

Autumn 2011



## St George Foundation Grant

*Funding received for Part time  
Youth Development Officer  
12 month contract*



## Getaways

*The Youth Group takes a  
break in Mandurah*



## Website Launched

*Visit us now at  
[www.huntingtonswa.org.au](http://www.huntingtonswa.org.au)*



*Note From Dee Pg 3*

*Letter From the Board Pg 4*

*Member's Corner Pg 5*

*Research Pg 7*

*Events Pg 10*

*Announcements Pg 13*

*Thank You Pg 14*

*Calendar Pg 15*

*Library Resources Pg 16*



# *About us*

**Autumn 2011**



### **Mission :**

*'To enable the best possible quality of life for people with Huntington's Disease, their families and carers, through advocacy, support and education.'*

### **Contact Us :**

**☎:** (08) 9346 7599  
**✉:** [admin@huntingtonswa.org.au](mailto:admin@huntingtonswa.org.au)  
**🌐:** [www.huntingtonswa.org.au](http://www.huntingtonswa.org.au)  
**📍:** The Niche  
11 Aberdare Rd  
Nedlands WA 6009

### **Photography :**

Huntington's WA  
iStock Photos

# Note from Dee

What an amazing start to the year. We have a brand new website courtesy of Lotterywest, some wonderful new brochures courtesy of Clayton Utz Foundation and lovely new T Shirts courtesy of Embroidme in Claremont. What more could we ask for!! Well there is more.....

The St George Foundation has given us a grant of \$47,351.00 to employ a part time Youth Development Officer for 12 months. We thank them for recognizing the needs of young people at risk or living with someone who has HD. We are very excited at the prospect of starting a new service. Thank you to those that came along to Movies at Burswood and witnessed the cheque presentation. Thank you to the St George Foundation for a lovely evening.



Our Community Advisory Group had a very active first meeting coordinated by Sarah Morris. The Board and I hope that this will be the avenue for the HD Community to channel their concerns, issues, praises, suggestions and good ideas. (See further details in the newsletter)

Our own movie night raised about \$1500. Once again thank you to those that supported the event and brought their friends. Thanks also to United Way and Chokey Road for donating door prizes and to Denise Wellington, Marg Gibson, Nikki Roberts and Sally Harrison for all their efforts in organizing the evening. We need to continually raise funds to support and maintain all our programs.

In the next few months we have organized some awareness booths in shopping centres. So far we have booked Karrinyup, Joondalup, Garden City and Bunbury. We need to build awareness in the wider community to attract more support. If you can help at any of these centres we would really appreciate your time and energy for a couple of hours. Just email Nola at [admin@huntingtonswa.org.au](mailto:admin@huntingtonswa.org.au) or phone 93467599 for further details.

Hopefully most of you will have seen the new website [www.huntingtonswa.org.au](http://www.huntingtonswa.org.au), don't forget to sign up for e news so that you don't miss out on any updates and events. We welcome any feedback you may have or any ideas for relevant content.

We love people to visit us in the office and our doors are always open so feel free to drop in for a coffee and chat if you are passing or if you need assistance we will try and point you in the right direction.

As always my very best wishes

Dee

# *Letter From the Board*

On behalf of the Board I would like to congratulate and acknowledge our Executive Director Dee Sidhu for her success in HWA being awarded a number of significant grants which will be outlined in this newsletter.

This is a very exciting and encouraging start to the year and while it would be easy to “rest on our laurels”, it is extremely important to remember that these grants are for specific projects over a certain period of time. HWA will need to continually demonstrate the value of these projects and our services, in order to pursue on-going funding. The Board, together with Dee, is committed to monitoring their performance and will pursue every avenue available to achieve our goals.

The Board looks forward to receiving feedback from the newly formed Community Advisory Group and the addition of a Youth Worker who we feel will complement our staff in this very important area.

The smooth running of the HWA is a reflection of the tireless work done by all our dedicated staff, our volunteers and supporters all wishing to enhance the life of our HD community.

