

Annual Report 2005 – 2006





Our Vision

Seeking solutions to the challenges of genetic conditions.

Our Mission

To promote and develop awareness of genetic conditions within the community, provide information and advocacy to individuals and families, foster research, encourage and support service delivery by Genetic Support Groups.

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GSCWA location and Contact details

Unit 9, Level 1

Oasis Lotteries House

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☎ Fax: 08 9389 9377

✉ Email: info@geneticsupportcouncil.org.au

🌐 Web: <http://geneticsupportcouncil.org.au>

Office Hours:

Monday to Friday

9.00 am to 4.00 pm

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 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.

GSCWA Services

The Genetic Support Council WA (GSCWA) Inc is a not for profit organisation that working 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 newsletters, 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 access 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.

Chair's Report

I am pleased to report that over the past twelve months the Genetic Support Council has taken the opportunity to be involved in a range of activities. The Council continues to provide a high level of practical and personal support to its members and manage its affairs in an efficient and effective manner maintaining best practice standards in relation to its finances, resources and its assets.

2005 has been a year of significant change within the GSCWA. Sharon Van der Laan was appointed Executive Director of the Council just prior to the 2004 Annual General Meeting. Sharon has now settled into her role and has made a very positive contribution to the organisation.

The Council continues to strengthen links with genetic support group peak bodies in other parts of Australia and New Zealand through the Australasian Genetic Alliance (AGA) providing 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.

This year the GSCWA undertook the task of developing a new Genetic Support Group Directory. While this required a huge amount of effort from all involved, they have produced a very valuable resource that is both very professional and will be widely used in the community.

The Board of Management of the GSCWA would like to express its appreciation to its member Genetic Support Groups, the GSCWA staff and the Office of Population Health - Genomics of the Western Australian Department of Health for their contribution and support of the Council during this time.

I am stepping down from the position of Chair of the GSCWA Board having served two consecutive terms. I look forward to further contributing to the GSCWA as a Board Member.

I would like to personally thank the GSCWA Board of Management for their work during the past year. Finally, I wish to express my thanks to retiring Board members Del Weston, Neurological Council,, Teresa Alvaro, Thalassaemia Association of WA Inc. and Irene Gray, WA Tourette Syndrome Organisation for their support to the Council during their term as Board members. Their efforts are acknowledged and appreciated.

I also thank those Board members who are continuing, Kerrie Duff, Disability First Stop, Sue Fraser Periodic Paralysis Society of Australia, Susan Herrmann, Health Consumers Council, Mitch Messer, Deputy Chair Cystic Fibrosis, Amanda Samanek, Office Population Health Genomics, and Steve Sandilands, Cornelia De Lange Syndrome Support Group for their continued involvement.

I commend this Annual Report to the members of the GSCWA.

Professor Charles Watson
Chairperson

Executive Director's Report

It is good to have an opportunity such as this to review what has been achieved over the past year – especially as this time also marks the completion of the my first 12 months with the GSCWA. I am pleased to report that although we have been presented with many new challenges it has also been a year of consolidation, and a successful year with many achievements.

This year the GSCWA has built upon the work undertaken by the inaugural Executive Director Terry Keating and past Board members and staff to see the organisation continue to develop into a well respected professional agency recognised not only here in Western Australia but also interstate and overseas.

We farewelled Anja Hermann our Administrative Officer who has taken to full-time Motherhood and welcomed onto the GSC team Joan Ryder as book-keeper. Joan has brought a wealth of knowledge and expertise as well as a sense of humour much appreciated in the office.

Over this past year the Council has continued to engage member support groups in Western Australia, providing a wide range of practical support and services to members ranging from photocopying to financial planning to website development. Brochures, information sheets and promotional flyers on behalf of member groups continue to be designed, and printed in house and widely distributed.

Another area of significant Council activity is acting as a referral point to individuals and their families, Genetic Support Groups and members of the community who are seeking information about genetic conditions, Genetic Support Groups and genetic services. This is an area that has steadily increased as the GSCWA continues to increase its profile in the community and broadens its networks.

