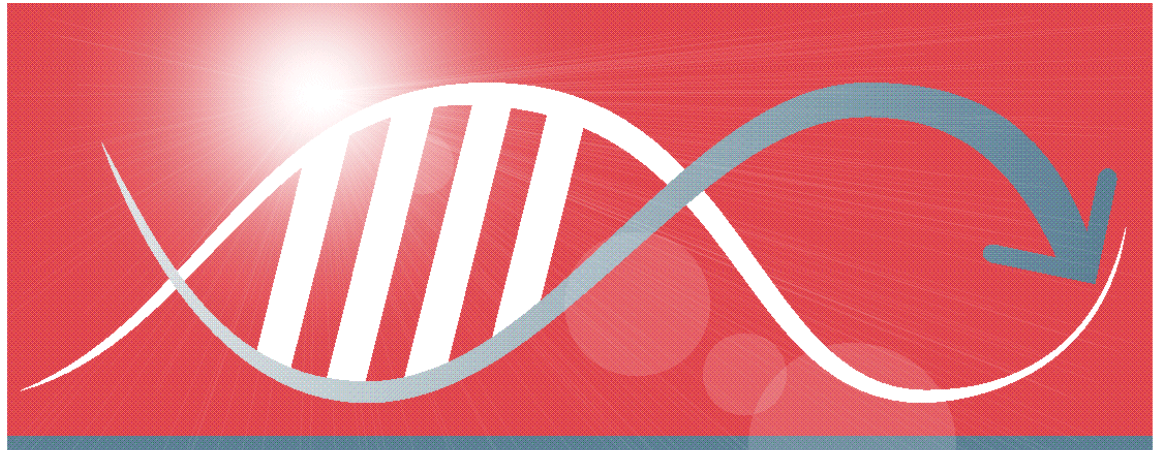


GENETIC SUPPORT COUNCIL WESTERN AUSTRALIA INC.

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GENETIC SUPPORT COUNCIL WA

# Annual Report 2004 - 2005

# We are more than just the sum of our Genes !

## We are more than just the sum of our Genes !

GENETIC SUPPORT COUNCIL OF WESTERN AUSTRALIA (INC.)

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### **Our Vision**

Seeking solutions to the challenges of genetic conditions

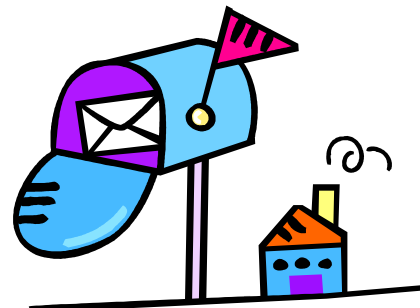
### **Our Mission**

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

Created and designed by © Genetic Support Council of WA  
Level 1, Oasis Lotteries House  
37 Hampden Road  
NEDLANDS WA 6009  
Phone (08) 9389 6722 • Fax (08) 9389 9377  
Email [admin@geneticsupportcouncil.org.au](mailto:admin@geneticsupportcouncil.org.au)  
Website: <http://geneticsupportcouncil.org.au>

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## GSCWA LOCATION AND CONTACT DETAILS



*Unit 9, Oasis Lotteries House*

*37 Hampden Road*

*Nedlands WA 6009*

*Telephone: 08 9389 6722*

*Fax: 08 9389 9377*

*Email: [admin@geneticsupportcouncil.org.au](mailto:admin@geneticsupportcouncil.org.au)*

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

***Office Hours:***

*Monday to Friday*

*9.00 am to 5.00 pm*

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## INTRODUCTION

### *THE ROLE AND HISTORY OF THE GENETIC SUPPORT COUNCIL WA INC.*

The Genetic Support Council WA (Inc) is a not for profit organisation that acts as a peak body for Genetic Support Groups in Western Australia. The need for this peak body to coordinate and enhance the effectiveness of community Genetic Support Groups was identified in the *Review of State-wide Delivery of Genetic Services in Western Australia*, conducted in April/May 2000.

Following that review, a number of Genetic Support Groups established a working committee to bring this to fruition. The Committee proposed that the Genetic Support Council WA (Inc) fulfil the following roles:

- Promote awareness of genetic diseases in the community
- Encourage and support effective and efficient management and service delivery practices within Genetic Support Groups
- Assist in the greater participation of consumers in policy, planning, research and service delivery across the genetic services field
- Develop and contribute to policies of common concern to Genetic Support Groups
- Provide genetic support information, resources and referral services to individuals and Genetic Support Groups
- Promote leadership and cooperation between non government and community organisations within the genetic services field
- Act as a mentor for the Genetic Support Groups

The first Annual General Meeting of the GSCWA was held on the 20 May 2002 and a Board of Management appointed. The Council commenced operations in July 2002.

The Genomics Directorate of the Western Australian Department of Health has been responsible for allocating resources for the development of this initiative.