Ann Jones  
Chairperson



# Members' Corner

## Youth Group Getaway



In December, the Youth Group spent a relaxing weekend in Mandurah. Highlights of the weekend included the Christmas lights canal cruise, splash jump and slide at the Just 4 Fun Aqua Park, kayaking, mini golf, bumper cars and a visit to the movies.



## First Aid Training

On Saturday 26th February, our Youth Group were invited to attend an all day Senior First Aid Training Course conducted by Keith Emin from Revive Emergency Medical Training.

This is an accredited Senior first Aid Course and the Certificate will be valid for 3 years.

The course provided participants with the confidence and practical skills required to deal with common first aid emergencies.



Our thanks go to the Department for Communities for providing the funding for our Youth Group activities in 2010.



## Day Centre

On the last Wednesday before Christmas we were privileged to have Professor Lyn Beazley, The Chief Scientist, join us for our Christmas celebration at the Day Centre.

Entertainment was provided by Joe Caruana and his band with a surprise performance by our very own Liz Retamal, Ann Jones and Rensie Matthews.

A very cheerful and positive way to round out the year!



Early in the New Year the Day Centre was visited by Mr Peter Conran, Director General of the Department of Premier and Cabinet and the Hon. Helen Morton, Minister for Mental Health and Disability Services. We thank them for their interest in our existing services and understanding of our ongoing and future needs .

## Short Term Wheelchair Loan Available

With the assistance of HBF Workplace Giving and United Way we have been able to purchase three lightweight wheelchairs. Two of these will be used by HWA for Outings and Retreats. One will be specifically made available for short term loan for holidays, occasional outings or to try before you buy. Should you wish to borrow a wheelchair please contact the Office for an equipment loan application .





**HEROs Research Project**  
**(Huntington's Enrichment Research Optimisation**  
**scheme)**  
**Dr Jennifer Thompson, Travis Cruickshank &**  
**Assoc. Prof. Mel Ziman**

Huntington's WA (Inc) in collaboration with Edith Cowan University, the Neurosciences Unit, the Brightwater Group, the Cambridge Centre for Brain Repair and the Howard Florey Institute are currently undertaking a clinical research trial investigating the effects of environmental enrichment on Huntington's disease. Environmental enrichment is the use of mental, social and physical activities to provide brain stimulation, and it is theorised that this strategy will slow the progression of Huntington's disease in the participants of this research project.

We recruited 25 participants at early to mid stages of Huntington's disease into the project in 2010, and performed an array of baseline assessments which included testing brain function, muscle strength, walking, fine motor skills (eg finger dexterity), balance, and brain and body imaging. We used the results of these assessments to assign participants into two equal groups, and then randomly assigned the groups to either receive the intervention (exercise group) or not (control group). The participants that are receiving the intervention (exercise group) commenced weekly gym-based exercises in September, 2010 under the supervision of accredited exercise physiologists (Luis and Todd). The exercise physiologists have proved to be a firm favourite with the participants, who affectionately refer to them as their "personal trainers". In December, 2010 the exercise group commenced a home-based program of exercises and activities designed to support the training they receive in the gym, and to further provide mental and fine motor stimulation. Occupational therapists visited the exercise group in their home and performed assessments, which they used to design an occupational therapy home-based program focused on improving mental stimulation. Occupational therapy visits occur in the home environment on a fortnightly basis, and our exercise group appear to be really enjoying this aspect of the research project.

The intervention participants have therefore been very busy working to slow the progression of their disease and to demonstrate to the rest of the world whether this type of intervention is capable of impacting the progression of Huntington's disease. Their hard work seems to be paying off, as they have exhibited statistically significant gains in muscle strength (Figure 1).