The Council is recognised as the most significant consumer organisation representing Genetic Support Groups, individuals with genetic conditions and predispositions and their families in Western Australia. The Genetic Support Council WA's role as a consumer representative both at a state and national level has continued to develop with participation in the Australasian Genetic Alliance (AGA), WA Genetics Council (WAGC) and attendance at the Human Genetics Advisory Council (HGAC) consultative meeting in Melbourne.

We have had to opportunity to provide stakeholder feedback on consultations relating to new born screening, the Birth Defects Registry, Centre for Genetics Education Resource for GP's and the Patient and Family Volume and the FSANZ Folate consultation.

The Office of Population Health Genomics of the Western Australian Department of Health has provided a three year funding contract for the Council for the period 2005/2008 and it has been through this funding that the GSCWA has been able to provide its services. The support and assistance in a range of

areas by the Genomics staff and Director Peter O'Leary is greatly appreciated.

Negotiations have been taking place between the Oasis Lotteries House Committee and Lottery West regarding refurbishment of our building. This negotiation is ongoing and until this has been finalised and we will be able to continue at our very central and comfortable 'home'.

Without ongoing funding and a 'home' we certainly wouldn't be able to continue. It is encouraging that we can move into our fourth year of operation with confidence and an air of celebration. During the year staff have been working on a new edition of the GSCWA Genetic Support Group Directory which was originally published in 2001.

The 'new' directory builds on the support group information contained in the original publication and includes a community support organisations listing. The Directory is available to groups, individuals and professionals thus promoting the services of Genetic Support Groups in the community.

Raising community awareness of genetic conditions and the role of Genetic Support Groups is still the most challenging aspect of the Council's role.

The Council continues to address this need for increasing community awareness through a range of strategies, these include, information displays in libraries and participation in events and community expo's including Wheat Belt Carers Expo

in Northam, Disability First Stop Expo, the NCWA Conference and the Neuro Expo at Sir Charles Gairdner Hospital.

In May 2006 the GSCWA was invited to participate in the Cutting Edge Lecture Series presented by the CSIRO Science Education Centre at SciTech. The Council's participation in this event and our presence at the Parent and Baby Expo were in conjunction with Office of Population Health Genomics and are examples of how the Council is working with the Genomics Directorate to raise community awareness and develop a meaningful understanding of the complexities and issues that confront individuals with genetic conditions and their families. This support is vital and I am sure this partnership will grow stronger as we face new social challenges and look for effective ways to address the community's needs.

The Gene Advocate has continued to receive very positive feedback about the new layout and content of the newsletter from groups, professionals and service providers. The newsletter is distributed bi monthly to over 320 individuals, groups and service providers across the state – an increase of 15% in the past 12 months.

In addition, the Council continues to circulate significant numbers of brochures and information sheets. Some of these are through member Genetic Support Groups, community service organisations and the Office of Population Health, whilst others result from direct requests from with health professionals, tertiary institutions and individuals seeking information and general mail outs.

Throughout 2005-2006 the GSCWA database has been extended to now include over 234 specific genetic conditions and the details of 513 Genetic Support Groups and organisations worldwide that provide services to individuals and families living with a genetic condition or predispositions, and others seeking information. Links have been established to other data banks that enable information to be obtained with regards to some 1350 genetic conditions.

Credit for the continued development of our services must go to the combined expertise and dedication of the GSCWA staff and Board members. Thank you to Kristina, Joan and Anja for your valuable work and helping us to reach our goals for the year.

Sincere thanks also to the GSCWA Board:

Professor Charles Watson (Chairperson),
Executive Dean Health Services Curtin University

Del Weston (Vice Chairperson),
Chief Executive Office, Neurological Council

Mitch Messer (Treasurer),
Deputy Chairperson, Cystic Fibrosis Society

and Board members:

Teresa Alvaro representing Thalassaemia Association,

Kerrie Duff, Project Officer, Disability First Stop

Sue Fraser representing Periodic Paralysis Society Australia,

Irene Gray representing WA Tourette Syndrome
Organisation,

Susan Herrmann representing Health Consumers Council,
Amanda Samanek, Education Officer, Office of Population
Health,

Meredith Doyle representing Huntington's Disease
Association

and; Steve Sandilands representing Cornelia De Lange
Syndrome Support Group.

