumer Health Forum

- Voting Membership

Human Genetics Society of Australasia

- Membership including SIG
- Committee member ESIC



COMMUNICATIONS

PRINT AND E FORMAT

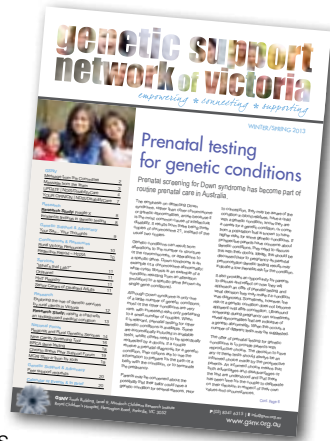
The GSNV has over the last two years consolidated its communications into two main publications:

- A quarterly Newsletter
- Regular E-News Bulletin – 'Bits and Pieces'

Our communications are sent to more than 600 individuals, groups and professionals with our newsletter readership also extended through wider circulation amongst our networks.

Due to the closure of the MCRI internal graphics department, GSNV currently outsources major printing and publications to M&M Printworks.

In order to sustain the ongoing professional full colour look of our newsletter the GSNV will in 2013 need to look at further funding sources and/or grants. It is a goal of the organisation to continue to produce quality and reliable information in a professional manner.



WEBSITE, DATABASE AND SOCIAL MEDIA

There has been noticeable increased traffic to the GSNV website between 1 July 2012 and 30 June 2013.

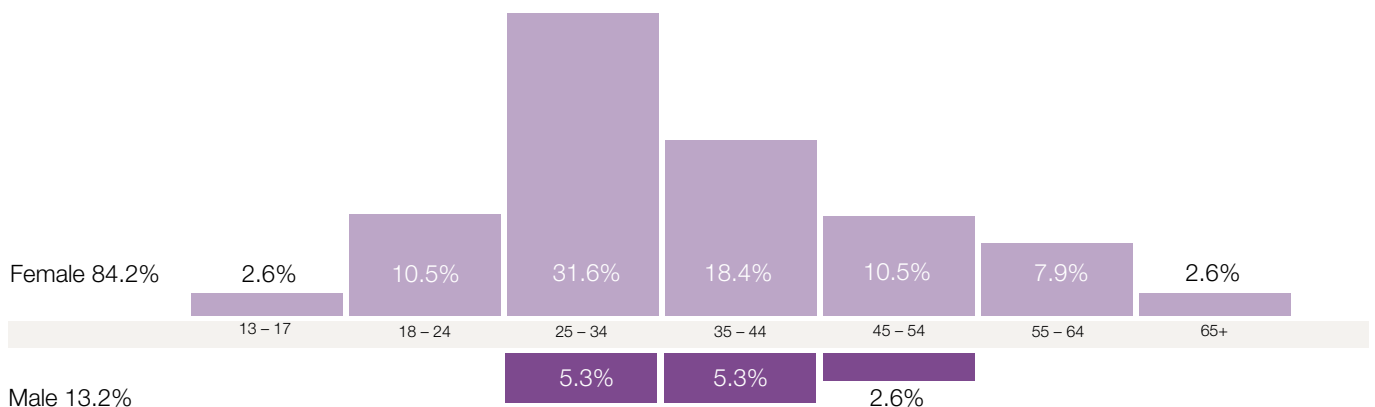
This represents a change in how the community, our members and health professionals access our services and communicate with us. Via our 'contact us' portal on the website, we have a steady flow of traffic and an efficient process to ensure we do not miss a request. With a full integration of our web and database platforms, we have significantly improved our ability to accurately update, store, report and evaluate membership data and enquiries processes.

We are committed to a providing a better service through our website and social media formats. The GSNV has created a Facebook group and Twitter profile to keep up with social media trends. This has proved to be an effective communications strategy.

WHO ARE WE REACHING ON FACEBOOK?