## OUR SERVICES

### Providing support to Genetic Support Groups through:

- information
- advocacy
- education
- referral

### Services to Genetic Support Groups include:

#### *Increasing awareness of genetic conditions in the community by:*

- Participating in forums and member Genetic Support Group awareness events
- Providing an up-to-date website
- Widely circulating a monthly newsletter
- Seeking opportunities to engage the media, including community and regional newspapers and access radio
- Establishing and maintaining an annual “Genetic Support Group Awareness Day”
- Publishing a Directory of Genetic Support Groups in WA

#### *Providing administrative support and facilities by:*

- Assisting member Genetic Support Groups in the establishment and maintenance of sound administrative processes
- Making available the GSCWA office and staff to assist in these processes
- Assisting with the development and maintenance of budgets
- Assisting with the development of strategic and business plans

*Providing forums for policy development and matters of common interest by:*

- Conducting forums for members on issues of interest or concern
- Providing a forum to enable members' views to be represented to Government and others in the field of genetics
- Written and verbal submissions to Government and others in the field of genetics
- Actively pursuing opportunities to ensure that the views of the Genetic Support Council WA and its members are considered
- Providing a vehicle for recommending Consumer Representatives to committees and the like, considering matters concerning the field of genetics and genetic support
- Participating with like bodies nationally to further represent the Genetic Support Groups and their members

*Specialised support to smaller member Genetic Support Groups by:*

- Providing an office base for smaller member Genetic Support Groups
- Making available seminar facilities
- Assisting with the development of information packages relating to their specific genetic conditions or predispositions
- Printing of material and pamphlets
- Providing opportunity to these groups to publish articles, advertise and promote awareness of their Support Group in the GSCWA newsletter "Gene Advocate"
- Facilitating the provision of industrial relations advice
- Assisting in researching information regarding particular genetic conditions or predispositions
- Keeping members aware of matters of interest, changes of legislation that may impact on the area or opportunities for them to participate in making comment on matters of concern

*Maintaining a Resource Centre that:*

- Includes information on the services provided by member Genetic Support Groups
- Provides information on a range of associated topics such as online resources, families living with a family member with a genetic condition, parenting and education in association with a genetic condition
- Maintains a wide range of website links on genetic conditions and organisations and groups that may provide support
- Maintains a database of Genetic Support Groups throughout Australia and with some international links
- Provides ongoing research for developments and up to date information on genetic conditions

*Assisting in sourcing funding by:*

- Providing information on possible funding/grant sources
- Giving assistance when applying for grants
- Assisting and facilitating opportunities for member Genetic Support Groups to engage in fundraising

*Providing a direct support service to individuals for whom there is no Genetic Support Group available and a referral service to individuals requiring assistance by:*

- Providing information on specific genetic conditions
- Referral to appropriate expert organisations such as Genetic Services WA
- Assisting in linking individuals and their families with others with the same condition in either Western Australia, Australia, New Zealand or internationally
- Advocate where appropriate on behalf of individuals with other organisations and service providers

## GSCWA BOARD OF MANAGEMENT



The Board of Management met eight times during the Financial Year 2004/2005. During the past year, the Board of Management has overviewed the operation of the GSCWA as it continued to expand its services to Genetic Support Groups. The Board of Management has paid particular attention to maintaining effective administrative policies, practices and procedures that have ensured the GSCWA carries out its business in an accountable, transparent and ethical manner. The Council maintains an ongoing strategic and business plan which has provided sound planning in the operations of the GSCWA.

### **CHAIR**

*Professor Charles Watson*  
Executive Dean, Health Sciences Curtin University

### **DEPUTY CHAIR**

*Mitch Messer*  
Executive Director, Cystic Fibrosis WA Inc.

### **TREASURER**

*Vicki Mort*  
Financial Manager, Holyoake Institute

### **BOARD MEMBERS**

*Teresa Alvaro*  
President, Thalassaemia Association of WA Inc.

*Kerrie Duff*  
Client Service Coordinator, Spina Bifida Association of WA

*Sue Fraser*  
President, Periodic Paralysis Society of Australia

*Irene Gray*  
President, WA Tourette Syndrome Organisation

*Susan Herrmann*  
Representative, Health Consumers' Council WA Inc.

*Dr Peter O'Leary*  
Director Genomics Directorate  
Department of Health

*Jackie Softly*  
Information and Development Officer, Down Syndrome Association of WA

*Del Weston*  
Executive Director, The Neurological Council WA Inc.