Having a voluntary Board with a good mix of grass roots and professional expertise has been invaluable in the development of the organisation.

On behalf of the GSCWA I would also like to take this opportunity to thank all the individuals and organisations who have supported us throughout the year.

I look forward to working with you in the year ahead to represent and support those whose lives are affected by these complex conditions.

Sharon Van der Laan
Executive Director

GSCWA Activities

During the year the GSCWA provided information and promoted the services offered by the GSCWA and its member support groups to the general public at community events such as the Every Woman Expo, Parents and Babies Community Expo (in conjunction with Office of Population Health Genomics), the Wheatbelt Carer's Expo, Disability First Stop Expo and the Neuro Expo at Sir Charles Gairdner Hospital.



Wheat Belt Carers Expo
March 2006



Talk on living with a disability
April 2006

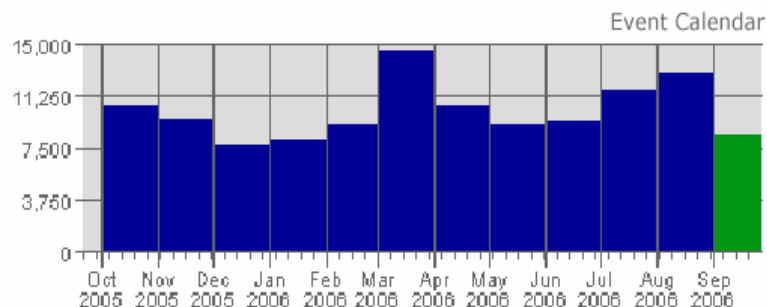
Through the GSCWA Resource the Council is able to coordinate and develop resources, research issues and distribute information, as well as seek opportunities to reach the community.

The Council's bi-monthly newsletter the "Gene Advocate" continues to increase in circulation. The newsletter is distributed to members, key community support organisations and professionals in WA and interstate.

We receive frequent requests for permission to reproduce 'Gene Advocate' extracts in other organisational newsletters. The current circulation contains just over 320 listings.

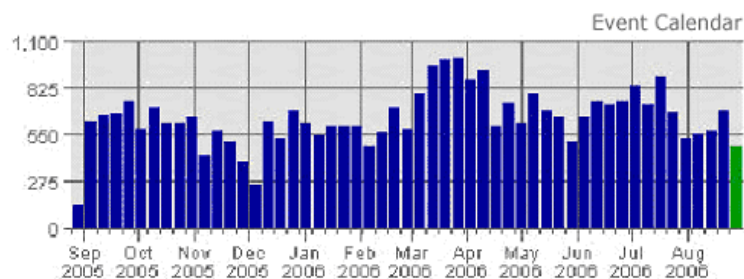
During the year the number of visitors to our website has continued to grow. Every month an average of 8,760 visitors log on in search of information.

Year Graph - Hits

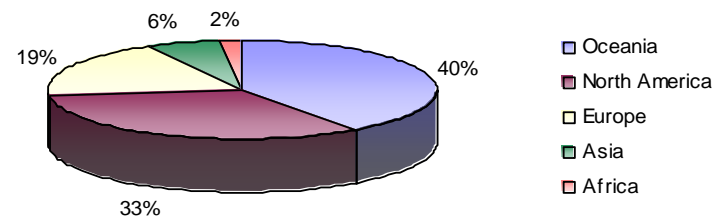


The GSCWA website now receives an average of over 2000 return visits per month.

Year Graph - Repeat Visitors



More than 50% of website visits originate from overseas users.

