

# Priceless



**Clifford  
Craig**  
Medical  
Research Trust

THE NEWS BULLETIN FOR SUPPORTERS OF THE CLIFFORD CRAIG MEDICAL RESEARCH TRUST

## Our community gives: Sophie wins new life thanks to you



*Northern Tasmania's princess Sophie Hart, together with Patch the monkey, being taken to surgery at the Prince of Wales Hospital, Sydney in December 2008.*



**“God has answered my prayer and I’ve got my children. I’m so thankful to everyone who gave to Sophie, I’m so thankful that I’ve been able to keep both my beautiful children.” Lisa Hart.**

During Christmas 2008, the Northern Tasmanian community rallied in a very special way to raise the funds needed to allow little 4 year old Sophie Hart her life-saving operation to remove a dangerously growing tumour (pilocytic astrocytoma) from her brain. Arising out of a chance meeting between Sophie’s mother Lisa and the Trust’s CEO Michael Ferguson, the Clifford Craig Medical

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Proudly assisting the Clifford  
Craig Medical Research Trust

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### For the Diary

**Launceston Business and Professional Breakfast**  
**Dates:** April 23, July 30, October 1 and December 3,  
 7:15am for 7:30am  
**Venue:** Hotel Grand Chancellor  
**Cost:** \$30.00 per person – reservations required  
**RSVP:** April 16 with payment at [www.cliffordcraig.org.au](http://www.cliffordcraig.org.au)

**Devonport Friends Soup and Sandwich Luncheon**  
**Date:** May 29  
**Venue:** Pinegrove’s refreshment lounge,  
 163 Steele Street, Devonport  
**Cost:** \$10 per person  
**RSVP:** 6424 5187

**Rainbow Ball**  
**Date:** May 30, 7pm for 7.30pm  
**Venue:** Burnie Civic Centre  
**Dress:** Black Tie  
**Contact:** For more information or to RSVP call 6440 3555

**Dare Shott Lecture**  
 Eminent ophthalmologist and world-renowned eye researcher Professor David Mackey will deliver the 2009 Dare Shott Lecture. This will be a most interesting lecture from one of ophthalmology’s true high achievers and will be presented for a non-scientific audience. Prof Mackey is the lead researcher on the Trust-funded twins eye study, is responsible for discovering a gene which causes glaucoma and was recently appointed as Managing Director of the Lions Eye Institute and Professor of Ophthalmology and Director of the Centre for Ophthalmology and Visual Science at the University of Western Australia. Prof Mackey will speak on developments in eye research and share his vision for what the future should hold.  
**Date:** May 31 2009  
**Venue:** Lecture Theatre, Level 3,  
 Launceston General Hospital  
**Cost:** Free admission –  
 a donation would be appreciated at the door

**John Morris Society**  
 The dates for JMS luncheons in 2009 are 17 March, 18 August and 17 November. At the March meeting, Ronnie and Maggie Burns will bring a presentation on their work with Appin Hall, bringing joy into the lives of children at risk in Tasmania and Australia. The John Morris Society is exclusively for supporters who have remembered the Trust in their Will. For more information, please contact the Trust office.

**Thank Goodness its Friday**  
 The dates for TGIF in 2009 for members of our Baby Boomers group are 15 May, 14 August and 27 November. For more information, please ask for our brochure when you contact the Trust office.

### The John Morris Society – people giving the gift which lasts forever

It’s amazing to hear and read about cases where people have died without a Will or who had one which was out of date due to some change in circumstances. We always urge anyone in doubt to get professional advice on the preparation of a Will to ensure that your own wishes are respected rather than what might otherwise be imposed on one’s estate.

Many of our great supporters have left provision in their Will for medical research by naming the Clifford Craig Medical Research Trust as a partial or full beneficiary.

A Bequest is the one donation that lasts forever and the Trust has been extremely fortunate to have received several significant donations through Bequests since we began in 1992. We have a leaflet explaining how to leave a Bequest, the correct wording to use and who to contact for advice when preparing your Will.

We encourage discussion with your family and recommend advice from a qualified legal advisor or trustee officer. If you would like further information about leaving a Bequest or donation to the Trust, please send for our leaflet today or contact our CEO Michael Ferguson for a private and confidential discussion.

