

under the microscope

2 Enduring generosity

3 Clinical test for cancer

4 Jeans for Genes

6 Committee Power

Emma's World - a little step

can be a big problem

Watching Emma Scollary, aged 3, playing on the lawn at home, you may not notice anything unusual. But when she runs toward the concrete path at the edge of the lawn she stops still - unable to take that next step that will simply move her onto a different surface. This problem with perception of depth and space is just one of the lesser problems experienced by Emma who has Williams syndrome (WS).

The more severe symptoms include cardiovascular problems, some musculoskeletal problems and mild mental disability. Along with this, WS children also have pixie-ish faces and a very chatty and friendly nature.

"Personality-wise Emma is a delight and as gutsy as they come," says her father Brendan, but he and his wife Kim have realised more than most people how a childhood genetic disorder affects lives, not only of the child but each member of the family. For this reason they have really got behind the Jeans for Genes Day campaign to raise funds for research, not only into WS, but also the many other genetic disorders that can affect children.

Continued page 3



Three year-old Emma Scollary's cheeky smile sees her family through the difficulties of living with Williams syndrome. Seen here with mum Kim.

Director's desk



Generosity that endures

In celebrating the outstanding success of our Jeans for Genes appeal over the past ten years we must also remember, with gratitude, the generosity of those who in providing resources from their estates have contributed towards the health and wellbeing of future generations of Australians. Over the 45 years of our existence we have received some 555 gifts from the estates of individuals from all walks of life. In this issue we recount the extraordinary story of the late Myrtle Thompson, whose deep interest in and involvement in the lives of the children in her extended family, despite having no children of her own, is reflected in her magnificent bequest to the Institute. Interestingly, but perhaps not surprisingly, seventy five percent of our benefactors were women and of the relatively few whose personal histories are known to us, most were strong minded, independent, quiet high achievers. The terms of their wills were clear and precise. Often several organisations, such as the CMRI, were designated as final beneficiaries and it was evident where they felt their social obligations for the future lay.

It is fair to say that the current financial strength of the Institute, based on its Capital Fund investment, ultimately lies with the generosity of its benefactors over the years. The Institute has the responsibility to ensure that their confidence in their final investment for future generations is never misplaced.

Professor Peter Rowe



Ross McFadyen, Yetty Ardill (left), and Peter Ardill (far right) with Professor Peter Rowe on their recent visit to CMRI to honour Myrtle Thompson's generous legacy.

An "iron lady" with a heart of gold

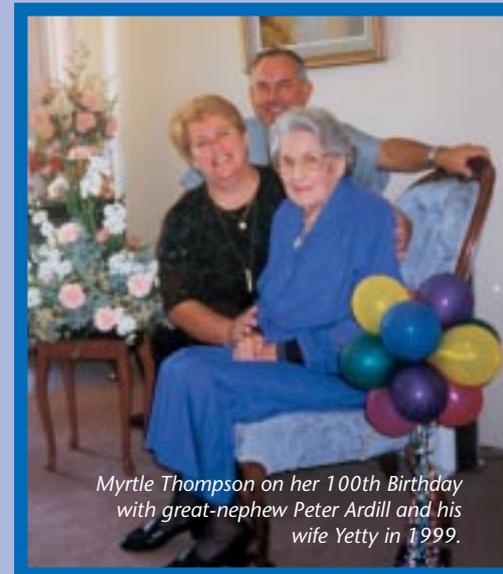
Miss Myrtle Thompson lived a very long and remarkable life, but perhaps her most enduring contribution is yet to come - Miss Thompson has made a bequest in excess of \$1.5million to CMRI that will provide an enormous benefit to the health of future generations of children.

Miss Thompson's great-nephew Peter Ardill, his wife Yetty and family friend and colleague, Ross McFadyen, recently came to CMRI to present the cheque and learn how Miss Thompson's legacy would help CMRI to search for the answers to childhood genetic disease.

Myrtle never had children of her own but took a close and loving interest in the children of her extended family right through to her great-great-nieces and nephews. Myrtle died in December 2000 at the grand age of 101, having lived a full life that spanned three centuries.

She was born in 1899 and as the smallest of six children she earned the affectionate family nickname of Dot, however, amongst her colleagues she was always called Miss Thompson or the "iron lady". Myrtle came from a family that was neither educated nor wealthy, however, her own brilliance at school propelled her into a lifelong career in stock broking. From walking barefoot to Lane Cove Primary School in Sydney, through to becoming Dux at Chatswood Superior Public School and earning a string of A's and B's at North Sydney Domestic Science School Myrtle understood the value of education.

She began work in 1917 to learn her trade from broker F.O. Furner and later worked with Lionel McFadyen and Co. The "iron lady" only retired at the age of 76 after more than 50 years with the Australian Stock Exchange!



Myrtle Thompson on her 100th Birthday with great-nephew Peter Ardill and his wife Yetty in 1999.