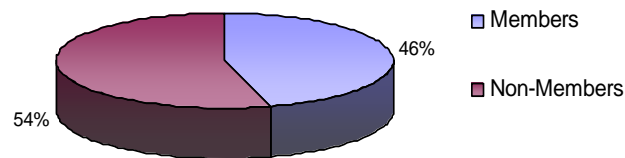


The website is regularly updated with links to information, news and events relating to genetic health and statistics show this resource is valued by service providers, educational institutions, health professionals, students and the wider community.

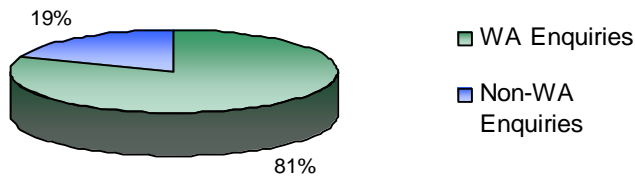
The website also contains an online version of the Genetic Support Groups and Community Services Directory, "Gene Advocate" newsletters as well as range of group support information and resources.

With the increased awareness of the role of the GSCWA as a peak body by health professionals, the genetic scientific

community, Genetic Support Groups and individuals with genetic conditions and their families, demands on GSCWA services and participation by the Council is increasing.

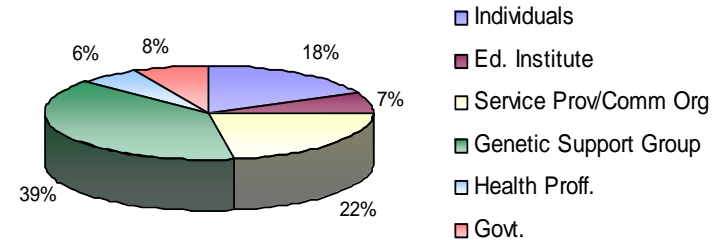


The GSCWA is now well recognised, both in Western Australia and nationally as a consumer representative and advocate for Genetic Support Groups.



The GSCWA Resource Centre includes up-to-date information on Genetic Support Groups such as pamphlets, brochures, newsletters and leaflets about their services as well as a diverse range of resource materials of interest to families seeking information and referral as well as maintaining a wide range of links to sites that can provide well documented information on genetic conditions. Currently approximately 1350 genetic conditions can be researched through this process.

Responding to enquires and requests for information and assistance is a steadily increasing activity. During the year the GSCWA received 735 requests for information and/or assistance. Enquiries come from a wide variety of sources as well as our Genetic Support Group membership.



What is in the Future for the GSCWA

This past year Genetics has rarely been far away from the spotlight. The implications of new discoveries and developments have increased our understanding of the links between our genes and our health and for a growing number of families, there is now at least the prospect of new treatments being developed.

Continued advances in genetic technology will be accompanied by complex issues for Genetic Support Groups and individuals with genetic conditions and their families. This will no doubt, increase the pressure on Genetic Support Groups and the demands on their services.

In the coming year as well as maintaining a responsive service to help groups meet these challenges, the GSCWA will focus on a number of areas, these include:

Partnership

Patient participation in healthcare has moved up the political agenda and the need for the consumers voice to be heard by professionals and policy makers is now widely acknowledged. The GSCWA has the opportunity to play an active role on the work of one of the Department of Health's key advisory groups – the West Australian Genetics Council (WAGC). The role of this body is to provide expert advice on the complex issues relating to genetics and genetic services. These issues include assessing

and prioritising new technologies; participation in national initiatives; monitoring quality and ethical standards and working with community and consumers. The outcome of this is to improve the quality, efficiency and access of genetic services to the WA community.

During the year we have also had the opportunity to make active inputs into the work of other bodies including the Human Genetics Advisory Committee (HGAC) in developing its communication and public engagement strategies and the Biotechnology Australia/GEM Consortium's GP Resource Patient and Family Volume.

The GSCWA will seek to build on these foundations in the coming year recognising that such activities are essential if we are to ensure that our members' voices are heard by those with the power and resources to influence change.

The GSCWA and its Members

GSCWA member groups represent the entire spectrum of genetic disorders and range from very large organisations with staff and thousands of members to groups which exist because of the effort of a few dedicated volunteers, many of whom are affected by or are carers of someone with a very rare genetic disorder.