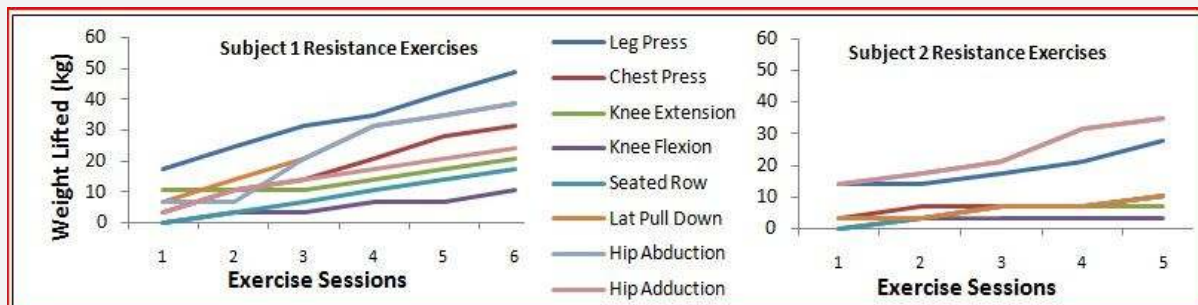


Figure 1 – Examples of strength gains in two individuals participating in the HEROs project.

Compliance with the intervention has been excellent, with exercisers making most gym sessions (Luis and Todd are very popular despite working the group hard!) and keeping up with the home-based exercises, too.

The current intervention will continue until June 2011, where a second set of assessments will be taken to assess the effectiveness of the intervention, and the groups will be swapped so that the current non-intervention group will be able to undertake the intervention.

The Researchers in this exciting, world-first project sincerely thank all the participants, in both the intervention and non-intervention groups, their families and support people for their sterling efforts and for helping us to investigate whether this therapeutic intervention can benefit people with Huntington's disease.

If you are symptomatic and in the early to mid stages of Huntington's disease and would like to know more about the research project, please contact Dr Jennifer Thompson (Phone 6304 5635; mobile 0419 917 649; email [jennifer.thompson@ecu.edu.au](mailto:jennifer.thompson@ecu.edu.au)) or A/Prof Mel Ziman (Phone 6304 5717; mobile 0419 929 851; email [m.ziman@ecu.edu.au](mailto:m.ziman@ecu.edu.au)) at Edith Cowan University. This project has been approved by the Human Research Ethics Committees of Edith Cowan University and the North Metropolitan Area Mental Health Service.



- Huntington's disease research news.
- In plain language.
- Written by scientists.
- For the global HD community.

### **What is HDBuzz?**

HDBuzz is the first internet portal for the rapid dissemination of high-quality Huntington's disease (HD) research news to the global community, written in plain language, by HD clinicians and scientists. It covers laboratory and clinical research, with the aim of helping HD people to understand the latest HD science, on their own terms.

All content is disseminated from [hdbuzz.net](http://hdbuzz.net) via free syndication to other HD community websites, blogs and social media platforms like Facebook and Twitter.

### **Who are you?**

HDBuzz was founded by Dr Ed Wild and Dr Jeff Carroll, HD scientists in the UK and USA, respectively. We recruited a number of people to help – see the [people page](#). Everyone involved is already active in the HD community, in various capacities.

### **Is HDBuzz impartial?**

We hope so. We go to great lengths to be impartial in our reporting:

We don't accept funding from any drug company or organization with a vested interest in a particular treatment or technology.

No funding organization gets any editorial control over HDBuzz content. An oversight committee of independent clinicians, scientists and lay community members meets regularly to ensure our content is impartial, scientifically accurate and understandable. All our authors make financial disclosure statements, which they review whenever they contribute new content.

**Please check out this excellent website @ <http://hdbuzz.net/>**

# Events

## Movie Fundraiser “Conviction”

Thank you to everyone who supported this great evening. We managed to make \$1500.00 which will go toward our Support groups and Getaways. Look out for our next Movie Event!



## Swallowing Master Chef Workshop for Carers

On Thursday the **21st of April** HWA will host a Master Chef class for Carers. The workshop which will be held from 10am—1pm at the Niche, and will be run by Sarah Hammond who is a Speech Pathologist from the NSU.