## OUR STAFF MEMBERS

<b>Terry Keating</b>	Executive Director (retiring)
<b>Sharon Van der Laan</b>	Incoming Executive Director
<b>Anja Hermann</b>	Administrative Officer
<b>Kristina Johns</b>	Resource Officer
<b>Krystyna Durston</b>	Social Work Student

## **GSCWA MEMBERS**

### **FULL MEMBERS**

Acoustic Neuroma Association of Australia  
Alzheimer's Association of WA  
Angelman Syndrome Association  
Arthrogryposis Support Group  
Australasian CHARGE Association WA  
Australian Huntington Disease Association  
Australian Pituitary Foundation WA Branch  
Australian Tuberous Sclerosis Society Inc.  
Coeliac Society of WA  
Cornelia De Lange Syndrome Support Group  
Cushing's Disease Support Group  
Cystic Fibrosis WA  
Diabetes Australia -Western Australia  
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  
Motor Neurone Disease Association of WA Inc.  
Mucopolysaccharide & Related Diseases Society (MPS)  
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)

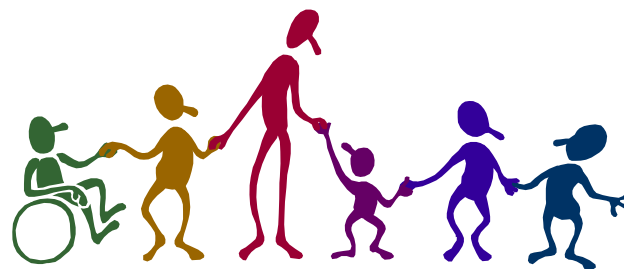
Support Organisation for Trisomy and Related Disorders of WA (SOFTWA)  
Western Australian Retinitis Pigmentosa Foundation  
WA Tourette Syndrome Organisation (WATSO)

### **CORPORATE ASSOCIATE MEMBERS**

ARAFMI Western Australia  
Association of Genetic Support of Australasia  
Australian Kidney Foundation  
Carers Association of WA Inc  
Genomics Directorate, Dept. of Health  
Gynaecological Awareness Information Network  
Health Consumers Council WA  
Lone Parent Family Support Service (LPFSS)  
OzED Ectodermal Dysplasia Support Group  
The Kalparrin Centre  
The Neurological Council of WA Inc  
Western Australian Deaf Society Inc.

### **INDIVIDUAL ASSOCIATE MEMBERS**

Linda Bovill  
Mark Bovill  
Bonita Anne Eaton  
Anja Hermann  
Kristina Johns  
Terry Keating  
Professor Charles Watson  
Darren Webb



## CHAIRPERSON'S REPORT



I am pleased to report that the Council continues to provide a valuable and significant role as a peak body for Genetic Support Groups in Western Australia. Following its first three years of operation, the Council now provides a wide range of services and support to Genetic Support Groups, individuals with genetic conditions and predispositions and their families. These services and activities of the Council provide a sound base on which to move forward in the coming 12 months. Links have been established with a wide range of health professionals, the genetic scientific community, academic institutions and genetic support group peak bodies across Australia and New Zealand.

The ongoing challenges that confront Genetic Support Groups, individuals with genetic conditions and predispositions and their families are most complex. The rapid developments and advancements in the field of genetics continue to raise difficult and emotive issues for which there are no easy answers. The Council is now well placed to work with members to confront these challenges.

The Council continues to manage its affairs in an efficient and effective manner and administratively, maintains best practice standards in relation to the management of its finances, resources and its assets. It continues to provide the high level of accountability that is necessary when making use of funds that are provided by government.

In addition to its services to members, over the past 12 months the Council has played a significant role in another range of activities. These included participation on the National Advisory Group on Genetics Education for General Practitioners, further development of the role of the Australasian Genetic Alliance (AGA) as National Secretariat and a range of presentations to increase community awareness of genetic conditions and predispositions and the role of genetic support groups.

The Board of Management of the GSCWA would like to express its appreciation to its member Genetic Support Groups, the GSCWA staff and the Genomics Directorate of the Western Australian Department of Health for their contribution and support of the Council during this time. It is with regret that I must report the resignation of our Executive Director Terry Keating who leaves us to take a new position. Terry's service in establishing the Council is both acknowledged and appreciated and we wish him well in his new endeavours. I would take this opportunity to welcome Sharon Van der Laan who has taken up the position of Executive Director.

I would like to also personally thank the GSCWA Board of Management for their work during the past year. The role of the Board is to set strategic direction of the Council and to overview its operations to ensure that it carries out its business in an ethical, accountable and transparent manner. I am able to report that I believe this to have been the case.

Finally, I wish to express my thanks to the resigning Board members Treasurer Vicki Mort, Holyoake Australian Institute for Alcohol and Drug Resolutions, Dr. Peter O'Leary, Genomics Directorate Department of Health and Jacky Softly, Down Syndrome Society of WA for their contribution and support of the Council during their term as Board members. I would also like to thank Deputy Chair Mitch Messer, Cystic Fibrosis WA, Kerrie Duff, Spina Bifida Association of WA, Sue Fraser, Periodic Paralysis Society of Australia, Susan Herrmann, Health Consumers Council and Del Weston Australian Huntington Disease Association WA who have completed their terms on the Board. Their efforts are acknowledged and appreciated. Further I would like to thank the current sitting Board members Teresa Alvaro, Thalassaemia Association of WA Inc. and Irene Gray, WA Tourette Syndrome Organisation for their continued involvement.

