



Genetic Support Council of WA

Annual Report



We are more than the sum of our genes!

2008

Acknowledgements

The Genetic Support Council of WA (Inc) received significant support from numerous individuals, agencies and organisations who contribute to our efforts to deliver an effective, professional and successful service to the West Australian community.

We would like to take this opportunity to thank the WA Department of Health who has provided our core funding. We also acknowledge the support and assistance of the Office of Population Health Genomics, individual community based centres and the many non government agencies that collaborate with our organisation.

Without your continued support and dedication we would not be able to provide our services or assistance to the West Australian community.

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Our Services

The Genetic Support Council WA (GSCWA) Inc is a not for profit organisation that works to promote awareness of genetic conditions in the community and to assist in the greater participation of consumers in policy, planning, research and service delivery across the genetic services field.

The GSCWA can provide information to individuals and families about genetic conditions including information on the services provided by genetic support groups.

The diagnosis of a genetic condition in a family member, particularly a child, can place enormous stress on a family. Individuals and families may feel the need for personal support offering a specialised understanding of their particular condition. Genetic support groups provide support and can assist affected individuals and families with information about community resources as well as an understanding and empathetic ear.

In Australasia, there are hundreds of such groups each focussing on a specific genetic condition. The Council can help put families in contact with these groups and may also be able to provide information and support for families affected by conditions so rare that there is no specific support group.

The GSCWA can also provide referral to expert organisations such as Genetic Counsellors and where appropriate advocate on behalf of individuals with other service organisations and providers.

Information

The GSCWA has established a Resource Centre to provide information on the services provided by member genetic support groups. Our library includes group brochures, books, journals and online resources providing information on a range of associated topics such as living with a family member with a genetic condition, parenting, and education in association with a genetic condition.

Resources of interest to health and allied professionals such as the 2006 edition of the Genetic Support Group and Community Service Organisations Directory are available in hard copy upon request or can be accessed on our website.

The GSCWA maintains a database of genetic support groups throughout Australia and with international links can provide up to date information on genetic conditions including the latest information on research developments.

Advocacy

The GSCWA conducts forums for members on issues of interest or concern to enable member's views to be represented to the wider community and State and Federal Governments. We also provide written and verbal submissions to Government and others in the field of genetics and participate with like bodies nationally to further represent genetic support groups and their members.

Workshops and Forums

The GSCWA aims to provide forums and awareness events for members to enable participants to increase their skills and knowledge and access information about resources for people affected by genetic conditions and their families.

Services to genetic support groups

A range of services are available to provide practical, personal support and information for individuals involved in genetic support groups. Assistance and resources can be provided to promote ongoing group development in areas such as incorporation, strategic planning and funding opportunities. Workshops can be conducted on an as needs basis on issues such as meeting procedures, promoting your group, conflict resolution etc.

We are able to assist unfunded genetic support groups with the design and printing of resources such as information packages, pamphlets and promotional material. Groups can also publish articles and advertise and promote awareness of their group's activities in the GSCWA's bi-monthly newsletter the 'Gene Advocate'.

GSCWA staff can assist groups and individuals in researching information regarding particular genetic conditions or predispositions and help keep members aware of matters of interest such as changes of legislation etc.

Our Vision & Mission

Our Vision

“A world where genetics is an integral component of health and health care, where human genetic variation is celebrated and where all people benefit from advances in genetic science and technology.”

Our Mission

“To be an independent and representative voice for genetic support organisations, promote and develop awareness of genetic conditions and their impact on families and community, to foster research, encourage and support service delivery by genetic support groups and facilitate their development by linking and empowering individuals, families and communities.”

Chairperson's Report

As the peak body representing genetic support groups and individuals whose lives are affected by genetic conditions in Western Australia the Council fulfils a vital role. It is a source of information for its members and the Western Australian community and also provides input to government and others about issues that impact on people living with a genetic condition or the wider community. It develops its positions in consultation with its members.

2007/8 has seen the Council continue to provide a high level of support to our members and has also managed its affairs in an efficient manner and maintaining best practice standards in relation to its finances, resources and its assets. As with all organisations there have been challenges as we seek to do more and retain valuable staff without any meaningful increase in funding.

The council has a small but dedicated team headed by our Executive Director Sharon Van der Laan. Sharon and her team of Kristina Johns, Alison Morse and Joan Ryder are responsible for the day to day management and operations for the Council. They continue to support our members and to play a role as advocates for our community and its members.

The Council continues to be involved closely with genetic support group peak

bodies in other parts of Australia and New Zealand through the Australasian Genetic Alliance (AGA). The AGA provides a national network through which to raise awareness of genetic support groups and promote and highlight issues of concern for people living with genetic conditions.

The Board of Management of the GSCWA would like to express our appreciation to its member genetic support groups, the GSCWA staff and the WA Department of Health Office of Population Health Genomics for their contribution and support of the Council during this time.

You will read about the activities and events the Council has been involved in over the past year elsewhere in this report, however this would not have been possible without the hard work and support of the GSCWA Board of Management. I would like to take this opportunity to thank them for the work they have done in the past year. It is especially important to recognise the work of Charles Watson the inaugural Chair of the Council who has decided to step down from the Board. Charles provided great leadership in his time with the Council and we wish him well.