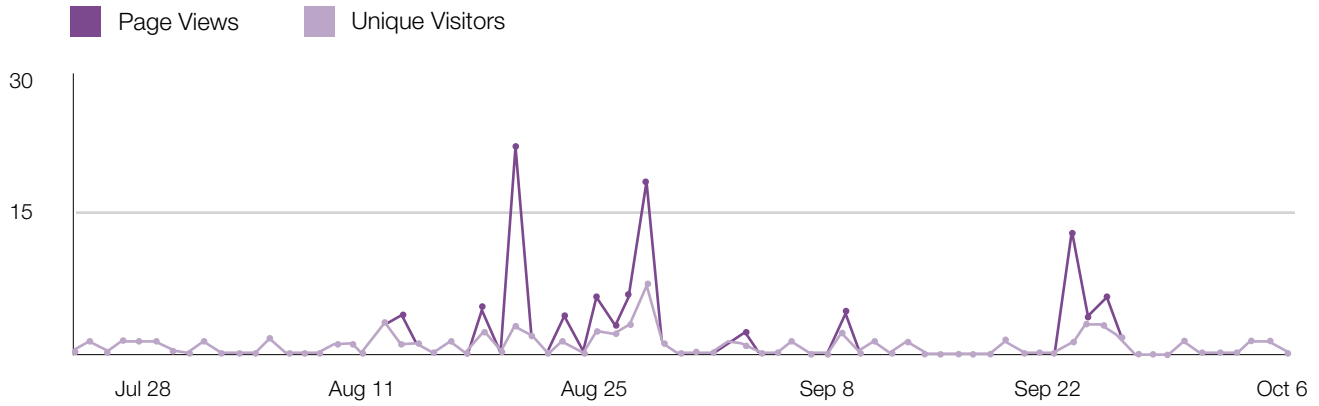
GENDER AND AGE OF FACEBOOK AUDIENCE

Gender and Age

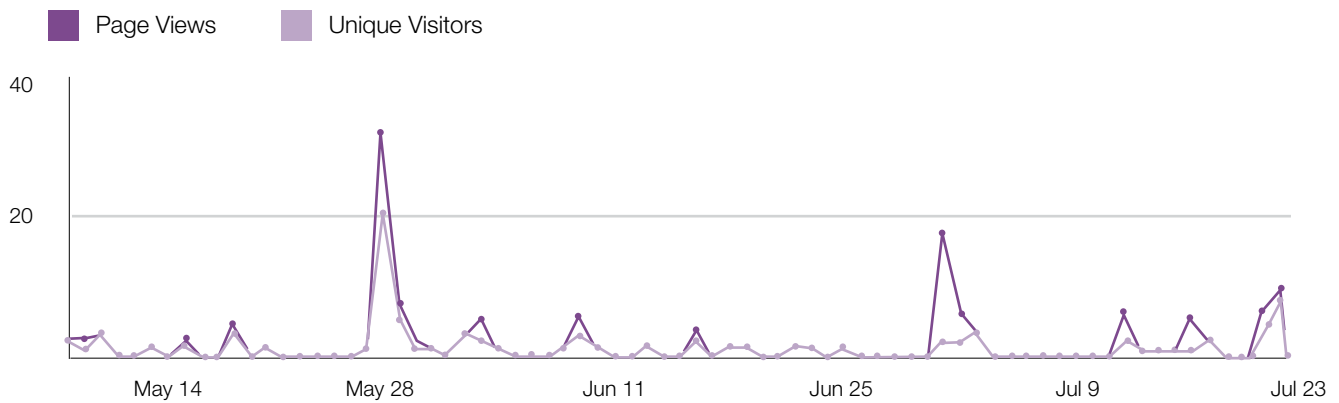


FACEBOOK PAGE VISITS

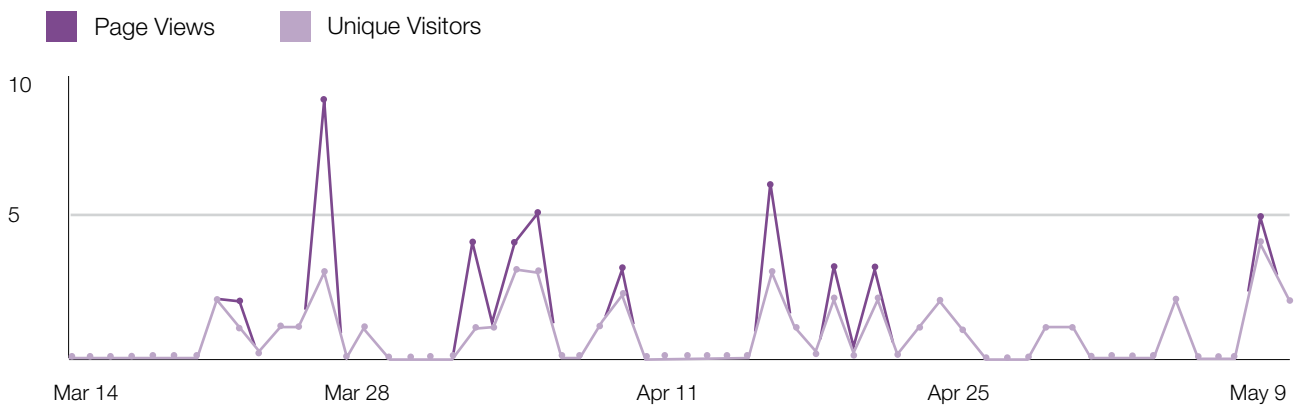
July 2013 – October 2013



