

**AUSTRALIAN
HUNTINGTON'S DISEASE
ASSOCIATION
(QLD) INC.**

**2006-2007
ANNUAL REPORT**

AUSTRALIAN HUNTINGTON'S DISEASE ASSOCIATION (QLD) INC.

LIFE MEMBERS:

MR. RAY BELLERT
MRS. EUNICE BROOKS
MR. CLIFF FARMER
MR. ROB FARMER
MRS. BARBARA GRAY
MRS. ALISON HOPGOOD
MR. ATHOL MEWETT
MS. ANITA SMITH
MS. GWEN PRATTEN
MRS. MAIDA WHITE

HONORARY MEMBERS:

MR. GARY JOHNSTON
DR. JOAN LAWRENCE
DR. CHRISTINE OLEY
MS. IRIS SIMPSON
DR. ARNOLD WAUGH

MANAGEMENT COMMITTEE FOR 2006/2007

EXECUTIVE:

PRESIDENT: MR. RAY BELLERT
VICE-PRESIDENT: MR. ALLAN FOX (01/07/06 – 18/04/07)
SECRETARY: MRS. JAN SZLAPAK (17/4/07 –
MS. KERRY FOX (01/07/06 – 17/04/07)

TREASURER: MR. CHARLES MCDONALD

COMMITTEE:

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MR. DENIS KELLY
MS. JAN MEALY
MRS. LORRAINE NORTH
MS. ANITA SMITH (01/04/06 – 21/02/07)
MR. GERRY DOYLE (15/05/07 –

FAMILY SUPPORT GROUPS:

TOWNSVILLE

CHAIRPERSON: MRS. SUE BOURNE
TREASURER: MS. JANELLE MAINS
SECRETARY: MR. BILL KLAASSEN
CONTACT PERSON: MRS. JEAN PATERSON

STAFF:

WELFARE COORDINATOR MS. GWEN PRATTEN
WELFARE OFFICERS MS. JULIE MORROW
MS. HELEN FOX (01/07/06 – 13/04/07)
DAY RESPITE FACILITATOR MS. IRIS SIMPSON (PROJECT OFFICER,
QLD HEALTH)
DAY RESPITE ASSISTANT FACILITATOR MRS. THERESSA BYRNE
DAY RESPITE ASSISTANT MRS. DEANNA PARKER
ADMINISTRATION OFFICER MRS. BARBARA GRAY
TELEMARKETING ADMINISTRATOR MRS. HELEN JOHNSTON

PROFESSIONAL COMMITTEE:

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MS. HELEN FOX
DR. MICHAEL GATTAS
DR. JOHN MACMILLAN
MS. JULIE MORROW
DR. JOHN O'SULLIVAN

MS. GWEN PRATTEN
DR. JOHN ROWELL
MS. IRIS SIMPSON
DR. SANDY TAYLOR
DR. ARNOLD WAUGH
MS. JULIE WHITE

AUDITOR:

MR. PAUL GALLAGHER, BDO KENDALLS

HONORARY SOLICITOR:

MR. KHORY MCCORMICK,
MINTER ELLISON

PRIVACY POLICY

The Association is bound by the *National Privacy Principles* introduced by the *Privacy Amendment (Private Sector) Act 2000*. This legislation is designed to protect your rights with respect to personal information held by private organisations.

The Association will review this Privacy Statement periodically and reserves the right, at its discretion, to modify or remove portions of this Statement at any time.

The Association recognises that individual privacy is very important. The goodwill of clients, donors and customers is important to us. We recognise that we must earn your trust through demonstrating that we have high standards for maintaining your privacy.

For the purposes of this Privacy Statement, personal information means information, whether true or not, and whether recorded in a material form or not, about an individual whose identity is apparent, or can reasonably be ascertained, from the information.

Donors and Telemarketing Customers: We collect and store the names, contact details, donation and /or sales history for both donors to the Association and customers of the Huntington's Disease Appeal, our telemarketing operation. None of this information is regarded as *sensitive*, as defined by the Act.