Individual membership to the John Morris Society is automatically available to supporters who have named the Clifford Craig Medical Research Trust in their Will. The society meets for luncheons with an interesting guest speaker three times per year in a most convivial atmosphere. Please send for our JMS leaflet and let us know of your wishes so that we can recognise and thank you.

### Secure, online giving

We’ve upgraded the Clifford Craig Medical Research Trust website to allow our supporters to make easy, secure, credit card payments online.

This helpful service is provided by a major bank, not an internet provider, which allows you to confidently make a donation or pay for a Trust event whenever it suits you.



### From the Chief Executive Officer



Since our last edition of Priceless before Christmas your favourite charity has been involved in the extraordinary but wonderful initiative of facilitating the collection of funds to ensure that young Sophie Hart was able to have a dangerous brain tumour removed by renowned Australian neurosurgeon Charlie Teo.

Medical research into the diseases that affect our community is and remains our core business and mission. However by reason of urgency we felt that making our fundraising facilities available to the family and their donors was the right thing to do on this occasion. It was urgent because the operation was scheduled immediately after Charlie saw Sophie, allowing the family just a few days to raise and deposit the needed funds.

The staff at the Clifford Craig Medical Research Trust were magnificent during this period – some even donating their time out of normal hours to collect, count and bank funds. We are a small team and the pre-Christmas period was already a busy time.

The loveliest aspect to all of this is that our community has once again demonstrated the amazing generosity it is capable of in doing what’s necessary to assist those with challenges too big for themselves alone. While it is unlikely that the Trust will be involved in this sort of fundraising in future, we have been so delighted to be able to provide this assistance and to have been able to witness first-hand the remarkable generosity and sacrifice which was displayed, often through tears, when kind people brought their donations to us.

The start of this year has also seen some changes to the Trust internally and at this point I’d like to make particular special mention to Maree Biber who’s no longer with us, having served the Trust for more than five years as office manager. Maree brought many positive qualities to the Trust, especially her strong interest and passion for our baby boomers’ group (B4X) and her enthusiasm and flair for helping the Trust organise excellent events for the wider community. We sincerely wish her and her husband Garry well for the future and particularly thank Maree for the positive contributions she has made toward our work since 2003.

Finally I’m very happy to report that the our newest nine research projects (a record number in one year) are off to a great start in 2009. The new research programme is looking for answers to some important medical mysteries relating to many diseases, including: chronic kidney disease, respiratory illness, diabetes, cardiovascular disease, cystic fibrosis, lung infections, Barrett’s oesophagus and anaemia in pregnancy. As you can tell, these are certainly some of the diseases that cause alarm in our community, consistent with our stated goal of focussing on such illnesses.

Thank you for your continuing support, together we’ll have a great year supporting medical research and finding answers to important questions.

**Michael Ferguson**  
CEO

### Yes, I would like to help the Clifford Craig Medical Research Trust

I would like to make a one-off donation of \$\_\_\_\_\_

I would like to have monthly donations of \$\_\_\_\_\_ deducted from my credit card.

All donations over \$2 are tax deductible.

### Please complete the following details:

Title/s: Mr / Mrs / Miss / Other \_\_\_\_\_

Given Name/s: \_\_\_\_\_

Surname: \_\_\_\_\_

Address: \_\_\_\_\_

Postcode: \_\_\_\_\_

Telephone: ( ) \_\_\_\_\_

Email: \_\_\_\_\_

### Please accept my donation/s in the form of:

Cash  Cheque/Money Order\*

\*Payable to the Clifford Craig Medical Research Trust

### OR

### Please debit my:

Visa  Mastercard

Credit Card No.: \_\_\_\_\_

Expiry Date: / \_\_\_\_\_

Name on card: \_\_\_\_\_

Signature: \_\_\_\_\_

Please send me information on remembering the Trust in my Will.

Please send me information on making an annual gift using our courtesy reminder service.