The GSCWA derives its authority from the relationship that it has with its member groups and the trust and confidence that they have that we will speak from their perspective, put across their

concerns and promote their interests. Keeping our members engaged and informed is, and will continue to be, a high priority.

Reaching a Boarder Public

The number of visitors to the GSCWA website has continued to grow. Every month an average of between 8,000 – 10,000 visitors from around the world log on in search of information. 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.

In the coming year we intend to re-design the website to make the site more interactive. A major addition to the contents will be an electronic version of the new GSCWA Directory of Genetic Support Groups and Community Service Organisations and copies of our resources in a downloadable format.

The site content will be further developed to include the responses that the GSCWA has made to government and other bodies on policy matters. Position statements addressing a number of topics of importance to our members will also be available. Such improvements will greatly extend the impact and usefulness of the website.

During the year we have had opportunity to provide information to journalists and media researchers on issues relating to genetics stories. Genetics continues to be a 'hot topic' and we need to be alert for opportunities to remind the public of the

needs and opinions of people who live with the impact of genetic disorders on themselves and their families everyday. Developing further contacts with the media will be a priority in the coming year.

Facilitating Access to Expertise.

The GSCWA will endeavour to find ways to engage with individuals and families affected by genetic disorders and to increase community awareness of the range of human genetics related issues. By providing opportunities for those with experience and expertise in particular areas of common concern to engage directly with service users we hope to facilitate greater understanding and encourage the sharing of information and ideas.

Additionally, efforts will be made to seek out opportunities throughout the next 12 months, whereby the Council can present a public face. Planned events in 2007 include a hosting a Genetic Support Group Awareness Day and a Consumers Rights and Education Seminar. Participation in the 2007 Neurological Expo and the proposed International Neurological Conference in Perth in 2008 are further examples.

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.

It is pleasing to note that the Council had a surplus of \$2500 in 2005/06 compared to a deficit of \$14,544 in 2004/5.

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.



MITCH MESSER
Treasurer
18 September 2006

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 18 to 24 presents fairly the financial position of the Genetic Support Council WA (Inc) as at 30 June 2006 - and its performance for the period ended on that date, in accordance with the basis of accounting as described in Note 1 to the financial statements.

This statement is made in accordance with a resolution of the Board made on 29th August 2006 and is signed for and on behalf of the Board by:



PROFESSOR CHARLES WATSON
MESSER
Chairperson
29 August 2006



MITCH
Treasurer
29 August 2006

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 9Inc) for year ended 30 June 2006 as set out pages 4 to 11. 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 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 that 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. These procedures have been undertaken to form an opinion whether, in all material respects, the financial reports are presented fairly in accordance with the accounting standards and 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 organisations 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 fundraising was limited to amounts recorded.

Audit Opinion

In my opinion, bearing in mind the effects of the above qualification, if any, the financial reports as presented on behalf of the Genetic Support Council WA (Inc) for the years ended 30th June 2006 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

20TH August 2006

Statement of Financial Performance

	NOTES	2005	2006
Revenue from ordinary activities	2	169164	160876
Employee expenses		-113185	-102525
Depreciation		-6575	-6481
Administration expenses		63948	49369
		-----	-----
		-14544	2501
		-----	-----
Total changes in equity		-14544	2501
		-----	-----

Statement of Income for the Year Ended 30 June 2006

Income	2005	2006
Operating Income		
Unspent funds brought forward	23000	0
Less unspent monies carried forward	0	0
	-----	-----
	--	
	23000	0
	-----	-----
	--	
Grant received – Dept Health	115266	150000
Contract work	22813	1589
Printing	2309	0
Other	0	6887
Interest	1191	475
Gen Ethics	0	1925
	-----	-----
	164579	160976
	-----	-----
Non-Recurrent Income		
Lotteries Grant	0	0
Unamortised balance brought forward	9572	4585
	-----	-----
Less unamortised	-4987	0
	-----	-----
	4585	0
	-----	-----
Total Income	169164	160876
	-----	-----