I commend this Annual Report to members of the GSCWA.

**PROFESSOR CHARLES WATSON**  
*Chairperson*

## EXECUTIVE DIRECTOR'S REPORT



The past 12 months have been a time of considerable development in relation to the Genetic Support Council WA's role as a consumer representative both at a state and national level. The Council is now recognised as the most significant consumer organisation representing Genetic Support Groups, individuals with genetic conditions and predispositions and their families in Western Australia. This recognition also extends to the national stage due to the very active role the GSCWA has played in the Australasian Genetic Alliance (AGA)

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 its members. Links have been strengthened with other stakeholders in the genetics community and this has resulted in partnerships being developed between the GSCWA and other stakeholders. The Council is well placed to work with its members in responding to difficult and often emotive issues that arise due to the rapid changes taking place in the field of genetics and genetic technology.

The Genomics Directorate of the Western Australian Department of Health continued to provide funding for the Council during 2004/2005 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 other areas by the Genomic Directorate is greatly appreciated. I am happy to report, the Council has now negotiated a 3 year funding contract for the period 2005/2008 with the Western Australian Department of Health. This will enable the Council to plan its activities more effectively.

### ***Membership***

The Council has a total of 44 Full Member Genetic Support Groups, 12 Corporate Associated Member organisations and 8 Individual Members. This represents all but a very few of the Genetic Support Groups functioning in Western Australia at this time. The Council has actively participated and supported the establishment of several new genetic support groups. A significant number of individuals and groups have contributed to the achievements of the Council over the past 12 months.

### ***Administration***

Over the past year, the Council has continued to maintain effective and efficient administrative systems and managed its finances, resources and assets appropriately. The Council has operated within budget and expended its funds in a manner that has enabled it to maximise its services to its members. This has resulted in sound financial management, documented procedures and the ability to report on activities in a detailed and meaningful manner. Accountability reports as required under the Council funding contract have been presented to the Western Australian Department of Health. The Council continues to maintain an updated and well developed Strategic and Business Plan which is the subject to annual review and provides measures of performance.

Throughout 2004/2005 the GSCWA database has been extended by a further 100 genetic conditions which brings it to a total of over 200 genetic conditions. This includes details of any Genetic Support Groups that provide services to individuals with genetic conditions or predispositions, their families and others seeking information. Some of these groups are in other states and in New Zealand. Links have been established to other data banks that enable information to be obtained with regards to some 1300 genetic conditions.

Brochures, information sheets and promotional flyers on the activities and services of the GSCWA continue to be designed, updated and printed in house and widely distributed.

### ***Links with other related organisations***

The complexity of advances in genetic research and technologies will continue to raise issues for individuals with genetic conditions, their families and Genetic Support Groups. There are a wide range of psycho-social issues that will impact on Council members and the Council is well placed to respond on behalf of its members.

Links have been strengthened with a range of health organisations and other groups and organisations and some of these are shown in the appendices of this annual report.

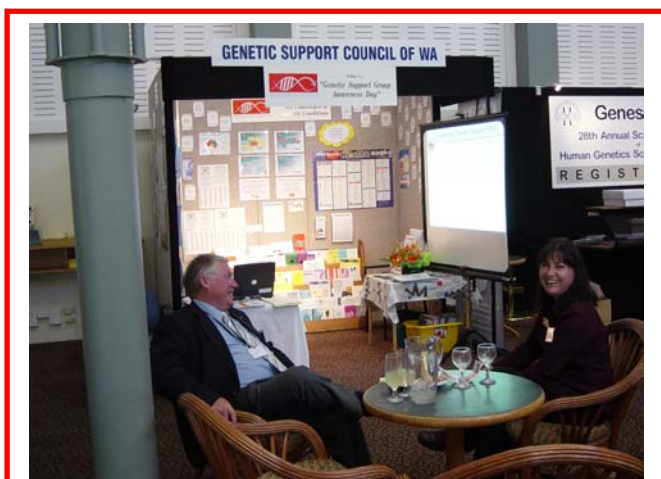
In 2002/2003 links were being established with genetic support group peak bodies in other parts of Australia and New Zealand. These included *The Association of Genetic Support of Australasia (AGSA) New South Wales*, *Genetic Support Network Victoria (GSVN)*, *Self Help Organisations United Together (Shout) Australian Capital Territory*, *Self Help Queensland (SHQ)*, *New Zealand Organisation for Rare Disorders (NZORD)*.



The outcome was the establishment of the Australasian Genetic Alliance (AGA) which was formally launched in Melbourne at the Human Genetics International Congress in early July 2003 (see appendices).

AGA's objectives include: Contributing and commenting on policy relating to human genetics and health services, networking and sharing resources to promote genetic support services and raise community awareness of Genetic Support Groups and the impact of genetic conditions on

individuals and families. The Executive Director of the GSCWA was elected as the inaugural Chair of AGA and the GSCWA is the National Secretariat for 2003/2005.