We hold this information securely. It is used only to meet our business and legal obligations and to assist us with our fundraising. We may contract with other organisations to assist us with our fundraising, however they must meet the same privacy requirements as the Association.

We are happy for donors and customers to see the information we hold about them, and to correct any mistakes. To exercise this right you need only write to us, giving your full name and address so that we can identify you. You may also ask us to remove your name from our mailing and callings lists and we will comply with your request. In this case, we will remove all the information that we hold about you unless there are legal or business reasons why we cannot do this. For example, we must by law hold records of tax-deductible donations for 7 years.

Clients: We collect some information about our clients that is regarded as sensitive as defined by the Act. The identification of a named person as someone with Huntington's Disease is an example of *sensitive* information. We collect and hold only the minimum information required to provide services. We hold this information securely, and it is accessible only to staff of the Association who need to know it so as to provide you with a professional client service. We will not pass this identifying information to other organisations or medical professionals unless you consent, and it is in furtherance of the services you have asked us to provide.

Members: We collect and store the names, addresses, contact details, membership categories and payment details of all classes of members of the Association. None of this information is regarded as *sensitive*, as defined by the Act. We hold this information securely. It is used only to meet our legal and statutory obligations and to assist us with the administration of the Association.

Access: Members and clients have entitlements under the *National Privacy Principles* to access the information that we hold about them. To exercise this entitlement, please write to the Association's President.

Website: We do not collect personal information on our website (www.qahda.com) using cookies or other covert devices.

Further Information: Further information about the National Privacy Principles can be obtained from the Office of the Privacy Commissioner. (Website: www.privacy.gov.au or Privacy Hotline 1300 363 992.)

REPORT ON THE ACHIEVEMENT OF STRATEGIES PRESIDENT'S OVERVIEW

The Annual Report for the Financial Year 2006/2007 highlights our Association's determination to continue to provide the best possible care and assistance for all families affected by Huntington's Disease in Queensland.

During the year the Association has undertaken two major management initiatives:

The first was to produce a sound management plan for the next three years based on the recommendations of our strategic plan which was completed in 2006. As a result, we have restructured our Welfare and Administration systems to enable us to be better prepared to meet the challenges and new legislative requirements in the changing environment affecting our families.

Our Welfare service now consists of two full time Welfare Officers – Julie Morrow and Christine Parfitt. Julie Morrow was appointed full time Senior Welfare Officer to replace Gwen Pratten who has retired after 20 years. Julie Morrow is supported by full time Welfare Officer, Christine Parfitt.

By returning to the employment of two full time Welfare Officers instead of part time personnel, we are able to provide a more comprehensive service to all people affected by Huntington's Disease throughout the state of Queensland.

To provide appropriate support for our Welfare service and the administration of the total operation of the Association, Barbara Gray has been appointed Operations Manager with Lisa Gordon being engaged as Administration Officer. Helen Johnston is book keeper for our Telemarketing Program. These staffing alterations have in fact been put in place since the end of June 2007.

To complete the management role for our Association, the Management Committee will maintain responsibility for all policies and decisions to ensure that our Association remains focused on all legislative and administration requirements for Queensland Health and associated organisations.

The second major management infrastructure has been the production of the Association's Policies and Procedures Manual which has taken over 10 months to complete. This manual which covers the extensive range of workplace policies and management procedures has been finalised and approved by the Management Committee. A copy of the manual has been sent to Queensland Health for their consideration.

These two major initiatives – The three year Strategic Plan and the Policies and Procedures Manual has involved many extra hours of work by staff and volunteers and sincere thanks go to everyone who contributed.

Our Day Respite Facilitators have continued each week at the Annerley headquarters and special thanks goes to Iris Simpson and Theresa Byrne for their commitment to providing support and care to our Huntington's Disease clients. We should not forget the assistance provided to Iris and Theresa by the regular volunteers who assist each week; without them we would not be able to provide the help that we do. Thank you all for a wonderful job well done.

