



SCGRF

Sir Charles  
Gairdner  
Research  
Foundation



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Sir Charles Gairdner Research Foundation

# Newsletter

## Foundation ups grant to research at Charlies

The Sir Charles Gairdner Research Foundation has been raising funds for research over many years. These funds have helped our researchers to produce significant world class research and this is happening right here at 'Charlies'. In addition to research specific grants, the Foundation has increased the size of the annual contribution to the Research Advisory Committee to \$250,000.

This is in response to the number of very high quality research applications received from some of the younger researchers that are based at Charlies.

*“With the Foundation experiencing a growth in income that looks set to continue into the future, we are grateful to all the people over many years who have made this possible. Charlies is one of Australia’s leading tertiary teaching hospitals treating more than 420,000 patients each year.*”

*Charlies researchers are most grateful for the support that the Foundation has provided to the research community at Charlies and to those people who have supported the Foundation with their donations.”*

*In the end, high quality research results in better patient care and better patient outcomes; thank you.*



Dr John Beilby  
Chair, Sir Charles Gairdner Group  
Research Advisory Committee

# RESEARCH PROJECT FOCUS:

## Cell Banking for WA Patients with Duchenne Muscular Dystrophy

Duchenne Muscular Dystrophy (DMD) is an X-linked fatal muscle wasting disease with an incidence of about 1 in 3,300 live male births, caused by mutations in the dystrophin gene. Boys with DMD show signs of muscle weakness as infants, are restricted to a wheelchair by the age of 12 and 90% will die from cardiac and/or respiratory complications before their mid twenties. DMD is a relentlessly progressive disease with a predictable course, affecting all muscles including heart and smooth muscle. As the disease progresses, boys with DMD suffer osteoporosis and digestive tract and endocrine problems in addition to muscle weakness. Currently there is no cure for DMD and treatment is predominantly palliative in nature.

A 'genetic band aid' is a potential treatment for approximately 80% of DMD sufferers. Recent clinical trials in the UK on one of our compounds, demonstrated that the missing protein, dystrophin, was restored in the muscles of DMD patients and this result will support the imminent global expansion of trials. An impediment to the implementation of this therapy is that many different compounds will be needed for patients with mutations in different regions of the dystrophin gene. To date, we have designed compounds to address the majority of the more common mutations; however, strategies for the less common mutations can only be optimised in appropriate individual patient cells.

We have accessed patient cell lines from a number of researchers, both in Australia and overseas, but until recently, did not have cells from local patients.



Investigators: **Dr Sue Fletcher & Dr Clayton Fragall**

It is important to compare the effectiveness of each strategy in a number of cell lines with clustered mutations, in order to verify that we have developed the most favourable compound, and to ascertain if the compound is broadly applicable, or if we need to design more personalised treatments.

The support from Sir Charles Gairdner Research Foundation is allowing us to expand our cell collection, adding depth to our cell bank and diversity to the range of mutations we can address. This has permitted us to carry out pre-clinical testing in cell lines from local patients who may be candidates for clinical trials. In addition, the Sir Charles Gairdner Research Foundation grant was noted in our petition for clinical trial infrastructure support, submitted to Mr Kim Hames, Minister for Health, and subsequently further funding was obtained from a State Government research initiative. This will promote the role of Western Australia in the international effort to develop treatment for Duchenne Muscular Dystrophy.

# Videostroboscopy funded by the Foundation finally arrives

*“A voice is a human gift; it should be cherished and used, to utter fully human speech as possible. Powerlessness and silence go together.”*

The feelings described here by Margaret Atwood are felt by many Western Australians with voice problems.

The human voice is a magical thing, occurring out of a complex process involving many muscles and nerves. It can be affected by so many medical conditions, such as stroke, neurological disease, cancer and surgery.

The Speech Pathology and ENT departments at Charlies would like to thank the Foundation and SCGH Department of Research for supporting the purchase of a Videostroboscopy unit.

The new SCGH Videostroboscopy unit provides first class technology to assess, diagnose, guide treatment, report and educate patients about their voice. It also provides an objective means to compare pre and post voice treatment outcomes for patients. In summary, it will give patients a voice.

A launch event was held on Monday 11th April to celebrate this wonderful achievement and to thank those who gave so generously to make this dream become a reality. Guests included Janet Holmes



**Janet Holmes à Court, Patron of the Sir Charles Gairdner Research Foundation; Tony Dolan, Executive Director Nursing Services; Linda Wayman, General Manager Austereo Perth; Kim Brookes, Allied Health Coordinator/Speech Pathology Head of Department; Ronald Frank**

à Court (Foundation Patron), Foundation Board Members, SCGH Executive and Staff, KayPENTAX Staff, and some of the donors, without whose support this purchase would not have been possible.

## **Peter Friedland**

Professor  
Department Otolaryngology Head Neck Skull Base Surgery Sir Charles Gairdner Hospital

## **Kim Brookes**

Allied Health Coordinator  
Speech Pathology Head of Department

## STAFF PROFILE: Betty Whiley



Betty has worked at Sir Charles Gairdner Hospital for over 20 years. She is originally from Liverpool in the UK, and is proud of being a Liverpudlian, or ‘Scouser’ as natives of Liverpool are often called. She is married to Chris and has two sons, Robert and Stephen. Originally employed in the Public Relations Department at Charlies, she has been involved in the Foundation since its inception in 1989 and took over the reigns in 1998.

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# Lois and Alf Walton support the Tree of Life

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Photo: **Alf and Lois Walton**

Lois and Alf Walton became aware of the Tree of Life sculpture at Sir Charles Gairdner Hospital in the early eighties. Their twin daughters regularly attended the hospital for several operations over the course of 15 years.

Alf was a member of the Lions Club of Swan Districts and thought that a donation to the Sir Charles Gairdner Research Foundation from the Club would be a great project. The Swan Districts Club were friendly with the Forrestfield/High Wycombe Club and together, they sold raffle tickets with the proceeds to go to community projects.

After getting in contact with the Foundation, Alf brought up the idea with his Club of giving some of the funds raised from the raffle to the Foundation. After everyone agreed, a cheque was presented to the Minister for Health, Mr Bob Kucera, on the 14th of February 2002. As a sign of gratitude, a 'leaf' was inscribed with the Lions Logo and added to the Tree. This leaf is proudly admired by the Club members who are sure in the knowledge that their contribution has benefited the many patients that have passed through

Charlies in the years that followed.

After helping the Lions Club make a donation to the Foundation, Alf and Lois decided they too wanted to personally donate and have a leaf on the Tree of Life. Sure enough, after many years of saving, in 2009 Alf and Lois presented a donation to Dr Stephen Wilson, the Vice President of the AMA to pass on to the Foundation. Alf and Lois have now received their own leaf and are proud to take part in this wonderful project. They both believe that not many people go through life without seeing a doctor or spending time in hospital.

Alf and Lois' generous gift will help researchers continue in their quest to discover new treatments, procedures and hopefully, cures, well into the future.

The Tree of Life can be found in the Sir Charles Gairdner Hospital, G Block. If you would like more information about the Tree of Life, please contact Betty Whiley on (08) 9346 2042.

## Tell us your story!

Everyone who supports Charlies Research Foundation does so for a reason. Tell us why you support Charlies and when you send us your donation we will invite you into the hospital for a look around, meet and have a chat with some of the researchers who are doing such great work and then have a coffee (or tea) with us.

**Your support is vital to our future success!**