I commend the Annual Report to you and look forward to continued success in the coming year.



Mitch Messer
Chairperson
15 September 2008

Executive Director's Report

The staff and Management Committee of the Genetic Support Council WA have again had a busy year representing members views on a number of issues of importance. We have worked hard to achieve positive outcomes for individuals and provide ongoing support and guidance to genetic support groups throughout Western Australia.

Within WA we have increased our outreach and service provision to regional WA thanks to the ongoing development of the Council's website and distribution of resources such as the Resource Guide for Families and the GSCWA Directory of Genetic Support Groups and Community Support Organisations in Western Australia.

Over 1800 copies of the GSCWA Directory have been distributed across the state to GP's and community support organisations from the Kimberley to Albany.



The inclusion of an electronic Directory downloadable from the GSCWA website further ensures this valuable resource is available to individuals in our community as well as service providers and professionals seeking information on genetic support groups throughout the state.

It is pleasing to note that during the year the number of online searches for the Directory has steadily increased.

We have continued our outreach into the Peel and South West region with networking meetings held during the year in Rockingham and Bunbury. These meetings have provided an opportunity to strengthen our relationship with a number of regional groups and service providers.

The Genetic Support Council's role as an independent and representative voice for genetic support groups has continued to develop with participation in the WA Genetics Council (WAGC), the Telethon Institute Child Health Research Consumer Advisory Committee (TICHRAC), WA Genomics Society and Human Health Committee (GSHH).

The GSCWA has continued to work collaboratively with other stakeholders and this has enabled us to work across project areas rather than maintain a single project focus leading to an increased ability to respond to new initiatives and projects.

The Council Submission on the National E-Health Transition Authority (NEHTA) Privacy Blueprint for the Individual Electronic Health Record (Individual EHR) considered key issues outlined in the Privacy Blueprint including governance, audit functionality, sensitivity labels, what controls individuals have over information in the Individual EHR and secondary uses.

NEHTA is currently developing a business case for funding the Individual EHR. The business case will be considered by the Council of Australian Governments (COAG) in late 2008.

Recognition of the Council as an important advocate on behalf of members in both a local and national setting has been recognised through invitations to contribute to special projects undertaken by the Consumer Health Forum (CHF). These projects included:

- Safety and quality on health care
- Optimising health outcomes for people with chronic conditions; and
- Individual Electronic Health Record.

As a founding member of the Australasian Genetic Alliance (AGA) the Council has provided input into a number of policy documents. Through AGA representation on the HGSA

(Human Genetics Society of Australasia) Ethics and Social Issues Committee, the Council has contributed to the drafting of a number of policy documents including:

- Direct to consumer genetic testing
- The protection of human genetic information
- Use of assisted reproductive technology to select for disability

These policies are posted on the HGSA website (www.hgsa.com.au) and can be viewed or downloaded.

During the past twelve months we have had opportunity to provide stakeholder feedback on consultations including

- the Food Standards Australia New Zealand (FSANZ) Folate consultation
- participation on the WA Biobanks Advisory Group
- Disclosure of genetic information to relatives

The Genetic Support Council has been keen to reach as many of our members as possible and to provide them and other interested stakeholders with information that is relevant and useful to them.

Executive Director's Report

We continue to receive a very positive response to our bi-monthly newsletter 'The Gene Advocate' which now has a circulation of almost 480. We have updated the newsletter and made some changes and are always interested to hear your feedback. While many of our members prefer to receive a hard copy of the Gene Advocate we also make it available electronically and on our website.

The GSCWA website plays an important part in our communications strategy.



During the year we have recognised that a major review of the site was needed to ensure its operation meets the needs of our members and other stakeholders. With statistics indicating an increasing number of people accessing the website for information in 2007/08, the upgrade of the website will be a major priority in the coming year.

At a practical level we work directly with member genetic support groups to help them develop the essential tools and resources needed to provide support services. This increases the capacity for groups to assist families coping with a genetic condition and the challenges they face, whatever these are and however common or rare the condition is.

During the year this assistance has included:

- graphic design and development of group promotional brochures and information sheets and newsletters
- development of survey instruments
- development of group constitutions and governance guidelines
- free or for cost printing of promotional resources
- access to office, internet and meeting room facilities.
- assistance with developing and promoting group events

These achievements would not be possible without the commitment of my co-workers Kristina, Alison and Joan who have been a great support to me. On behalf of our members I would like to sincerely thank them for their wonderful sense of spirit, their enthusiasm, hard work and commitment throughout the year.

We are indeed fortunate to have staff with such drive and dedication to their work.

Credit for the continued development of the GSCWA must also go to our Board and I thank all current and former members for their valued contribution guiding the Council on behalf of the membership.