As always, our Association continues to rely on the many fundraising activities – these have continued throughout the year and again our volunteers continue to step forward and assist at sausage sizzles at Bunnings and cookie drives etc. New initiatives have been decided for 2007/2008 to improve our income in these areas.

Telemarketing has also instigated new marketing initiatives for 2007/2008 and although we saw a decline in the funding from Telemarketing in 2006/2007, the recent results are very encouraging and these trends should continue.

Special thanks go again to the wonderful members and wives of the Acacia Ridge Rotary Club who continue to support our funding requirements. They have again sponsored the employment of Cate Barrett, Speech Pathologist at the HD Clinic Royal Brisbane Hospital, as well as many other programs during the year. Thank you sincerely to a wonderful band of people.

Sincere thanks also go to the Sherwood Forest Runners who continued to support us through the Bridge to Brisbane Run in August 2006.

Queensland Health has again provided major funding of \$124,956 this year which continues to support our Welfare and Respite services throughout Queensland and we sincerely thank Queensland Health for their ongoing support.

National HD Awareness Day was held on the 31 March this year and morning teas were held throughout the state. The extra income raised at these functions is amazing and to all who participated – Thank you – you do make a difference.

This year has been an extremely busier year than most with the workload placed on our small staff heavier than usual. There have been some very difficult periods when circumstances have strained their personal resources. However, all members can be very proud to know that the staff at Annerley remains committed and never waiver from the goal of providing the best possible care and support to all Huntington's people – clients, carers and families.

I would like to thank the members of the Management Committee for their commitment during the year. Your support to me has been appreciated and your support to our staff has been exemplary.

Despite difficulties, our Welfare staff has continued to service all of Queensland from Cairns to the Gold Coast, Toowoomba and the Darling Downs. Thank you sincerely.

A special thank you must go to Gwen Pratten who has decided to call it a day after 20 years guiding the Association from a small gathering of concerned Huntington's people to an Association recognised throughout Australia and internationally as an organisation that knows what it is doing. Gwen is a wonderful ambassador for our people and our Association has been fortunate indeed to have been guided unselfishly in the right direction by her. We wish her a happy retirement and thank her for being a major part of our life – Gwen has certainly made a difference.

In closing, my sincere thanks to everyone whose contribution has given the Queensland Huntington's Disease Association another successful year.

Ray Bellert
President

AUSTRALIAN HUNTINGTON'S DISEASE ASSOCIATION (QLD) INC.

MISSION

***To provide professional support and advocacy
for all persons affected by Huntington's Disease in Queensland***

The primary focus of the Association is the support of individuals and families affected by Huntington's Disease through information, education, referral, respite and emotional support. This support is offered to all families throughout Queensland.

The Association is committed to improving quality of service through regular evaluation of its practices and through improving funding.

WELFARE SERVICE

Information Provision:

The Association provides up to date information through various methods of communication and resources to inform families about Huntington's Disease, services offered by the Association, and services available in the community that families can readily access. Information is distributed through mail outs; the Association's Newsletter, Web Page, Library facility; and through our HD Awareness Program.

The provision of this service to families is provided with the aim of empowering them to make informed decisions regarding their health and wellbeing. Our information handouts are currently under review.

Membership of the Association ensures that families receive a regular Newsletter, featuring up to date information on the activities of the Association in addition to current worldwide research and carer support information.

To improve understanding of Huntington's Disease to services providing direct care to our families, the Welfare staff provides support and information to professionals, residential care facilities and community support groups by way of in-service training, education seminars and information mail outs.

In addition, presentations were conducted at Bond University, service clubs such as Rotary and Lions, a council library and at HD Awareness Day functions held during the year.

Non Clinical Counselling:

Welfare staff provides a non clinical counselling service to families, either on an individual basis or group counselling. Clients can access this service via home visits, telephone and by visiting the HD Centre. Clients and their families are supported to develop strategies and skills to manage issues impacting on their physical, emotional and social health. The Association facilitates access and referral to a range of services within the community.