### Thank you for your support.



Please post to:  
 CLIFFORD CRAIG  
 MEDICAL RESEARCH TRUST  
 PO Box 1963  
 Launceston  
 Tasmania 7250

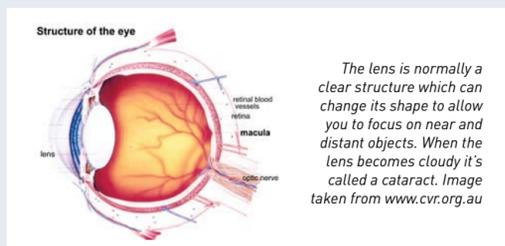
## Research update: Twins, genes and cataracts

by Professor David Mackey

How your donations and one Tasmanian family played a key role in identifying an important gene for adult cataract

Cataract in adults is the leading cause of blindness throughout the world. Although surgical treatments are already available, a greater understanding of the mechanism of cataract formation may help prevent the disease. Even just delaying the onset by six months would help reduce the societal cost and the personal suffering associated with the disease.

Twin studies in the UK and population studies in Australia have shown there is a genetic contribution to adult cataract. Childhood cataract is much less common, with an incidence of 2.2 per 10,000 in Australia. It was hoped that identifying the genes linked to childhood cataract would increase our understanding of adult cataracts as well. This research model was correct and results of research on a Tasmanian family with congenital cataracts, first described by Dr JB Hamilton in the 1930s, helped locate the region of the gene. Professor David Mackey's research team discovered a new gene region on chromosome 1, near a previous cataract gene location. Recent research discovered the gene was involved in both paediatric and adult cataracts. Other researchers



The lens is normally a clear structure which can change its shape to allow you to focus on near and distant objects. When the lens becomes cloudy it's called a cataract. Image taken from www.cvr.org.au

concurrently identified the *Epha2* gene as a major cause of childhood and adult cataract.

This example shows the importance of research work done in Tasmania and supported by the Clifford Craig Medical Research Trust in guiding international researchers to help identify this important gene.

Don't miss Prof Mackey's free talk on May 31. See back page for more.

## Spud Club supports our North West Medical Research Fund agenda

Staff at Ulverstone's Simplot factory have worked together to raise an amazing \$6164.75 for medical research projects on the North West Coast through their own initiative called Dollar Difference.

The Simplot staff social club is called The Spud Club and conducted a trivia night along with special days where staff on the production line were offered distinctive fluorescent yellow hair nets (instead of the usual white ones) on condition that they donated a gold coin toward the Dollar Difference campaign.

The Spud Club nominated the Clifford Craig Medical Research Trust because of the top quality research it can produce from what may seem like a small amount of money compared to other grants. At the Trust, we take special care to ensure that funds which come to us from the North West



community are generally applied to projects coming from or being conducted in the North West.

The Trust congratulates the Spud Club and especially volunteer Wendy McMullan for their incredible initiative, efforts and such an impressive result.

Spud Club Committee members Jan Roles, Carolyn Intveld, Spud Club President Lee Davis, CEO Michael Ferguson, Mrs Val Britton and Mrs Marlene Chequeer both from our Devonport Branch and Wendy Templar.

## The role of the biostatistician

Did you know that the Clifford Craig Medical Research Trust gives special support by funding a biostatistician? This important resource person is provided to, and forms part of, our dedicated research team. In his own words, Dr Iain Robertson outlines aspects of his role, which is made possible by donations toward our organisation.

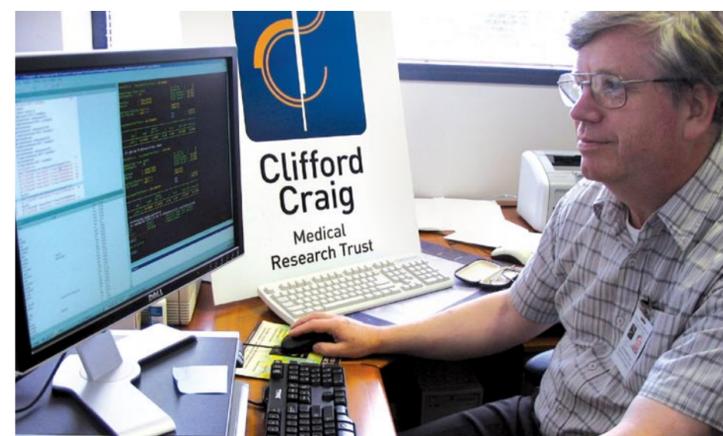
Medical research is a process of movement from ignorance through uncertainty and finally to clarity. The symptoms people bring to their doctors identify the problems for which the health care system must find solutions. Much has been discovered, but much uncertainty remains.

The Clifford Craig biostatistician's job is to assist our researchers to design their studies so that maximum benefit can be achieved from their work (and the inconvenience to the patients!) and to accurately describe the results of the study.