Our sincere thanks to:

Chairperson

Mitch Messer

Director

Thinking Beyond

Vice Chairperson

Steve Sandilands

Cornelia De Lange Syndrome Support Group

Treasurer

Kerrie Duff

Senior Policy Officer

People With Disabilities WA

Professor Charles Watson

Health Services, Curtin University

Teresa Alvaro

Thalassaemia Association

Kerry Gavey

Klinefelter's Syndrome Support Group

I would like to say a special thank you to Professor Charles Watson for his support over the past six years. Charles was the Council's inaugural Chair and served four years in this position. Charles has decided not to seek re-election after completing another two year term on our Board as an ordinary member. Charles we will miss your advice and council and wish you every success.

We also say goodbye to Steve Sandilands, Irene Gray and Meredith Doyle. Your skills and dedication will be missed.

These are challenging times for all not for profit organisations. Sustaining adequate funding is more difficult than ever and we acknowledge the West Australian Department of Health who through the Office of Population Health Genomics provide our core funding.

Finally, thank you to all those individuals and organisations who supported us during the year. I would also like to take this opportunity to send my best wishes to the support groups and individuals that make up our membership and on whose behalf we are working.



Sharon Van der Laan
Executive Director

Our Achievements

The Council continues to address the need for increasing community awareness of genetic conditions through a range of strategies. These include information displays in public libraries and participation in community events such as the Carer's Expo, the NCWA Conference, and the Neurological Support Services Expo at Sir Charles Gairdner Hospital. The GSCWA also had an information stand at the Involving People in Research symposium at the University of WA.

Opportunities have also arisen for the Council to participate with other stakeholders on current health issues of relevance to our members. We contributed to the Health Consumers Council Priority 1 submission to the Australian Commission on Safety and Quality in Health Care on a draft National Patient Charter of Rights.

The aim of this program is to develop a national patient charter of rights that describes what a patient can expect from an encounter with the health system. The charter will include a nationally agreed set of principles that will underpin the provision of safe and high quality health care and support a shared understanding of the rights and responsibilities of patients, consumers and health care providers.

As a founding member of the Australasian Genetic Alliance (AGA) the Council has been able to have input into a number of national policy documents. Through AGA representation on the HGSA (Human Genetics Society of Australasia) Ethics and Social Issues Committee, the Council has contributed to the drafting of a number of policy documents including Direct to Consumer Genetic Testing.

Tests are available for an increasing number of health-related genetic conditions, ranging from cystic fibrosis to the predisposition to develop breast cancer. Estimates of the number of tests currently on the market worldwide total at over 1000.

Although typically such tests are performed in a medical setting with the support of health care professionals including genetic counselors, a growing number of laboratories and private companies offer 'direct to Consumer' (DTC) genetic testing through advertisements on the internet.

The home use of genetic tests may be more problematic than use in a clinical laboratory setting, resulting in the potential for increased risk.. At home consumers may not conduct the test correctly. The person collecting the sample and sending it to the laboratory may lack the technical training to ensure that the specimen arrives at the clinical laboratory in the same condition as when it was collected.

Further, the consumer may not be able to interpret test results in a clinical context (e.g. against the background of relevant family medical history). The likelihood of a false negative is higher with home testing, and the consumer may not engage in follow-up actions that would have been recommended by clinicians following a positive test result.

At present the DTC genetic tests on offer in Australia are largely from overseas, via the internet, so regulation is almost out of the question. Consumer awareness informed by self education and encouraged by open dialogue with health authorities, consumer advocates, medical practitioners and genetic counselors may provide some safeguards.

The protection of human genetic information was also addressed when amendments to the Privacy Act 1988 (Cth) required the National Health Medical Research Council (NHMRC) to develop Guidelines to assist health professionals in making decisions about the circumstances in which they may disclose certain personal information to their patient's genetic relatives. This amendment creates a discretion for organisations to use or disclose genetic information about an individual where necessary to lessen or prevent a serious threat to the life, health or safety (whether or not the threat is imminent).

The issues surrounding genetic information are amongst the most controversial of all privacy issues. Unlike many other dimensions of personal information that relate to behaviour and lifestyle, genetic information is entirely outside the control of individuals. And yet, on the basis of that information, other organisations may make decisions about individuals that can have serious adverse effects—whether in relation to employment, insurance cover, medical treatment or other issues. Genetic information may form the basis of discrimination that could seriously affect the lives of individuals.

The other side of this argument is that gene technology also offers many benefits. Genetic information can help to identify the presence of a certain condition in an individual or predict an individual's likelihood of developing a certain condition. Adopting an appropriate framework to regulate the use and privacy of genetic information has therefore emerged as a key issue in public policy.

The GSCWA responded to the public consultation paper (Disclosure of genetic information to a patient's genetic relatives under Section 95AA of the *Privacy Act 1988* (Cth) – Guidelines for health practitioners in the private sector) noting that the handling of individuals' health information should continue to afford individuals an appropriate degree of control and choice over how it is used and by whom.

Our Achievements

However, in some circumstances, the disclosure of genetic information could allow the prevention of serious health consequences in genetic relatives—for example, where an individual's test results are positive for mutations linked to breast cancer: Ideally, and in many instances, the patient will consent to informing relatives, so that they may seek their own medical advice, including screening.

The amendments do not oblige disclosure of information but provide the framework for this to occur under the appropriate circumstances. The Guidelines specify legal obligations that apply when disclosing genetic information, and also provide explanatory material to guide and advise health practitioners on how to meet those obligations.