Support Groups:

The Association offers a range of planned social, interactive activities that support clients, carers and their families to increase their resilience and develop strategies to improve personal coping skills. Support, in the form of groups, offered by the Association includes:

The Annerley Day Respite Program – The Day Respite Program in Annerley continues to operate every Tuesday, with an average of 17 clients attending; and on the second and fourth Friday of the month with an average of 8 clients attending. The program is in recess during the school holidays.

This service benefits both clients and carers. Transport is provided where necessary and morning tea and a hot midday meal are provided. The daily program includes: social interaction, a range of small group activities designed for memory and cognitive stimulation; therapies such as relaxation, music and exercise; monitoring of the general health of attendees; and outings.

Respite Holidays – A Respite Holiday for clients and carers was held in December 2006. Two Welfare staff and 14 clients and carers travelled to Tin Can Bay for a very enjoyable three day break. The holiday provided an opportunity for everyone to relax and socialise with other family members.

Family Support Group Meetings – Meetings are well attended and provide both social and emotional support for families. Regular meetings are held in Toowoomba and the Gold Coast with Rockhampton, the North Coast and the northern and southern suburbs of Brisbane having met once during the year. Welfare staff facilitate these meetings.

In addition, the Townsville group meets informally on a regular basis without the involvement of the Welfare staff and women from the North Coast area have formed a craft group and keep regular contact.

Carers' Meetings – The recently re-grouped Brisbane Carers' Group meets approximately every 6 weeks. Some meetings are held at the HD Centre when a guest speaker may be present or alternatively the group meets for coffee and a chat at an outside venue. The group is keen to continue with the support of the Welfare staff.

Socialisation for small groups – Our target group for this type of activity is for younger clients who are socially isolated in the community. Outings are offered for individual clients or small groups of up to 5 people. Activities included outings to the railway museum, movies and the maritime museum.

Outings for children – While Welfare staff do not directly offer support to the children of families affected by Huntington's Disease, we recognise the need to support the entire family. Currently outings during school holidays are offered to children who are accompanied by a parent and a Welfare staff member and in December 2006 some Christmas hampers were distributed to families facing financial hardship. We are planning a three day holiday for families with children later in the year.

ACCOMMODATION FOR YOUNGER PEOPLE IN NURSING HOMES

This issue is an ongoing agenda item for National Meetings and teleconferences between the States. In addition, the Senior Welfare Officer attended a meeting with Disability Services to obtain information about available support for clients under the "Younger People in Residential Aged Care" (YPIRAC). The main points of discussion at this meeting were:

- The Commonwealth and State Governments have each committed \$23.9 million in funding over a five year period to reduce the number of younger people with a disability living in residential aged care facilities.
- The initiative aims to address three areas:
 1. assisting younger people with a disability in residential aged care to more appropriate accommodation;
 2. divert younger people who are at risk of admission to residential aged care; and
 3. provide disability support for younger people who remain in residential aged care.

Under the YPIRAC banner, Disability Services Queensland has developed five models of support including:

1. Living Independently Model
2. Living with Family and Network Supports
3. Shared Support Model
4. Assessment and Options Planning
5. Integrated Living Model

All of these models are in their infancy. We welcome a service that provides more aged appropriate support and accommodation options; however it is difficult to ascertain at this stage how accessible these services will be for our clients. The Senior Welfare Officer will continue to gather information and report to families through the Association's Newsletter and one on one discussions.

PROFESSIONAL COMMITTEE

A Professional Committee meeting was held in November 2006. Welfare staff and the Association's President met with Ms Julie White and Dr Michael Gattas (Qld Clinical Genetics Service); Ms Iris Simpson, Project Officer, Queensland Health; Dr Arnold Waugh, Consultant Psychiatrist and Dr John O'Sullivan, Consultant Neurologist. The main focus of the meeting was an exchange of information on the services of the HD Association, Queensland Clinical Genetics Service and the Huntington's Disease Clinic.