"Lies, damned lies and statistics" is the oft quoted comment. In fact, this highlights the lack of ethics of some people who use numbers to bolster their arguments, rather than the process of statistical analysis itself. The ethical task of a researcher is to accurately describe the results of their study, to get as much value from the effort and expense of the researcher and their patients - but not to mislead or exaggerate the findings.

Here are just a few examples of how appropriate use of statistics added value to important studies funded by the Clifford Craig Medical Research Trust:

- The LGH intensive care routine surveillance program for microbial colonisation of indwelling blood tubes, which can cause septicaemia, was able to be analysed and two clear messages were discovered: 1) that arterial lines previously thought to be less of an infection risk, compared to the central venous lines, were shown to be just as likely to be colonised, but were more likely to malfunction early before the colonisation was likely to occur; 2) that central venous lines placed in the veins below the collar-bone and sited in the intensive care unit were least likely to be colonised. These discoveries led to two publications last year in leading international intensive care journals, and in each



case, special attention was drawn to those articles by the editors of those journals.

- In the MINIMI study, the optimum amount of blood to be taken from the arterial lines of patients in the intensive care unit was measured using an innovative combination mathematical and statistical techniques, allowing the production of a calculator that recommends the minimum amount of blood that should be discarded to produce accurate results from laboratory tests of those blood samples avoiding draining too much blood from the multiple blood tests such patients must endure during their stay in ICU.
- In the D-Dimer in pregnancy study (which will finish data collection soon) innovative statistical analysis will allow a description of how this blood test (which detects breakdown products of blood clotting), and allow the examination of the relationship between the rise in levels of D-Dimers and the occurrence of clotting disorders in pregnancy or other pregnancy diseases such as pregnancy hypertension which produce secondary changes in clotting. This analysis may allow early detection of those diseases before overt symptoms appear.

## Recipe for Success by Simon Harris:

A packet of goals  
A lot of persistence  
A heaped tablespoon of research  
A spoonful of adaptability  
And a sprinkling of consistency

Mix it all with a handful of love, happiness and support, but the most important ingredient is of course, quality chocolate!



## Seventh annual Rainbow Ball

Our North West committee, the North West Medical Research Fund will hold the seventh annual Rainbow Ball on May 30, 2009 at the Burnie Civic Centre. This is renowned as an excellent night, 3 course meal, entertainment, expecting over 330 guests with record levels of donors and sponsors. For bookings contact Peter Mancell or his team on 6440 3555

## Launceston Professional Breakfast Series

We were delighted to welcome 97 people for breakfast nice and early for the first in the series for 2009. Simon Harris of the Tasmanian Chocolate Studio gave a fantastic talk "Recipe for Success" - about chocolate and succeeding in a new business venture. Our next breakfast on April 23 is one not to be missed, featuring one of Tasmania's leading businesswomen Keryn Nylander. Keryn is the chairman of B&E Ltd and together with husband Julian Alcorso is heavily involved in the Tasmanian wine industry. This breakfast series was commenced by the Trust as a service to our local business and professional community with the goal of offering fun, worthwhile professional development.



## There are many ways you can support Clifford Craig Medical Research Trust

Have you ever thought, "My gift won't make much difference"? If the answer is "yes", then let us pleasantly surprise you.

Your gift, however small or large, is important and valued by the Clifford Craig Medical Research Trust.

There are many ways you can show your support for the Trust, which will allow us to invest much-needed funds for medical research here in our region.

- One-off donation to our research fund.
- Monthly donation by credit card payment.
- Promise to give a "recurring gift" through regular instalments (eg \$1,000 per year) using our courtesy reminder service.
- Special appeal, allowing large gifts to fund specific new projects.
- Giving to one of our designated funds: North West Medical Research Fund; cancer research; heart research; child health research; gerontology research; or kidney research.
- Your Bequest, allowing your gift to be provided for in your Will. At the Trust we handle gifts by bequest with special sensitivity and show our gratitude by offering complimentary membership to the John Morris Society which meets for occasional luncheons in Launceston.

Remember, because our work is recognised by the Commonwealth Government, your gift is fully tax deductible.

Please consider what gift you can make, return the reply form in the envelope provided and allow us to contact you to express our appreciation for your generosity.

Thank you.