The sharing of information is integral to good doctor-patient communication and to high quality care. Health professionals have a responsibility to communicate clearly, to help health consumers understand the choices available and ensure that patients and provider share a shared understanding of how their health information will be handled. Building and maintaining consumer confidence in these processes is central to the acceptance and success of these guidelines.

The Council Submission on the National E-Health Transition Authority (NEHTA) Privacy Blueprint for the Individual Electronic Health Record (Individual EHR) considered key issues outlined in the Privacy Blueprint including governance, audit functionality, sensitivity labels, what controls individuals have over information in the Individual EHR and secondary uses.

GSCWA members support the development of an Individual EHR as it has the potential to make consumers active partners in their own health and improve the safety and quality of their health care.

At a local level, Council staff met with Michael Livingston — Director of Heart UK— to discuss the establishment of a support network for individuals and their families with familial hypercholesterolaemia (FH).

Interest in forming the FH network had arisen from the Office Population Health Genomics (OPHG) project to pilot test a clinical service to identify and treat index cases with familial hypercholesterolaemia and to cascade screen their relatives.

The GSCWA is working with OPHG, interested health professionals and patients to establish an FH support network which will:

- provide information, advice & support
- support health professional awareness
- promote healthier lifestyle options.

An FH forum is planned for November 2008 to facilitate the involvement of medical, nursing and allied health professionals, families, carers, supporters and advocates, in partnership with patients to establish the group and help support those West Australians at risk of inherited high cholesterol and cardiovascular disease.

A cornerstone of our service and support activities in WA is facilitated through networking and information sharing. The GSCWA Resource Centre continues to provide up-to-date information on genetic support groups including pamphlets detailing group services, newsletters and fact sheets as well as a diverse range of resource materials of interest to families seeking information and referral.

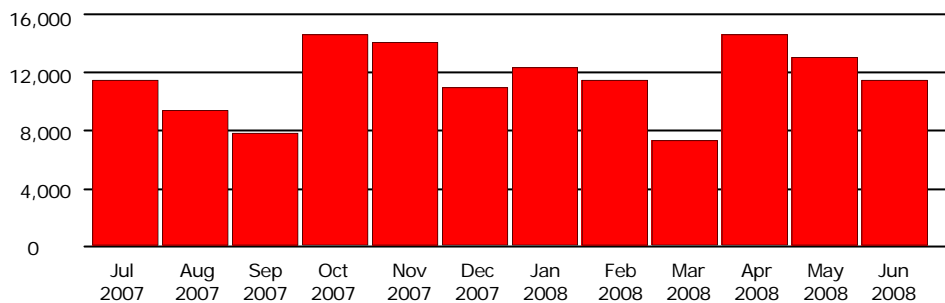
Throughout 2007-2008 the GSCWA database has been extended to include over 267 specific genetic conditions and the details of 575 genetic support groups and organisations worldwide that provide services to individuals and families living with a genetic condition.

Further links have been established to other data banks that enable information to be obtained with regards to some 1360 genetic conditions providing a comprehensive support and referral resource.

Our Achievements

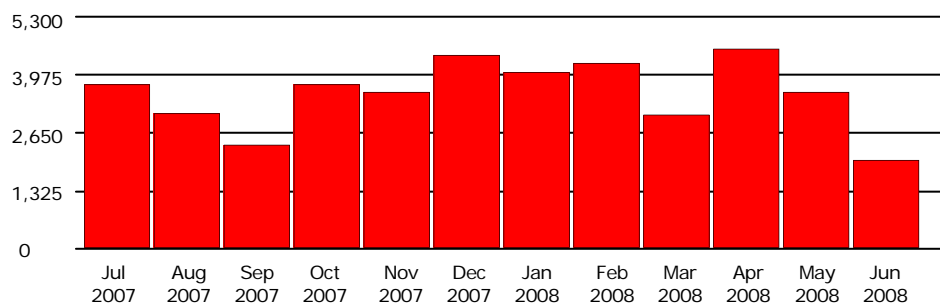
During the year the number of visitors to our website has continued to grow. Every month an average of 10,876 visitors log on in search of information – a 9.5% increase on last year.

Visits per month to GSCWA website



The web is an important way of reaching a wider audience, making sure they are aware of the impact of genetic conditions, and of the work that is being done by genetic support groups to assist those affected by them.

Repeat visitors per month to GSCWA website



The GSCWA website now receives an average of 2,878 return visits per month.