Come along to find out about how swallowing is affected in HD and learn how to manage these changes. The workshop will include live demonstrations of how to prepare foods and you will have the chance to put your questions to the Speech Pathologist.



If you would like to come along. Please contact Erin or Nola at the office: Phone 9346 7599 or email [admin@huntingtonswa.org.au](mailto:admin@huntingtonswa.org.au)

## Rare Diseases Symposium

For further information or to register visit [www.rare-disease.com.au](http://www.rare-disease.com.au)



## Community Advisory Group

Just want to tell you about our new Community Advisory Group. We held our first meeting Tuesday 8<sup>th</sup> March at the Niche. Apart from Ann Jones and Dee who were there to get us going and myself (Sarah Morris) as coordinator, we had Jennifer Morris, Vera Ingram, David Jeppesen and Tracey Jones present. Apologies were received from several other invitees who couldn't make this first meeting but are very interested in becoming a part of this mixed community group.

We'll be meeting usually about every 3 months and we are there to gather ideas, feedback and concerns from the wider Huntington's community by providing a more informal contact point than the Board or office. We can then talk to the Staff and Board on behalf of the community and pass back issues and ideas for further action or investigation. We will also provide feedback to suggestions made by management and Board.

It is hoped that you, out there, will contact one of us if you have a problem with something that you don't feel you can take to the Association yourself. There are loads of things that we can be doing to help ourselves and the Association and the HD Families, we just need to know what they are. Hopefully group members will bring back ideas from their own support groups (GP, Youth, Carer etc.) and be available for anyone in the wider community, family and friends, who may wish to have an issue or idea passed back.

. . . and they're not even necessarily 'issues', they might just be things that occur to you. They might be relatively small things in the overall scheme but if we can sort it for you and for the next person who will experience it, it's worth having a go at. There are things you'll have grappled with and beaten, tell us and we can pass the information out.

We had a lively discussion in our first small group and several issues were raised which were immediately passed back to Dee for further action and investigation. They included such diverse things as....

Finding a local Pharmacy or a chain of Pharmacies who will help out and provide the service of putting medications into blister packs where they may not be supplying all (or any) of the medications themselves.

Centrelink and getting the run around when trying to deal with them: Also the issue of how tricky the disability phone number is to use – for anyone with a disability. This is a much larger problem, ideally we would like to have one person/area to talk to who know the HD issues and can give correct information without having to pass you around to several different areas. Also, if the Association can contact someone there officially, it may be that the effective advice can then be passed on to all.

We would like to encourage members to make connections within our community. Not everyone wants to belong to a support group but it can be nice to find one person in a similar situation to you to talk to sometimes. Get more personal profiles in the newsletter, probably starting with us.

Friends of Huntingtons: Find and use anyone who is willing to help out. Take some of the pressure off the community and spread the load.

Mentoring and Youth Mentoring: Who is out there that can be of use?

For now call me at 92996976. We will soon have a central email address for you to contact us, [community@huntingtonswa.org.au](mailto:community@huntingtonswa.org.au), and have a regular spot in the newsletter and on the website. We are meeting again on Monday 2<sup>nd</sup> May, if you've got something in mind, let us know.

Can't wait to hear from you.

# Volunteering Opportunities For 2011

The following is a list of events we currently have scheduled for this year:

- **7<sup>th</sup> April 2011** Thursday 8.30 a.m.- 9.00 p.m. **Charity Booth Karrinyup Shopping Centre**  
Creating awareness of Huntington's Disease through information displays, quiz book sales and collection of donations. (3 hour shifts)
- **8<sup>th</sup> April 2011** Friday 2.00 p.m. – 6.00 p.m. **Rearrange Huntington's WA Office**  
Group required to assist with repositioning furniture, emptying cabinets etc to create a more effective workspace. Afternoon tea provided.
- **4<sup>th</sup> May 2011** Wednesday 8.30 a.m. – 5.30 p.m. **Charity Booth Lakeside Joondalup and Garden City Booragoon.** (3 hour shifts)
- **2<sup>nd</sup> September 2011** Friday 4.30p.m. – 11.30 p.m. **Quiz Night South Perth Yacht Club**  
Our major fundraising event! Assistance required 4.30 – 7.30 p.m. for set up and/or 7.30 – 11.30p.m. Continuous raffle, Heads and Tails, Arcade Games, silent auction etc.
- **7<sup>th</sup> September 2011** Wednesday 8.30 a.m. – 5.30 p.m. **Charity Booth Garden City Booragoon.** (3 hour shifts)
- **23<sup>rd</sup> September 2011** Friday 9.00a.m. – 4.00p.m. **Street Appeal City of Perth**  
Create awareness and raise funds through coin collection. Information stand located in Murray Street Mall. Any assistance welcome for as long or short a shift as you feel comfortable with.
- **30<sup>th</sup> September 2011** Friday 8.30 – 5.30 **Charity Booth Bunbury Forum.** (3 hour shifts)
- **29<sup>th</sup> October 2011** Saturday 8.30 a.m. – 2.00 p.m. **Tanya's Garden Dalkeith**  
The opportunity to have your morning coffee in a spectacular private garden and support HWA.
- **October/November** – date to be confirmed **Private Cocktail Party Nedlands**  
Assistance required with set up and serving of drinks/canapés—private residence in Nedlands.

The success of these events is made possible only with the assistance of our valued volunteers. Volunteering with Huntington's WA provides satisfaction in knowing that your efforts have contributed to improving the quality of life of people in the Huntington's community.

**We look forward to and thank you for your support!**



# *Announcements*

## **St George Foundation Grant**

Our sincerest thanks go to the St George Foundation for their generous donation of \$47,351.00. This money will allow us to employ a part time youth worker and enable us to build and develop services for youth members impacted by Huntington's Disease.

The cheque was presented to Ann Jones, Chairperson at a Movie night at Burswood Outdoor Cinemas . We were given the opportunity to invite 50 guests to participate in the event along with a number of other recipients.

Dee Sidhu, Executive Director HWA was invited to speak on behalf of all the recipients of St George Foundation Grants including Youth Support Services, Friends of Autism, Kids Camp, Sports Challenge Australia, DADAA, Canning Division of General practice, Therapy Focus, and Awesome Arts.



“There is now world wide recognition that our youth who often live and care for those with HD need specialised services and WA is leading the way in Australia. The grant from St George foundation will allow us to employ the first youth worker in Australia to work specifically with Huntington’s Disease” .

We look forward to keeping you informed as we begin the recruitment process for this very important position.



# Thank You!

## **Carine Masters Swimming Club**

once again supported HWA through donations and funds raised during their annual Australia Day Swim. Between 200 and 300 swimmers took part in this event with part proceeds being donated to local not for profit organisations.

## **West Greenwood Primary School**

surprised Maggie from HWA by presenting her with Christmas hampers of food and other goodies in support of HWA at their final school assembly last year.

Thank you to **Ace Cinemas** and **Hire Society** for their assistance in making our Movie Night a success.

**Clayton Utz** provided us with the funding to create a new range of professionally printed information brochures. After 6 months of planning and editing the final product came to fruition just prior to Christmas. Brochures are available by contacting the office.

Thank you to **EmbroideMe Claremont** for providing new T Shirts and Jackets emblazoned with our logo. Our new look was on show at the St George Foundation presentation evening.

Thank you also to Vilma's Neighbour for supporting HWA by holding a Christmas Fundraiser.

## **St George Foundation**

Once again we acknowledge and thank the St George Foundation for their generosity which will enable us to employ a part-time Youth Development Officer for 12 months.