Detailed Statement of Expenditure for the Year Ended 30 June 2006

Expenditure	2005	2006
Advertising	1511	256
Audit	1285	200
Bank Charges	657	452
Bookkeeping	600	2930
Catering	1558	0
Computer Costs	2272	0
Conference & Training	361	616
Depreciation	6575	6481
Equipment Purchases	0	1138
Forums & Events	12327	161
Furniture & Fittings	83	0
Insurance	4492	8603
Leave Entitlements	692	5287
Library	41	434
Membership Subscriptions	1212	936
Newspapers	371	0
Office Supplies	15495	13729
Photocopying	2044	3
Postage & Courier	2286	964
Rent	9447	9447
Repairs & Maintenance	0	2253
Salaries & Wages	103205	88955
Superannuation	9288	8283
Telephone	2415	3675
Travel & Accommodation	5491	3572
	-----	-----
Total Expenses	183708	158375
	-----	-----

Statement of Financial Position for the Year Ended 30 June 2006

	NOTES	2005	2006
CURRENT ASSETS			
Cash assets	3	20082	29603
Receivables	4	1150	0
Prepayments	5	623	0
		-----	-----
Total Current Assets		21855	29603
Non Current Assets			
Plant & Equipment	6	6481	0
		-----	-----
Total Assets		28336	29603
Current Liabilities			
Payables	7	8870	6124
Provision for employee entitlements	8	3980	9268
Deferred Income	9	4987	0
Visa 4794		0	1211
		-----	-----
Total Current Liabilities		17837	16603
		-----	-----
Net Assets / (Deficiencies)		10499	13000
		-----	-----
Accumulated Funds	10	10499	13000
		-----	-----

Notes to the Financial Statements for the Year Ended 30 June 2006

	2005	2006
Note 2: REVENUE		
Unspent funds brought forward	23000	0
Less unspent monies carried forward	0	0
	-----	-----
	23000	0
 Operating Grant receivable – Department of Health	 115266	 150000
Interest received	1191	575
Other	25122	8476
GenEthics	0	1925
	-----	-----
	165579	160876
 Non Operating Income		
Capital Grant	4585	0
	-----	-----
	169164	160876
	-----	-----
 NOTE 3: CASH ASSETTS		
Cash at Bank: Cheque Account	10147	20325
Investment Account	9177	6643
Donations Account	658	631
GenEthics Account	0	1925
Petty Cash	100	79
	-----	-----
	20082	29603
	-----	-----

Accompanying Notes

	2005	2006
NOTE 4: RECEIVABLES		
Debtors	1150	0
	-----	-----
	1150	0
	-----	-----
NOTE 5: PREPAYMENTS		
Prepaid expenses	623	623
	-----	-----
	623	623
	-----	-----
NOTE 6: PLANT & EQUIPMENT		
Plant & Equipment at cost	24430	24430
Accumulated Depreciation	-17949	-24430
	-----	-----
	6481	0
	-----	-----
NOTE 7: PAYABLES		
Creditors & Accruals	7223	1279
GST Liabilities	0	2647
PAYG Liabilities	0	2198
	-----	-----
	7223	6129
	-----	-----
NOTE 8: PROVISIONS - CURRENT		
Provision for employee entitlements	3980	9268
	-----	-----
	3980	9268
	-----	-----

Accompanying Notes

	2005	2006
Note 9: DEFERRED INCOME		
Deferred income	4987	0
	-----	-----
	4987	0
	-----	-----
 NOTE 10: ACCUMULATED FUNDS		
Accumulated funds/(deficit) at beginning of year	25045	10499
Accumulated funds/(deficit) for the year	-14544	2501
	-----	-----
Accumulated funds/(deficit) at end of the year	10499	13000
	-----	-----

GSCWA 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
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

Mental Illness Fellowship WA (Formerly: Schizophrenia Fellowship of Western Australia)
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)

GSCWA Members cont

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
The Kalparrin Centre
The Neurological Council of WA Inc
Western Australian Deaf Society Inc.

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