The website provides access to downloadable versions of the GSCWA Directory of Genetic Support Groups and Community Support Organisations in Western Australia, our newsletter the 'Gene Advocate' well as a range of resource materials of interest to families seeking information and referral. Statistics show this resource is valued by service providers, educational institutions, health professionals, students and the wider community

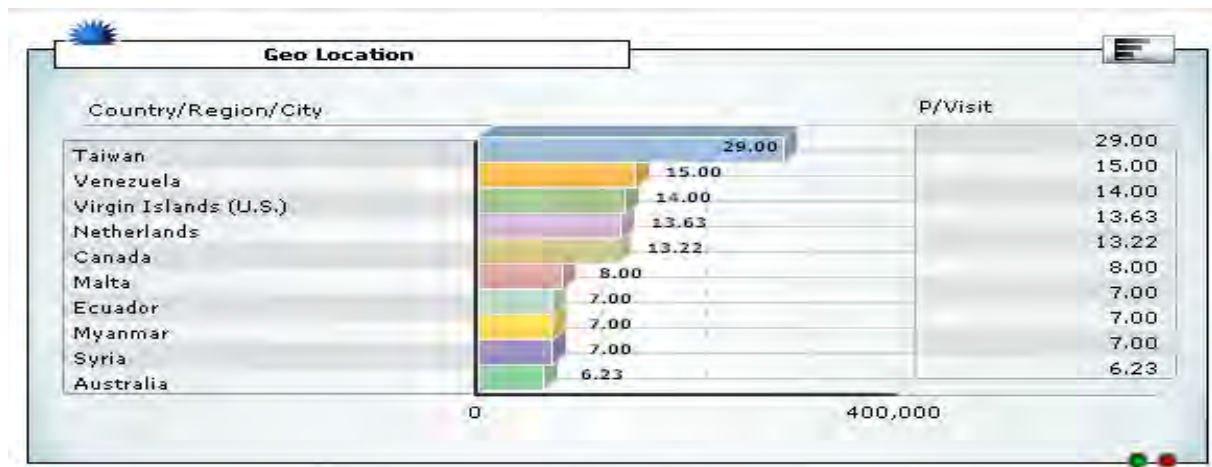
Website Snapshots



Our statistics show that up to 50% of website visits originate from overseas users as indicated above. This interest may reflect that while there is increased use of the Internet to obtain genetics information, genetics sites are often highly technical and not readily accessible to the lay public.

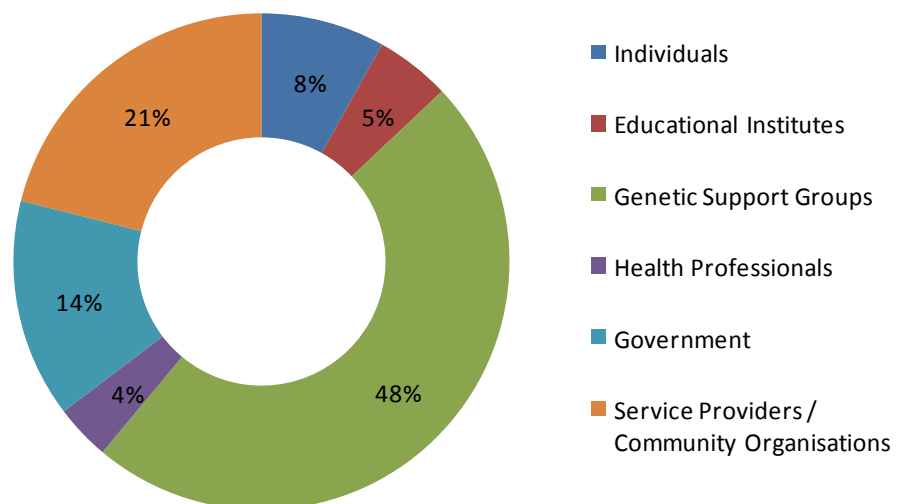
Our Achievements

The snapshot graph below indicates the number of pages per visit accessed and the users country of origin. The GSCWA website is regularly updated with links to information, news and events relating to genetic health.

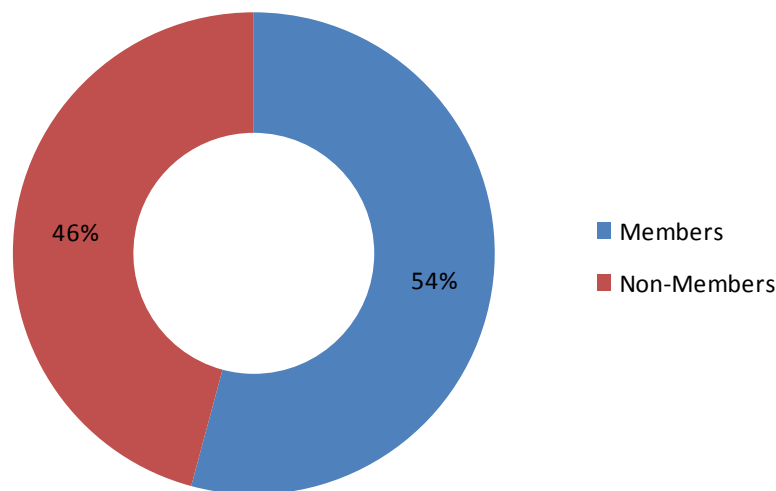


Enquiries by category

During the year the GSCWA received 568 requests for information and/or assistance.



Members verses non-members enquiries



The Council received 568 requests for information and assistance during the year. Enquirers may be looking for personal support and information following a genetic diagnoses or information and resource materials related to a specific genetic condition. In these circumstances the Council is able to assist with referral to genetic support groups and other appropriate services.