Queensland Clinical Genetics Service:

- The referral process, testing procedure for HD gene remains unchanged
- Approximately 50 clients a year have predictive testing
- Genetic Counsellors are based in Brisbane, Cairns, Townsville, Bundaberg, Toowoomba and the Gold Coast
- There is no current clinical research being undertaken at the Queensland Clinical Genetics Service
- Genetics students from Griffiths University Postgraduate program participated in the Day Respite Program at the HD Centre

Huntington's Disease Clinic, Royal Brisbane Hospital:

- Initially a research clinic, the HD Clinic has evolved to being primarily a treatment clinic
- Currently the HD Clinic is seeing 8-10 clients per month
- Cate Barrett, Speech Pathologist attends the HD Clinic and is funded by the HD Association. Swallowing problems are the main focus of intervention; however communication difficulties are also addressed
- Changes to Queensland laws that require disclosure of a condition that affects driving
- Welfare staff assist as required

HUNTINGTON'S DISEASE AWARENESS DAY – 31 MARCH 2007

A very successful HD Awareness Day was the result of forward planning and considerable support from families and supporters across Queensland. The following activities were held:

Meeting the Care Needs of Younger People Seminar held on 16 March 2007 at the HD Centre. Guest speakers were David Conry, Manager of Youngcare; and Elly Mander (Service Coordinator) and Vivienne Davis (Recreation and Volunteer Coordinator) from Arthur Preston Residential Services in Melbourne.

Posters highlighting the lack of options in Queensland for younger people with high care needs were mailed out to all residential facilities caring for HD clients in Queensland, Genetics Clinics and community care groups.

The Association's Awareness Day banner was displayed outside Florence Dannell House on Ipswich Road giving good exposure for 7 days.

Car stickers with the wording "*Supporting families affected by Huntington's Disease*" were printed and distributed.

Media coverage – Four radio interviews conducted by the ABC were transmitted across regional Queensland. The Gold Coast Bulletin also provided coverage.

Morning Teas were held in various locations in Queensland, raising awareness and much needed funds.

MANAGEMENT COMMITTEE

Currently there are eight members on the Management Committee. This small group meets monthly to manage the administration of the affairs, property and funds of the Association and to discuss and consider any business on the prepared Agenda.

During the year three people resigned from the Committee, they are Allan Fox, Kerry Fox and Anita Smith. We thank them for their contribution to the Association as Committee members and volunteers.

Two new Committee members joined us; they are Jan Szlapak, who accepted nomination to the Management Committee on the 21 November 2006 and Gerry Doyle on 15 May 2007. Lorraine North will not be seeking re-election to the Committee as she is relocating; however all other members have indicated their willingness to remain as Committee members. Thank you Lorraine for your valuable input and support.

STAFF AND VOLUNTEERS

Staff: With the pending retirement of Gwen Pratten, Welfare Coordinator and Barbara Gray, Administration Officer, a decision was made by the Management Committee to restructure the Association, both organisationally and functionally. The decision to adopt this approach was a managerial initiative to achieve, firstly, efficiencies in the provision of enhanced welfare services by the appointment of a Senior Welfare Officer, supported by a Welfare Officer, to full time positions from the former base of part time arrangements.

Secondly, the administrative and financial management stream was to be rationalised, quite distinct from the welfare delivery, by clearly defining the respective roles and responsibilities and seeking the appointment of an Operations Manager to oversee the Association's financial management, funding and administration.

Welfare – As a result of restructuring the tenure of both part time Welfare staff ceased with effect from 21 April 2007. Julie Morrow was appointed as Senior Welfare Officer with effect from 23 April 2007 with Gwen Pratten continuing in her role until her retirement on 30 June 2007. Helen Fox, part time Welfare Officer left the Association on 20 April 2007 and we thank Helen for the care and dedication to the families she supported during the 15 months of her employment. Christine Parfitt will join the welfare team as a full time Welfare Officer in July 2007. Theresa Byrne continued in her role as Day Respite Assistant Facilitator.