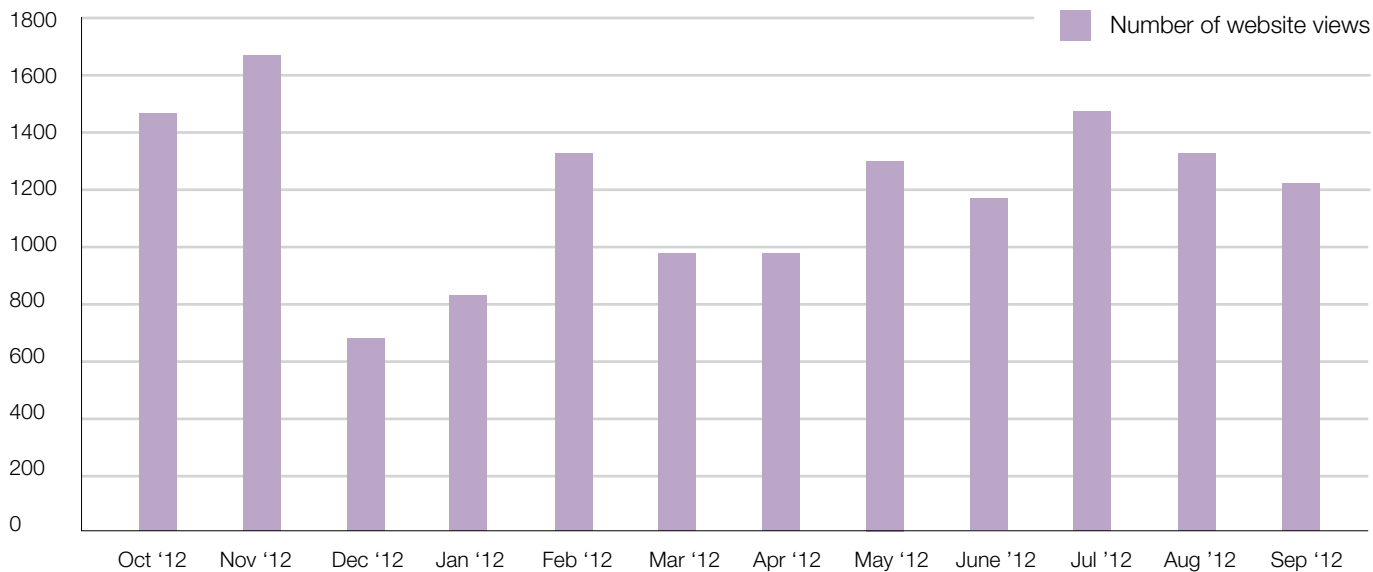
May 2013 – July 2013



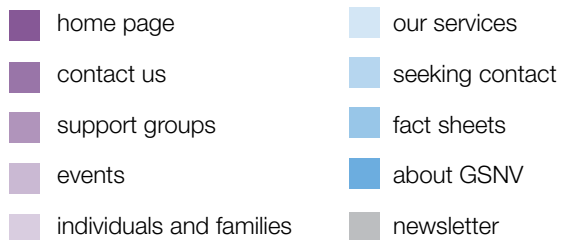
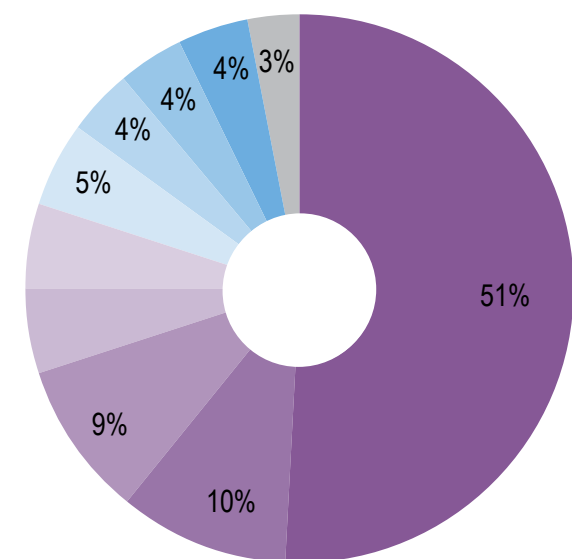
March 2013 – May 2013



WHO ARE WE REACHING ON THE GSNV WEBSITE?