Practical support is provided to our member genetic support groups. The GSCWA actively supports the ongoing development of genetic support groups by assisting with the development of group resources such as information packages, pamphlets and printing of promotional material, development of survey instruments, development of group constitutions and governance guidelines, free or for cost printing of promotional resources and access to office, internet and meeting room facilities.

Enquiries come from a wide variety of sources as well as our genetic support group membership.

Looking Ahead

Over the last decade genetics and bio technology have greatly increased the knowledge of the structure and function of human genes and their relation towards health, disease and behaviour. This knowledge has implications for society at large, for those working in health and healthcare and for (potential) patients and their family.

As a society we face controversial topics such as human embryonic stem cell research, therapeutic and reproductive cloning, and the commercialisation of genomic data. New models of healthcare are being proposed offering new options for health maintenance and an individualised approach to medicines and treatment.

These implications also raise ethical, legal, psychosocial and cultural questions for society, politicians, governments, healthcare workers, scientists and individuals. It will be essential for all parties involved to be able to understand the implications and to be able to find answers to imposing questions, to find solutions for the problems and to determine policy.

The need for a clear, strategic patient and family perspective in the debate about science and health policy has been demonstrated time and again. So has the need for the translation of good science into products, services and support that benefit those affected by genetic disorders.

The Genetic Support Council WA (GSCWA) has provided that voice, speaking from the perspective of our member organisations and the individuals and families that we support. The range of issues on which we have used that voice to good effect runs from the protection of human genetic information to the use of embryonic stem cells in medical research to privacy, confidentiality and disclosure of genetic information to third parties.

The Council's strength derives from the fact that it is an independent democratically led body (our Board is elected by the genetic support groups who are our members). We have an open, consultative structure that offers members the opportunity to have a say on issues of concern in science and health care. We are however uniquely placed to be much more than simply a conduit for the views of our membership.

A focus of our 2008-2011 Strategic Plan will be to undertake projects that break down the boundaries and improve the provision of genetic and other health care services for those who need them.

We will continue to support member organisations seeking specific changes, that will benefit their own members and provide information to individuals and the professionals who support them, so they can find their way to relevant sources of expert help quickly and efficiently.

Through membership of a range of committees and steering groups the Council has the opportunity to provide the patient and consumer voice. We will use this voice to look to providing informed opinion and comment on genetic issues for the press, policy makers and government.

In the coming year we will be developing policy and position statements following consultations with members on a number of issues including research priorities and Biobanks and health databases in WA.

Putting the views of our members into these discussions can help to “ground” the debate and address the reality of the situation for those whose lives are vitally affected by these issues.

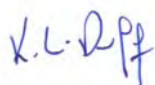
We will continue to engage with Office of Population Health - Genomics fostering a close working relationship with OPHG, Genetic Services WA and other key expert groups on issues of interest or concern to our members.

We are determined to continue to intervene actively on those issues and topics that are important to our members and the families they support, so they are able to benefit from new knowledge and opportunities arising from research and development quickly, equitably and safely – wherever they live and whatever their circumstances.

Treasurer's Report

The Board of Management is pleased to present this year's Financial Report. The report shows that the GSCWA operated within its approved budget and within the contractual requirements of the Western Australian Department of Health Funding Contract.

The GSCWA has been granted a 3 year service agreement for \$509494 which runs until 30 June 2008 with the Western Australian Department of Health. A new contract is currently being negotiated.



Kerrie Duff

Treasurer

18 September 2008

Statement by Board of Management

GENETIC SUPPORT COUNCIL WA (INC)

STATEMENT BY THE BOARD OF MANAGEMENT

The Board of Management has determined that the Association is not a reporting entity.

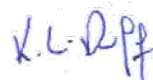
The Board has determined that this special purpose financial report should be prepared in accordance with the accounting policies outlined in Note 1 to the financial statements.

In the opinion of the Board the financial report as set out on pages 26 to 33 presents fairly the financial position of the Genetic Support Council WA (Inc) as at 30 June 2008 and its performance for the period ended on that date, in accordance with the basis of accounting as described in Note 1 of the Financial Statements.

This statement is made in accordance with a resolution of the Board and is signed for and on behalf of the Board by:



BOARD MEMBER



BOARD MEMBER

Dated this 18th day of September 2008

INDEPENDENT AUDITOR'S REPORT

To the Members

GENETIC SUPPORT COUNCIL WA (INC)

Scope

I have audited the attached Special Purpose Financial Statements of the Genetic Support Council WA (Inc) for the year ended 30th June 2008 as set out in pages 4 to 10. The Board of Management through the Treasurer is responsible for the preparation and presentation of the financial reports and the information contained therein. I have conducted an independent audit in order to express an opinion on them to the members.

The Financial Statements have been prepared for distribution to the Members for the purpose of fulfilling the Board's reporting requirements to its members. I disclaim any assumption of responsibility for any reliance on this report or on the financial report to which it relates, to any person other than the members, or for any purpose other than for which it was prepared.

My audit has been conducted to provide a reasonable assurance as to whether the financial statements are free of material misstatement. My procedures included examination, on a test basis, of evidence supporting the amounts and other disclosures in the financial statements, and the evaluation of significant accounting estimates. These procedures have been undertaken to form an opinion as to whether in all material respects, the financial reports are presented fairly in accordance with relevant accounting standards and professional reporting requirements, so as to present a view which is consistent with my understanding of the financial position and the results of the Association's operations and cash flows.