Administration – The Management Committee advertised for an Operations Manager in April 2007 and was not successful in filling this position. Barbara Gray, Administration Officer offered to

continue in her role indefinitely while the Management Committee considers its options regarding the overall structure of the administration base. Helen Johnston assists the Administration Officer while also undertaking the office duties associated with the Telemarketing program.

Volunteers continue to play an important role in the successful operation of the Association. We rely heavily on their support, particularly with fundraising, administration and the Day Respite Program. Two Volunteers' Dinners were held, one in December 2006 and the other in June 2007. This is a gesture on behalf of the Association to say "thank you" for the wonderful support of these dedicated people, some of whom have been involved since our inception in 1976.

Staff Training: The Association is responsible for ensuring that all staff are given appropriate opportunities to develop their core knowledge base in a way that enables them to perform their job at a high standard. Appropriate training has been identified and offered to staff and volunteers during the year.

Of particular significance was the attendance of all Welfare staff at the 2006 Australian Huntington's Disease Conference held in Melbourne. The program was balanced with an excellent range of topics including research, predictive testing and client care.

Other support offered to staff included professional supervision for the Senior Welfare Officer; Workshops on client care; and First Aid Training.

FUNDING

Adequate funding of the Association is critical to its success. It is important for the Association to maintain and seek to broaden its current funding base.

Community Self Care Funding Program, Queensland Health: The provision of many of the services provided by the Association is supported by Queensland Health and we express our sincere appreciation for the funding of \$124,956.00 for this financial year. Our Service Agreement with the Community Self Care Funding Program, Queensland Health expired on 30 June 2007.

The Association has signed a new Agreement for a three year period July 2007 – June 2010.

Telemarketing: Income through the Telemarketing Program has steadily declined this year; this has been a trend over several years. The directors of Kelgrove Holdings have been pursuing ways to reverse this trend and we have been buoyed by an increase in income in the latter part of the financial year.

Donations and Bequests: Funding through donations has remained constant with the majority of our donors having supported the Association for many years. In addition an amount of \$16,781.00 was bequeathed to the Association this financial year.

Community Fundraising: The Management Committee is mindful of the importance of community fundraising; not only are valuable funds raised, there is the opportunity to increase awareness of Huntington's Disease in the wider community. This year our main focus has been Sausage Sizzles at Bunnings, Raffles, a Garage Sale, the Bridge to Brisbane Run and a Cookie Drive.

Service Groups: Through our Membership, several service groups have given us support during the year. The Rotary Club of Acacia Ridge has continued to provide wonderful support, financial assistance and friendship. This year they have supported us through donations and funding of Cate Barrett, Speech Pathologist at the HD Clinic, Royal Brisbane Hospital.

HUNTINGTON'S DISEASE CENTRE, FLORENCE DANNELL HOUSE

The Huntington's Disease Centre, Florence Dannel House provides a venue for the Association's Administration base, Welfare Service, Day Respite Program, Family Meetings, Education Forums and individual counselling and support for families affected by HD.

The Association received advice in June 2007 that an application for funding to Jupiters Casino Community Benefit Fund to paint the exterior of the HD Centre, the downstairs indoor section and fences was successful. We extend our sincere thanks and appreciation to the Benefit Fund for their generosity. Painting of the premises will be complete by the end of 2007.

Minor maintenance is carried out to the premises as required and all the necessary inspections and maintenance is routinely undertaking to the lift, electrical equipment and fire extinguishers.

POLICIES AND PROCEDURES MANUAL

In June 2007 the Management Committee approved completed Policies and Procedures and supporting documents that make up the Policy & Procedures Manual. The Manual provides a framework for decision-making and action within the Association and has been developed as a living document. We recognise that policies will need to be reviewed as the contexts and reference points for them change, and that new policy statements will need to be added from time to time.

We express our sincere thanks to the following donors -

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H. G. Wilson

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Community Groups

Adventist Retirement Village Social
Committee
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Bunnings – Maroochydore
Bunnings – Underwood
Caboolture Shire Council
Chelmer Runners
Little Mountain Quilters (V. Moran)
Rotary Club of Acacia Ridge
Sherwood Forest Runners