WEBSITE VIEWS



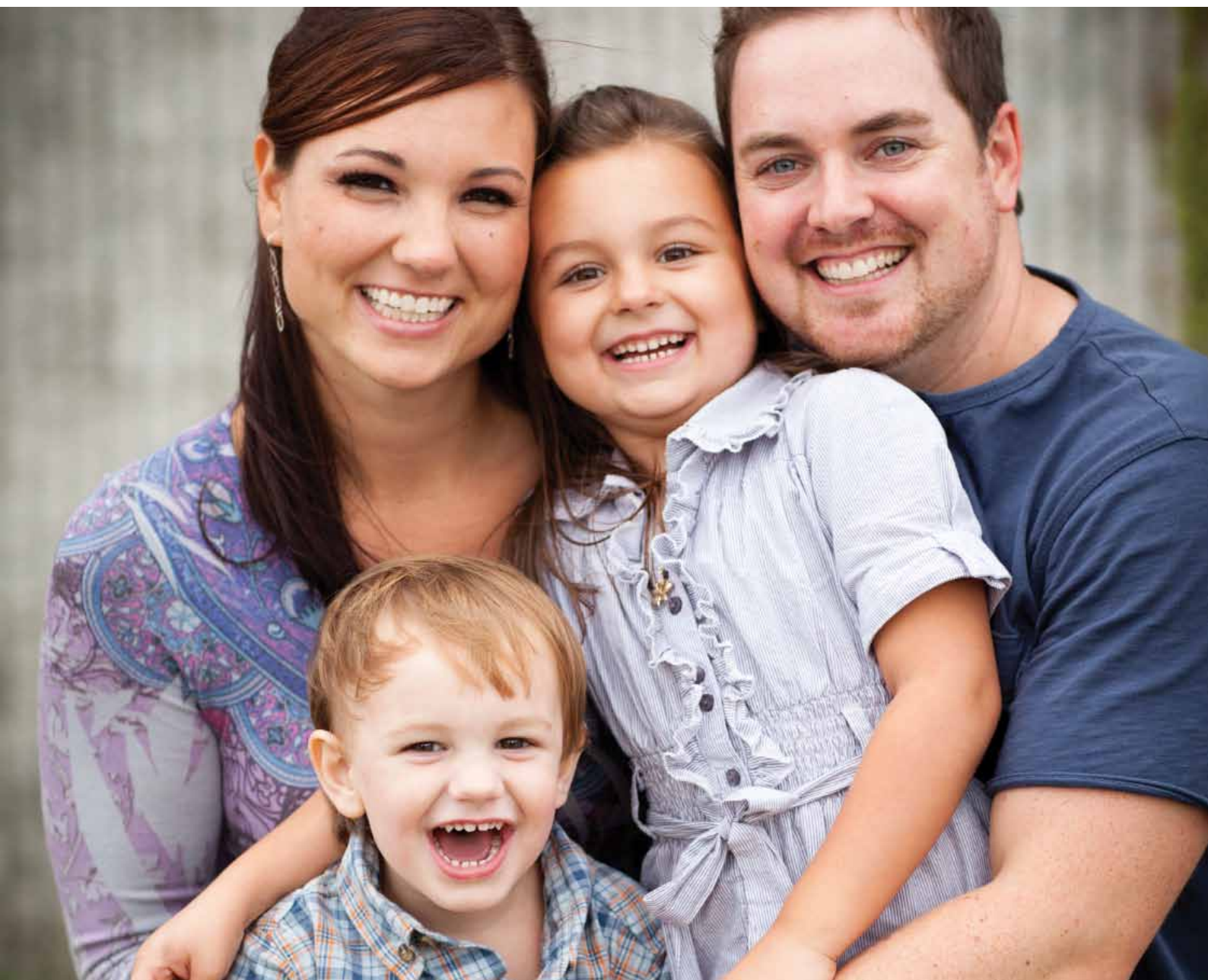
WHO ARE WE REACHING ON TWITTER?