***Genetics and Population Health Conference  
and HGSA Annual Scientific Meeting  
8 – 13 August 2004***

The GSCWA in its role as Chair and National Secretariat of the AGA was invited to join the *Advisory Group on Genetics Education for General Practitioners*. The Advisory Group has been established by the Commonwealth Government to develop a national resource for general practitioners on genetics. The GSCWA on behalf the AGA was funded to run six consumer workshops nationally and provide a report to include recommendations that would be taken into account when developing this resource.

### ***GSCWA's input on matters of interest to Genetic Support Groups***

- The GSCWA provided submissions to the Australian Law and Reform Commission (ALRC) on Issues Paper 27 and Discussion Paper 68, relating to *Genetic Patenting*.
- The Council worked closely with the convenor of the *International Genetic and Population Health Conference* and state organisers of the *Human Genetic Society of Australasia Annual Scientific Meeting* which were held conjointly in August 2004 to

ensure increased awareness of the role of the genetic support groups and the Council.

- This included maintaining an information booth over the six days of these two events, sponsoring the first *Western Australian Genetic Support Group Awareness Day* on 10 August 2004 and presenting a paper at the Conference.
- Additionally, the Council was instrumental in arranging for Professor Jai Rup Singh of the International Genetic Alliance to present several papers at the conference and meeting.
- The Council hosted the AGA Annual General Meeting in August 2004.
- The GSCWA in conjunction with the Neurological Council of WA Inc, Cystic Fibrosis WA & the Human Genetic Society of Australasia, conducted a series of presentations to mark the second *Genetic Support Group Awareness Day* on 20 April 2005 and to celebrate *DNA Day*.



The Council arranged:

- poster boards for member groups,
- Stepping Stones Triple P Parenting Program - *Lisa Studman, Developmental Psychologist*
- Genetic Testing and Discrimination - *Dr. C.-E. Kiraly-Borri*
- Alzheimer's disease - *Professor Ralph Martin*
- The Law and Embryo Diagnostic Procedures in WA....what it says and why! - *Dr Sandy Webb*
- Genetics and Cystic Fibrosis - *Professor Jack Goldblatt*

### ***Services provided by the GSCWA to member Genetic Support Groups***

Throughout the past 12 months, the Council has provided a wide range of practical services to member support groups. These include:

- Providing practical administrative support on matters such as budgeting, office administration, development of strategic and business plans, industrial relations and corporate governance
- 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.
- Advocating on behalf of individuals and member organisations seeking services and support
- Assistance in identifying funding opportunities and providing expertise in completing grant applications

- The provision of small grants from the GSCWA to members to assist in such matters as publications, seminars and forums, computer software, attendance at conferences. Due to limitations in funding, this service is no longer available.
- Assistance with the graphic design and in house printing of brochures, information material and flyers has been well received by a number of smaller groups. The cost to members varied from providing a free service to a cost only basis when a charge is made.
- Assisting member Genetic Support Groups in fundraising

### ***Increasing community awareness***

Raising community awareness of genetic conditions and the role of Genetic Support Groups is still the most challenging aspect of the Council's role. There is still a very poor understanding of the nature of genetic conditions and the role of Genetic Support Groups in the general community. Most of the information that reaches the general public is by way of the popular press and this tends to focus more on the sensational than providing meaningful understanding of the complexities and issues that surround the day to day dilemmas that confront Genetic Support Groups, individuals with genetic conditions and their families and the limited resources that are available.

The Council continues to address this need for increasing community awareness through a range of strategies, these include, *information displays in libraries* and *shopping centres* and events such as the *DNA Day celebrations*, *Genetic Support Group Awareness Days*, *public information presentations* and in conjunction with Genomics Directorate attended *Government High School Health Days*.



***Christmas Morning Tea  
20 December 2004***



***Talk on Genetic Support Group  
Awareness Day, 20 April 2005***

Additionally, the Council circulates significant numbers of brochures and information sheets. Some of these are through member Genetic Support Groups, the Genomics Directorate, Department of Health, whilst others result from direct contact with health professionals, tertiary institutions, individuals seeking information and general mail outs.

A monthly newsletter "Gene Advocate" to members, health professionals, social welfare agencies and other organisations with similar interests has been circulated. At present, the GSCWA mailing list is approximately 300.

### ***Conclusion***

The past 12 months has seen the Council further develop and strengthen its links with a wide range of stakeholders. It is currently able to respond to most practical requests from its members

and its links across Australia and New Zealand has enabled Genetic Support Groups, individuals and their families' significant access to information regarding genetic conditions and genetic support groups throughout Australia and the Region.

The progress that has been made throughout this year could not have been made without the guidance and support of the GSCWA Board of Management. I would also like to thank the Genomics Directorate of the Western Australian Department of Health for the ongoing assistance and advice that they have provided. The enthusiasm and commitment of the GSCWA staff Anja Hermann Administrative Officer and Kristina Johns Resource Officer has been exemplary and their contribution is most appreciated. To the Board of Management of the GSCWA, I wish to express my personal thanks and appreciation. I would like also to thank the members of the GSCWA for the manner in which they have engaged in the progress of the GSCWA and the support they have provided by their participation.