**Lotterywest** has generously supported us by providing funds which have resulted in the creation of our new Website. Please take a moment to have a look at [www.huntingtonswa.org.au](http://www.huntingtonswa.org.au)

At a pleasant morning tea at Waroona, Ann Jones and Dee Sidhu were presented with hand crafted blankets by **Coral's Charity Knitters**



**Thank you to all our regular supporters!**

## April 2011

Date	Time	Venue	Event / Group
7th Thursday	8.30 am—9.00 pm	Karrinyup Shopping Centre	Charity Awareness Booth
8th Friday	2pm—6 pm	Huntington's Office The Niche	Rearrange Office <b>Volunteers required</b>
11th—15th		Pelican's Holiday Village Albany	Carers' Retreat
21st Thursday	10 am—1 pm	The Niche, Passmore Room	Masterchef Workshop for Carers
22nd—25th		<b>Closed for Easter</b>	
27th Wednesday	7.30pm—9.30pm	Greenwood	Northern Carers Group

## May 2011

Date	Time	Venue	Event / Group
2nd Monday	6.00 pm—8.00 pm	The Niche, Passmore Room	Community Advisory Group
4th Wednesday	8.30 am—5.30 pm	Lakeside Joondalup and Garden City Booragoon	Charity Awareness Booth <b>Volunteers required</b>
5th Thursday	8.30 am—4pm	Dolphin Discovery Centre Bunbury	Eco Cruise Youth Group
17th Tuesday	12noon—3pm	7th Day Adventist Church	SW Support Group
19th Thursday	10.00am—2noon	The Niche, Passmore Room	Central Carers Support Group
25th Wednesday	7.30pm—9.30pm	Greenwood	Northern Carers Group

## June 2011

Date	Time	Venue	Event / Group
6th Monday		Office Closed	Foundation Day
8th Wednesday	7pm—9pm	The Niche Passmore Room	GP Support Group
16th Thursday	10.00am—12noon	The Niche, Passmore Room	Central Carers Support Group
29th Wednesday	7.30pm—9.30pm	Greenwood	Northern Carers Group

## Day Centre

Times	Venue	Exceptions
Every Wednesday 9.30 am—1.30 pm	Beechboro Day Centre Cnr Amazon and Darwin Crs Beechboro	

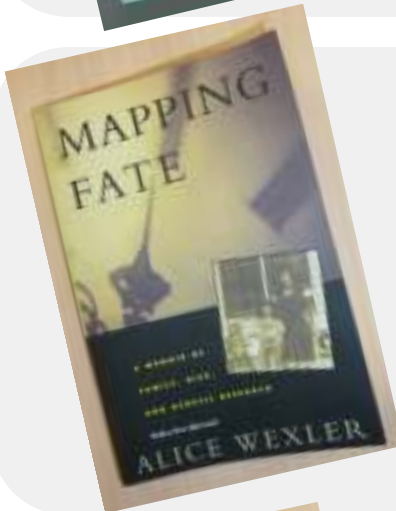
## Available now from our Library

Thanks to The Lions Club we have been able to purchase some new books for our library. A full list will soon be available on the website . Please contact Nola at the office on 9346 7599 or email [admin@huntingtonswa.org.au](mailto:admin@huntingtonswa.org.au) if you would like to find out more about borrowing any of the books available.



**Selfish Pigs Guide to Caring**  
**Hugh Marriott**  
**ISBN 978-0-7499-2986-2**  
**2003**

A must have read for anyone involved in caring for a partner or family member. This is a very practical and honest look at a carers role and in an easy to ready format. Written by a carer for carers.



**Mapping Fate**  
**Alice Wexler**  
**ISBN 978-0-520-20741-7**  
**1995**

This book tells the story of how the Wexler family were an integral part in the mapping of the HD gene. Although quite scientific in parts, it is a story about the courage and determination, of one family's HD journey and their involvement in HD research.



**The Woman Who Walked Into the sea**  
**Alice Wexler**  
**ISBN 978-0-300-15861-8**  
**2008**

“Detailed and evocative.....Wexler re-creates a picture of a long ago place where doctors lived next door to their patients and where generation after generation of a community's most prominent members struggled with a crippling disease”  
Amy Dockser Marcus, Wall Street Journal.



Printed at  
Officeworks Morley  
Lot 6, 137 Russell Street  
Morley WA 6062  
08 9375 4700