106
TWEETS

30
FOLLOWING

14
FOLLOWERS



THANK YOU

The GSNV gratefully acknowledges the support of all those who contributed and donated in many ways – from our core funding from the DoH Victoria to the charity of the HUGS and the in kind support and advice from many VCGS and MCRI staff. We appreciate the support we receive and extend our heartfelt thanks to all those who have assisted us to provide and run our services.

In particular we wish to thank A/Prof David Amor (Director, VCGS), Dr Paul Fennessy and Margaret Howard (DoH) for their support, and wisdom over the last 12 months. The GSNV is highly appreciative of all formal and volunteer efforts to provide and manage our services and make a valuable contribution to genetics health in Victoria and Australia.



FINANCIAL REPORT

On behalf of the Executive and Committee of the GSNV Inc. we are pleased to report on the financial details for the financial year 2012 – 2013.

With continued financial support from the Department of Health Victoria (DoH) and in kind contributions, the GSNV remains a viable and solvent organisation – but solvent only because it still has cash reserves. We must make a concentrated effort on financial and prudential management now that GSNV's operating resources are so closely related to VCGS activities and MCRI charges.

We thank Maria Telford and Viren Abeyasinghe for the financial services provided by the Murdoch Childrens Research Institute Finance Department.

All financials reported upon have been audited by VCGS, which currently manages the DoH grant, and are to be approved and signed off by the Public Officer, Treasurer and President for the financial year 2012 – 2013.

The 2012/2013 financial year was one of challenge, with expenses related to our programmes and services going

well beyond that originally anticipated and budgeted. This represents an exponential increase in the demand and improved quality of our services.

In the past the GSNV has retained a large amount of its funding and carried it over to the following year, as a surplus because of increased donations over a financial year and lower than anticipated salary costs. That is no longer the case, because we are far more active.

In the previous financial year GSNV has experienced much higher expenditure than DoH income due to higher salary costs, a fall in other income, charges based on full EFT and a significant increase in printing costs (higher than that budgeted).

Continuous improvement and remaining co-located on the MCRI/RCH campus has necessitated an increase in overall cost/expenditure in 2012 – 2013. It is anticipated that expenditure will continue to be on an upward trend. We are going to have to find extra funding from sources other than the current DoH grant. Planning is therefore essential.

The GSNV is conscious of the current economic pressures, changed governmental priorities our unique operating environment and the flow on effects that have affected the cost of operations and research in the RCH/MCRI environment. Individual support groups are also engaging in their own fundraising and grants applications, and competition for a very small pool of funds available to community and support groups/services is stiff.

Donations, membership fees, fee for service and cost recovery in the next financial year is a serious consideration for the GSNV Executive and must form part of our overall planning in order that we run a viable and cost effective service. So is fundraising.

In relation to expenses over the 2012-2013 financial year, the bulk of our costs have been related to salaries, infrastructure charges from the Victorian Clinical Genetics Services (VCGS) and Murdoch Childrens Research Institute (MCRI), travel, rural outreach, professional development and events.

INFRASTRUCTURE CHARGES EXPLAINED

Infrastructure charges refer to cost recovery for occupancy and support services, provided to the GSNV as a co-located group within the VCGS and MCRI facilities, on the Royal Children's Hospital Campus (RCH).

The Public Private Partnership that manages the new RCH campus charges all occupiers of the building a fee based on per square metre of space occupied. The MCRI is charged by RCH based on the total space and infrastructure it occupies, at approximately \$180 per m2 per annum. This charge is passed on to the VCGS and in turn passed on to the GSNV.

MCRI also currently charges VCGS a flat fee per Equivalent Full Time (EFT) staff member to recover the costs of all aspects of basic support services including; finance, HR, IT support, purchasing, engineering, energy charges, security, cleaning, maintenance of buildings and surrounds and all other costs of occupancy, save for rental. The amount of this charge currently equates to approx \$8,100 per EFT.

The GSNV is charged on an equivalent basis to VCGS as follows:

- \$180 per square metre of office space = \$9,900 per annum
- \$8,100 per EFT at 2.2 EFT = \$20,250

FUTURE PLANNING

A Finance sub-committee has been established with draft terms of reference accepted, pending a review from committee members (this includes but is not limited to the *Treasurer, President and Secretary of the GSNV Inc with an invitation open to interested community members and skilled volunteers working pro bono*) after the Annual General Meeting.