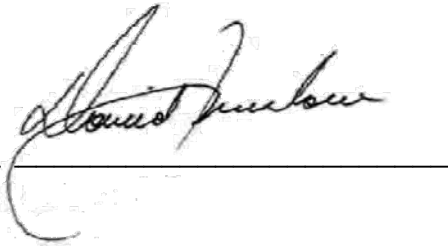
The opinion expressed in this report has been formed on the above basis.

Qualification

As is common for associations of this type, it is not practicable for the Association to maintain an effective system of internal control over donations, subscriptions and other fund raising activities until their initial entry in the accounting records. Accordingly, my audit in relation to fund-raising was limited to amounts recorded.

Audit Opinion.

In my opinion, bearing in mind the effects of above qualification, if any, the financial reports as presented on behalf of the Genetic Support Council WA (Inc) for the year ended 30th June 2008 present fairly the Income and Expenditure of the Association for the period then ended, and its financial position as at that date.



DAVID TRUSLOVE

Auditor

Dated: 17th September 2008

Guildford WA

Financials

GENETIC SUPPORT COUNCIL WA (INC)

STATEMENT OF FINANCIAL POSITION

AS AT 30 JUNE 2008

	NOTES	2007 \$	2008 \$
CURRENT ASSETS			
Cash assets	3	<u>50134</u>	<u>40567</u>
TOTAL CURRENT ASSETS		<u>50134</u>	<u>40567</u>
TOTAL ASSETS		<u>50134</u>	<u>40567</u>
CURRENT LIABILITIES			
Payables	7	10223	7768
Provision for employee entitlements	8	14123	21846
Visa 3801		180	0
Visa 4794		<u>2623</u>	<u>1205</u>
TOTAL CURRENT LIABILITIES		<u>27149</u>	<u>30819</u>
NET ASSETS / (DEFICIENCY)		<u>22985</u>	<u>9748</u>
ACCUMULATED FUNDS	10	<u>22985</u>	<u>9748</u>

GENETIC SUPPORT COUNCIL WA (INC)
STATEMENT OF FINANCIAL PERFORMANCE
FOR THE YEAR ENDED 30 JUNE 2008

	NOTES	2007 \$	2008 \$
Revenue from ordinary activities	2	185579	169635
Employees expenses		-91489	-111741
Depreciation		0	0
Administration expenses		<u>-84105</u>	<u>-66928</u>
Operating Surplus		<u>9985</u>	<u>-9034</u>
Total changes in equity		<u>9985</u>	<u>-9034</u>

**GENETIC SUPPORT COUNCIL WA (INC)
NOTES TO FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2008**

NOTE 1: SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

This financial report is a special purpose financial report prepared in order to satisfy the financial reporting requirements of the constitution of the Genetic Support Council WA Inc. (the "Association"). The Board of Management has determined that the association is not a reporting entity.

The financial report has been prepared in accordance with the requirements of the Associations Incorporation Act WA and the following Australian Accounting Standards:

AAS 1 :	Statement of Financial Performance
AAS 2 :	Depreciation
AAS 5 :	Materiality
AAS 6 :	Accounting Policies
AAS 36:	Statement of Financial Position

No other applicable Accounting Standards, Urgent Issues Group Consensus Views or other authoritative pronouncements of the Australian Accounting Standards Board have been applied.

The financial report has been prepared on an accruals basis and is based on historical costs and does not take into account changing money values, or except where specifically stated, current valuations of non current assets. The accounting policies adopted are consistent with those in the previous year, except where otherwise stated.

The following is a summary of the significant accounting policies adopted by Genetic Support Council WA (Inc) in the preparation of the financial statements: -

(a) Employee Benefits

Provisions for employee entitlements in relation to annual leave and long service leave, are brought to account, based upon employees pro rata entitlement calculated at current rates of pay.

GENETIC SUPPORT COUNCIL WA (INC)
NOTES TO FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2008

(b) Income Tax

The Association is exempt for Income Tax under Section 50-5 of the Income tax Assessment Act 1997. It is a registered tax exempt charity.

(c) Unspent grants

Grant income is brought to account as revenue in the year in which it is expended. To the extent that such grants remain unexpended at year end they are carried forward to future accounting periods.

(d) Capital Expenditure Grant Income

Grants received for capital expenditure are recognised as income progressively over the life of the asset acquired, in accordance with International Accounting Standard IAS 20 "Accounting for Government Grants and Disclosure of Government Assistance". The un-amortised balance of the grant is carried forward to future financial years to be matched against the costs associated with applicable capital expenditure.