It is with deep regret that I advise you of my departure from the Council. The past three years have been a very special time for me working with you all and I thank you for allowing me to be a part on this wonderful journey.

***TERRY KEATING***  
***Executive Director***

## **GSCWA RESOURCE CENTRE**



The GSCWA Resource Centre's role is to coordinate, develop, research issues and distribute information and resources, as well as seeking opportunities to reach the community.

Some key activities of the last 12 months included:

- Maintaining the GSCWA website which now receives an average of 2000 visits per month.
- Preparing the monthly GSCWA newsletter "Gene Advocate" and distributing it to members and key organisations to raise awareness about genetic support issues. At present, there is a circulation list of over 300 and created Gene Advocate *subscription flyers* in the first quarter of 2005.
- Providing information displays on the GSCWA and its members at libraries and shopping centres throughout the Perth metropolitan area. and in conjunction with Genomics Directorate attended 2 Government High School Health Days. This has resulted in some 300 pamphlets/information sheets being distributed through this process.
- Ongoing distribution of promotional key events for members and facilitating workshops and information sharing.
- Compilation of links to information on genetic conditions and contact data on Genetic Support Groups
- Maintaining a Resource Centre that includes information on Genetic Support Groups such as pamphlets, brochures and leaflets about their services as well as books and videos about genetic conditions.
- Advising Genetic Support Groups of possible funding sources.
- Maintaining a range of people resources that individuals may find helpful e.g. genetic counselling, financial assistance, parenting support and carer support services.
- Maintaining a wide range of links to sites that can provide well documented information on genetic conditions. Currently approximately 1300 genetic conditions can be researched through this process.

***KRISTINA JOHNS***  
***Resource Officer***

## WHAT'S IN THE FUTURE FOR THE GSCWA



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.

It is already apparent, that the Genetic Support Council WA has increasing demands in the following areas:

- 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 credible consumer representative and advocate for Genetic Support Groups.
- Services to member Genetic Support Groups, particularly in practical areas, are increasing. This is generally due to members being more familiar with the services the Council offers and the increased membership.
- Limited resources across the sector continue to impact on individuals with genetic conditions and predispositions and Genetic Support Groups. This has resulted in increased demand on the GSCWA to assist where possible.

In the coming year, in addition to maintaining a responsive service to its members, the GSCWA, will focus on a number of other areas, these include:

- Endeavouring to increase community awareness of genetic conditions and the role of Genetic Support Groups. This will commence with the *Genetic Support Group Awareness Day* and followed by participating in the *Neurological Expo* in November 2005.
- Regular information stands at libraries and shopping centres will also be a part of this campaign to increase community awareness. Additionally, efforts will be made to seek out opportunities throughout the next 12 months, whereby the Council can present a public face.
- Contributing to and commenting on issues relevant to Genetic Support Groups.
- Further developing the reference group of member Genetic Support Groups to identify options for group discussions and forums and opportunities to inform the general public of important issues.

## TREASURER'S REPORT



The Board of Management is pleased to present this year's Financial Report which shows that the GSCWA operated within its approved budget and within the contractual requirements of the Western Australian Department of Health Funding Contract. Although this financial year's expenditures exceeded the income by \$14,544, there is still an amount of \$10,499 as accumulated funds from previous financial years that could be carried over to the 2005/2006 Financial Year. No further funds are being held in the special projects account.

The GSCWA has received first quarter funding for the Financial Year 2005/2006 from the Western Australian Department of Health of \$41,250 (incl. GST). A three years' contract is expected to be finalised and signed soon. This will then run until June 2008.

A handwritten signature in black ink, appearing to read 'Mitch Messer'.

**MITCH MESSER**  
*Acting Treasurer*

Dated: **13 September 2005**

## 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 4 to 11 presents fairly the financial position of Genetic Support Council WA (Inc) as at 30 June 2005 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:

Dated: **13 September 2005**

A handwritten signature in black ink, appearing to read 'Charles Watson'.

**PROFESSOR CHARLES WATSON**  
*Chairperson*

A handwritten signature in black ink, appearing to read 'Mitch Messer'.

**MITCH MESSER**  
*Acting Treasurer*



## **INDEPENDENT AUDIT REPORT**

### **TO THE MEMBERS OF GENETIC SUPPORT COUNCIL WA (INC).**

#### **Scope**

We have audited the attached special purpose financial report, comprising the Statement of Financial Position, Statement of Financial Performance and Notes to the Financial Statements of Genetic Support Council WA (Inc) for the period ended 30 June 2005 as set out pages 4 to 11.

The Board of Management is responsible for the financial report and has determined that the accounting policies used and described in Note 1 to the financial statements are consistent with the financial reporting requirements of the Constitution and are appropriate to meet the needs of the members. We have conducted an independent audit of the financial report in order to express an opinion on it to the members of Genetic Support Council WA (Inc). No opinion is expressed as to whether the accounting policies used are appropriate to the needs of the members.