The purpose and function of a working finance committee will be to:

1. Improve the financial position of the GSNV to meet all operations and development costs
2. Secure the long term financial sustainability of the unique GSNV model
3. Identify cost recovery and cost effectiveness
4. Assist with identifying and successfully acquiring competitive funding
5. Encourage philanthropic support and awareness of the work of the GSNV
6. Improve financial transparency and management of income generated by the GSNV Inc directly

In the short to medium term the GSNV with the assistance of the finance sub-committee will identify critical cost recovery areas and opportunities to generate further income.

Measures already in place include a current review of the GSNV membership fees schedule, with changes to the schedule announced by June 2014 and a consideration of 'fees for service' where appropriate.

A GSNV 'major event', a donations portal, sponsorship opportunities and improved grants process will form part of the remit of finance sub-committee.

We thank you all for your generosity and ongoing support of GSNV and offer up the financials for approval at this AGM.

Margherita Coppolino
Treasurer

2012/2013

AUDIT STATEMENT



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

Audit Statement

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

The accounts of the VCGS are audited bi-annually by KPMG who are our External Auditors. The accounts for 2012/13 have been audited by KPMG in accordance with this practice. In the Financial Year 2012/13 GSNV recorded a deficit of \$11,722.41. However, with the brought forward funding at the beginning of the year it was able to carry forward \$131,951.52 to the current 2013/14 Financial year.

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

Best Wishes,

Viren Abeyasinghe MBA, FCPA, FCMA
Chief Financial Officer
Murdoch Childrens Research Institute/
Victorian Clinical Genetics Service.

STATEMENT OF INCOME & EXPENSES

STATEMENT OF INCOME & EXPENSES FOR THE MONTH ENDED 30/06/2013 70680 GENETIC SUPPORT NETWORK (V)

	Actual 2012		Budget 2012	
	For this Period	Year to Date	Year to Date	Year to 30/06/2013
BROUGHT FORWARD BALANCE @ 1/7/2012	143,673.93	143,673.93		83,377.00
INCOME				
DHS GRANT	11,917.50	173,010.00	119,175.00	143,010.00
NHMRC CONSULTING	0.00	0.00	0.00	0.00
LORD MAYOR'S TRUST	0.00	0.00	0.00	0.00
MEMBERSHIP FEES	0.00	0.00	1,666.70	2,000.00
DONATIONS	0.00	0.00	333.30	400.00
CONFERENCE FEES	0.00	0.00	0.00	0.00
SUNDRY INCOME	0.00	2,246.24	500.00	600.00
Total Income	11,917.50	175,256.24	121,675.00	146,010.00
EXPENDITURE				
SALARIES & RELATED COSTS	13,239.03	129,898.50	129,351.64	152,870.00
COMPUTER HARDWARE	0.00	405.81	833.30	1,000.00
COMPUTER SOFTWARE & EXPENSES	0.00	26.00	166.70	200.00
ADVERTISING	0.00	420.00	666.70	800.00
FREIGHT & CARTAGE	0.00	0.00	33.30	40.00
POSTAL SERVICES	0.00	742.93	666.70	800.00
PRINTING, STATIONERY & PHOTOCOPYING	696.73	9,550.28	5,000.00	6,000.00
BOOKS & SUBSCRIPTIONS	63.64	802.91	1,000.00	1,200.00
TELEPHONE CALLS	0.00	120.28	208.30	250.00
SMALL GRANTS	0.00	0.00	0.00	0.00
SPECIAL FUNCTIONS – OTHER	94.77	1,449.93	583.30	700.00
STAFF TRAINING & CONFERENCES	0.00	1,526.98	2,291.70	2,750.00
TRAVEL	190.92	4,383.79	4,166.70	5,000.00
CORP SERVICES – IT/HR/FIN	0.00	0.00	14,850.00	17,820.00
OTHER ADMINISTRATIVE COSTS	30,024.35	37,651.24	5,000.00	6,000.00
Total Expenditure	44,309.44	186,978.65	164,818.34	202,930.00
OPERATING SURPLUS/(DEFICIT)		131,951.52		26,457.00
CARRIED FORWARD @ 30/06/2013				

HIGHLIGHTS



*empowering * connecting * supporting*

genetic support network of victoria

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