Financials

GENETIC SUPPORT COUNCIL WA (INC)

NOTES TO FINANCIAL STATEMENTS

FOR THE YEAR ENDED 30 JUNE 2008

	2007	2008
	\$	\$
NOTE 2: REVENUE		
Operating Grant receivable		
– Department of Health	155100	159713
Interest received	354	425
Other	27045	9497
GenEthics Income	<u>3080</u>	<u>3080</u>
	<u>185579</u>	<u>169635</u>
NOTE 3: CASH ASSETS		
Cash at bank: Cheque account	39358	34916
Investment account	6996	7393
Donations account	434	332
GenEthics account	3208	-2102
Petty Cash	138	28
	<u>50134</u>	<u>40567</u>
NOTE 7: PAYABLES		
Creditors & accruals	5153	1378
GST Liabilities	2900	2760
PAYG Liabilities	2170	2724
Superannuation Liabilities	<u>0</u>	<u>906</u>
	<u>10223</u>	<u>7768</u>

GENETIC SUPPORT COUNCIL WA (INC)
NOTES TO FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2008

	2007 \$	2008 \$
NOTE 8: PROVISIONS - CURRENT		
Provision for employee entitlements	<u>14123</u>	<u>21846</u>
	<u>14123</u>	<u>21846</u>
 NOTE 10: ACCUMULATED FUNDS		
Accumulated funds/(deficit) at beginning of year	13000	22985
Accumulated funds/(deficit) for the year	9985	-9034
Accumulated funds/(deficit) at end of year	<u>22985</u>	<u>13951</u>

Financials

GENETIC SUPPORT COUNCIL WA (INC)

DETAILED STATEMENT OF INCOME

FOR THE YEAR ENDED 30 JUNE 2008

	2007	2008
	\$	\$
INCOME		
Grant received – Department of Health	155100	159713
Other Grants	26052	4937
Contract work	992	4375
Miscellaneous	0	0
Interest	354	185
GenEthics Income	3080	0
	<u>185578</u>	<u>169635</u>
Total Income	<u>185578</u>	<u>169635</u>

GENETIC SUPPORT COUNCIL WA (INC)
DETAILED STATEMENT OF EXPENDITURE
FOR THE YEAR ENDED 30 JUNE 2008

	2007	2008
	\$	\$
EXPENDITURE		
Advertising	330	0
Audit	800	800
Bank Charges	460	429
Bookkeeping	4164	3725
Conference & Training	1421	3119
Depreciation	0	0
Equipment Purchases	4055	7074
Forums & events	571	1557
Genethics Expenditure	1743	1106
Grant Acquittal	25884	0
Insurance	3571	6760
Library	866	587
Membership Subscriptions	1797	644
Office Supplies	16986	10315
Photocopying	1413	1806
Postage & Courier	736	844
Rent	9447	9449
Repairs & Maintenance	543	2529
Salaries, Wages & Accruals	84237	103450
Superannuation	7252	8291
Telephone	4407	5330
Travel & Accommodation	4911	10584
	<u>175594</u>	<u>178669</u>
Total Expenses	<u>175594</u>	<u>178669</u>

Our Members

Full Members

Acoustic Neuroma Association of Australia
Alzheimer's Association of WA
Angelman Syndrome Association
Arthrogryposis Support Group
Australian Cystinosis Support group
Australian Huntington Disease Association
Australian Pituitary Foundation WA Branch
Australian Tuberous Sclerosis Society Inc
Australasian CHARGE Syndrome Association
Cleftpals - Cleft Palate and Lip Society
Coeliac Society of WA
Cornelia De Lange Syndrome Support Group
Cushing's Disease Support Group
Cystic Fibrosis WA
Diabetes WA
Down Syndrome Association of WA
Dyslexia SPELD Foundation WA Inc
Epilepsy Association of WA
Even-Keel Bi-Polar Support Association Inc
Fragile X Support Group WA Inc
Haemophilia Foundation WA Inc
Heart Kids WA
Klinefelters Support Group
Learning and Attention Disorders Society of WA (LADS)
LQTS Support Group WA
Lupus Group of WA
Lymphoedema Association of Western Australia
Mental Illness Fellowship WA
Motor Neurone Disease Association of WA Inc
Mucopolysaccharide & Related Diseases Society Muscular Dystrophy Association of WA
Neurofibromatosis Association of WA
Parents of Children with Disabilities

Periodic Paralysis Society of Australia
PXE Support WA
Raynaud's Syndrome Support Group
Rett Syndrome Association of WA
Senses Foundation Inc
Short Statured People's Association WA Branch
SIDS and Kids Western Australia
Sjögren's Syndrome Support Group
Spina Bifida Association of WA
Thalassaemia Association of WA
Turner Syndrome Association of Australia (WA Branch)
Support Organisation for Trisomy and Related Disorders of WA (SOFTWA)
Western Australian Retinitis Pigmentosa Foundation
WA Tourette Syndrome Organisation (WATSO)

Corporate Associate Members

ARAFMI Western Australia
Association of Genetic Support of Australasia
Australian Kidney Foundation
Carers Association of WA Inc
Lone Parent Family Support Service (LPFSS)
Office of Population Health Genomics
People with Disabilities (PWD)
The Kalparrin Centre
The Neurological Council of WA Inc
Western Australian Deaf Society Inc

Individual Associate Members

Linda Bovill	Terry Keating
Mark Bovill	Darren Webb
Anja Hermann	Professor Charles Watson
Kristina Johns	Sharon Van der Laan

Genetic Support Council of WA Inc (GSCWA)

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