The financial report has been prepared for distribution to members for the purpose of fulfilling the Board's financial reporting requirements under the Constitution. We 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.

Our audit has been conducted in accordance with Australian Auditing Standards. Our procedures included examination, on a test basis, of evidence supporting the amounts and other disclosures in the financial report. These procedures have been undertaken to form an opinion whether, in all material respects, the financial report is presented fairly in accordance with the accounting policies described in Note 1 to the financial statements. These policies do not require the application of all Accounting Standards and Urgent Issues Group Consensus Views.

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

#### **Qualification**

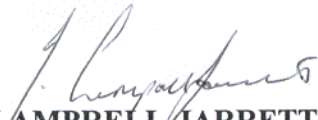
As is common for organisations of this type, it is not practicable for the Association to maintain an effective system of internal control over donations, subscriptions and other fund raising activities until their initial entry in the accounting records. Accordingly, our audit in relation to fund raising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

**Qualified Audit Opinion**

In our opinion, except for the effects of such adjustments, if any, as might have been determined to be necessary had the limitation discussed in the qualification paragraph not existed, the financial report presents fairly in accordance with the basis of accounting described in Note 1 to the financial statements, the financial position of the Association as at 30 June 2005 and the results of its operations for the year then ended and the manner in which the grant funds have been expended.

  
**DRY KIRKNESS**  
Chartered Accountants

Dated: 13 September 2005  
West Perth

  
**J LAMPRELL JARRETT**  
Partner

**GENETIC SUPPORT COUNCIL WA (INC)**

**STATEMENT OF FINANCIAL POSITION**

**AS AT 30 JUNE 2005**

	NOTES	2005 \$	2004 \$
<b>CURRENT ASSETS</b>			
Cash assets	3	20,082	50,669
Receivables	4	1,150	-
Prepayments	5	623	1,209
		-----	-----
TOTAL CURRENT ASSETS		21,855	51,878
<b>NON CURRENT ASSETS</b>			
Plant & Equipment	6	6,481	12,756
		-----	-----
TOTAL NON CURRENT ASSETS		6,481	12,756
		-----	-----
TOTAL ASSETS		28,336	64,634
<b>CURRENT LIABILITIES</b>			
Payables	7	8,870	3,730
Provision for employee entitlements	8	3,980	3,289
Deferred income	9	4,987	32,572
		-----	-----
TOTAL CURRENT LIABILITES		17,837	39,591
		-----	-----
NET ASSETS/(DEFICIENCY)		\$ 10,499	\$ 25,043
		=====	=====
<b>ACCUMULATED FUNDS</b>			
	10	\$ 10,499	\$ 25,043
		=====	=====

*This statement should be read in conjunction  
with the accompanying notes*

**GENETIC SUPPORT COUNCIL WA (INC)**  
**STATEMENT OF FINANCIAL PERFORMANCE**  
**FOR THE YEAR ENDED 30 JUNE 2005**

	NOTE	2005 \$	2004 \$
Revenue from ordinary activities	2	169,164	156,874
Employee expenses		(113,185)	(111,032)
Depreciation		(6,575)	(6,551)
Administration expenses		(63,948)	(34,106)
Member support grants		-	(2,367)
Operating Surplus		----- \$ (14,544)	----- \$ 2,818
Total changes in equity		----- \$ (14,544) =====	----- \$ 2,818 =====

*This statement should be read in conjunction  
with the accompanying notes.*

**GENETIC SUPPORT COUNCIL WA (INC)**  
**NOTES TO FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 30 JUNE 2005**

**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 4 : 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 historic 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) *Property, Plant and Equipment***

Depreciation is calculated on a straight line basis so as to write off the cost of each fixed asset over its expected useful life to Genetic Support Council WA (Inc). The principal bases are:

Motor Vehicles - modified vans and buses	10%
Computer hardware and software	33.33%
Other equipment and furniture	20%

**(b) *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 2005**

**(c) *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.

**(d) *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.

**(e) *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 unamortised balance of the grant is carried forward to future financial years to be matched against the costs associated with the applicable capital expenditure.

	<b>2005</b>	<b>2004</b>
	\$	\$
<b>NOTE 2: REVENUE</b>		
<b>OPERATING</b>		
Unspent funds brought forward	23,000	59,000
Less unspent funds carried forward	-	(23,000)
	-----	-----
	23,000	36,000
Operating Grant receivable – Department of Health	115,266	112,727
Interest received	1,191	2,163
Other	25,122	1,410
	-----	-----
	164,579	152,300
	-----	-----
<b>NON OPERATING</b>		
Capital grant	4,585	4,574
	-----	-----
	\$ 169,164	\$ 156,874
	-----	-----

**GENETIC SUPPORT COUNCIL WA (INC)  
NOTES TO FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 30 JUNE 2005**

**NOTE 3: CASH ASSETS**

	<b>2005</b>	<b>2004</b>
	\$	\$
Cash at bank - Cheque account	10,147	10,497
- Investment account	9,177	39,077
- Donations account	658	995
Petty Cash	100	100
	-----	-----
	\$ 20,082	\$ 50,669
	-----	-----

**NOTE 4: RECEIVABLES**

Debtors	1,150	-
	-----	-----
	\$ 1,150	\$ -
	-----	-----

**NOTE 5: PREPAYMENTS**

Prepaid expenses	623	1,209
	-----	-----
	\$ 623	\$ 1,209
	-----	-----

**NOTE 6: PLANT & EQUIPMENT**

Plant & equipment – cost	24,430	24,130
Accumulated depreciation	(17,949)	(11,374)
	-----	-----
	\$ 6,481	\$ 12,756
	-----	-----

**NOTE 7: PAYABLES**

Creditors & accruals	7,223	3,730
	-----	-----
	\$ 7,223	\$ 3,730
	-----	-----

**NOTE 8: PROVISIONS - CURRENT**

Provision for employee entitlements	3,980	3,289
	-----	-----
	\$ 3,980	\$ 3,289
	-----	-----

**GENETIC SUPPORT COUNCIL WA (INC)  
NOTES TO FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 30 JUNE 2005**

**NOTE 9: DEFERRED INCOME**

	<b>2005</b>	<b>2004</b>
	<b>\$</b>	<b>\$</b>
Deferred income	4,987	9,572
Unspent grants	-	23,000
	-----	-----
	<b>\$ 4,987</b>	<b>\$ 32,572</b>
	-----	-----

**NOTE 10: ACCUMULATED FUNDS**

**ACCUMULATED FUNDS**

Accumulated funds/(deficit) at beginning of year	25,043	22,225
Accumulated funds/(deficit) for the year	(14,544)	2,818
	-----	-----
Accumulated funds/(deficit) at end of year	<u><u>\$ 10,499</u></u>	<u><u>\$ 25,043</u></u>

**NOTE 11: LEASE COMMITMENTS**

	<b>\$</b>
Due within 12 months	2,006
Due within 1-2 years	9,447
Due within 2-5 years	9,447
	-----
	<u><u>\$ 20,900</u></u>

The Association has renewed its lease during the year for a further term expiring on 30 June 2008. Rental commitments disclosed above are based on current rental payments. Under the lease agreement rent may be reviewed annually which may lead to future rent increases.

**NOTE 12: ECONOMIC DEPENDENCY**

The Association is dependent on funds from the Department of Health, a department of the Government of Western Australia, in order to continue as a going concern.

**GENETIC SUPPORT COUNCIL WA (INC)**

**DETAILED STATEMENT OF INCOME  
FOR THE YEAR ENDED 30 JUNE 2005**

<b>INCOME</b>	<b>2005</b>	<b>2004</b>
	<b>\$</b>	<b>\$</b>
<i>Operating income</i>		
Unspent fund brought forward	23,000	59,000
Less unspent funds carried forward	-	23,000
	-----	-----
	23,000	36,000
Grant received – Department of Health	115,266	112,727
Contract work	22,813	-
Printing	2,309	330
Other	-	80
Interest	1,191	2,163
Donations	-	1,000
	-----	-----
	164,579	152,300
	-----	-----
<i>Non Recurrent Income</i>		
Lotteries Grant -		
Unamortised balance brought forward	9,572	14,146
Less unamortised	(4,987)	(9,572)
	-----	-----
	4,585	4,574
	-----	-----
Total Income	\$ 169,164	\$ 156,874
	=====	=====

**GENETIC SUPPORT COUNCIL WA (INC)**  
**DETAILED STATEMENT OF EXPENDITURE**  
**FOR THE YEAR ENDED 30 JUNE 2005**

<b>EXPENDITURE</b>	<b>2005</b>	<b>2004</b>
	<b>\$</b>	<b>\$</b>
Accounting	600	600
Advertising	1,511	254
Audit	1,285	1,000
Bank charges	657	1,053
Catering	1,558	754
Computer costs	2,272	3,011
Conferences & training	361	840
Depreciation	6,575	6,551
Forums & events	12,327	175
Furniture & Fittings	83	-
Insurance	4,492	3,272
Leave entitlements	692	170
Library	41	273
Licences & permits	-	107
Member support grants paid	-	2,367
Membership Subscriptions	1,215	1,133
Miscellaneous	(3)	-
Newspapers	371	364
Office supplies	15,495	6,283
Photocopying	2,044	500
Postage & courier	2,286	1,700
Rent	9,447	9,457
Repairs & maintenance	-	100
Salaries & Wages	103,205	101,708
Sundry equipment	-	8
Superannuation	9,288	9,154
Telephone	2,415	2,299
Travel & entertaining	5,491	923
	-----	-----
Total Expenses	\$ 183,708	\$ 154,056
	=====	=====