Myrtle Thompson never failed to read the Financial Report in the Herald before breakfast, but despite her dedication and passion for the business she still found time to create beautiful gardens with her "green thumb" and even run an orange orchard at Kurrajong Heights with her sister Ada. And of course she clearly had a passion and dedication to children, evidenced through her loving relationship with her many nieces and nephews and her legacy, through the CMRI, to the health of future generations of children.

Emma's World cont..

Williams syndrome affects about one child in 20,000 and occurs when a section of DNA on chromosome 7, up to 16 genes, is deleted. It is not known why this happens. Other than the gene Elastin, which causes the cardiovascular problems, it is not known which of the missing genes cause which symptoms.

'Even though we know current scientific discoveries will not help Emma, we were interested to find out what, if any, research was being done in Australia,' said Brendan.

Brendan and Kim were excited to learn of work by Dr Hardeman and her team in the Muscle Development Unit at CMRI. Dr Hardeman's team is investigating a gene called MusTRD, which lies in the deleted section of chromosome 7 and may account for some of the musculoskeletal problems that can be a part of WS. They discovered the gene four years ago when they were looking for the genes involved in growth and development of muscle cells and the genes that cause muscle disease.

"It gives us great encouragement to realise that there is study on Williams syndrome happening so close to home, and giving us the opportunity to further understand this syndrome that affects so very few people," said Brendan.

The Scollary's local running club will be supporting Jeans for Genes Day - www.kemblajoggers.org.au



CMRI research leads to clinical test for cancer prognosis

In just eight years, a fundamental discovery made by CMRI's Cancer Research Group looks like moving from concept to clinic. In the world of medical science, this is exceptionally rapid progress.

The first step in this story was their discovery in 1995 of another way cancer cells can escape from the normal limits on cell proliferation. Named ALT (for Alternative Lengthening of Telomeres), this is a mechanism used by some cancers to overcome the progressive erosion of telomeres (chromosome ends) that occurs when normal cells proliferate. Whereas the majority of cancers tested to date use a mechanism involving an enzyme called telomerase, a significant minority of cancers use the ALT mechanism.

Having discovered ALT the team was then the first to reveal in 2000, the nature of the ALT mechanism, a finding that received international acclaim and raised the prospect of eventually finding novel anti-cancer treatments that target this key aspect of cancer cells. They also discovered the presence of a structure inside the nuclei of ALT cells that can be used to test whether a cancer cell is using the ALT mechanism.

Most recently, a research group lead by Dr Janice Royds in Sheffield, UK, has collaborated with Dr Reddel to take these findings from the laboratory bench to the bedside. The study, carried out in Sheffield hospitals, showed that most of the longer term survivors of a common and lethal type of brain tumour, called glioblastoma multiforme, show the presence of the ALT mechanism in their tumour cells. This suggests that the ALT glioblastomas are biologically less aggressive. These results were published in the prestigious medical journal The Lancet in March this year.

"The presence or absence of ALT in these brain tumours appears to be the most accurate predictor of outcome yet found," said Dr Janice Royds. If the results are confirmed in further studies, a test for ALT may become a routine prognostic tool. Dr Royds, who now works in New Zealand, Dr Reddel and another collaborator on the study, Dr Antony Braithwaite, have just received funding to commence a major study in New Zealand to test this further.

Glioblastoma multiforme accounts for approximately 7% of all childhood brain tumours and more than half of all adult brain tumours.

Rotary award for Reddel

Dr Roger Reddel, Head of CMRI's Cancer Research Group, has received a great honour in the form of the Rotary Award for Vocational Excellence. The award was presented to Dr Reddel at the recent conference of International Rotary District 9680 held in Canberra. The award recognises Dr Reddel's "dedication and leadership in the drive to defeat cancer through understanding of its basic mechanisms and root causes."

A broad section of the community was represented at the Rotary conference. And for some it was particularly gratifying to see this recognition of Dr Reddel's huge contribution to the field of cancer research as they had worked closely with Roger either through fundraising or at a professional level. They included members of the Judith Hyam Trust Fund for Cancer Research and the Cancer Council of NSW, who have generously supported Roger's work over several years, and Professor Geoffrey Kellerman from John Hunter Hospital in Newcastle.



Harvey Bromwich (Left), President of the Rotary Club of Glenhaven nominated Dr Reddel (right) for the Rotary Award for Vocational Excellence.

Happy 10th Birthday Jeans for Genes®

On August 1, 2003 we celebrate our 10th Jeans for Genes Day! And what a fantastic 10 years it has been – the Australian public have raised over \$23 million in that time.

The first Jeans for Genes Day was held in Australia on August 9, 1994 and raised \$250,000. We have come a long way since then, but there is still a long way to go to find the answers to childhood genetic disease. Our goal for 2003 is to raise over \$4 million, and we will need your help to do it!

You can support us by becoming a Genie (someone who collects donations and sells badges at work or school), attending the events shown here, buying a badge, or really get into the Jeans for Genes spirit with a t-shirt to go with your jeans!

This year the \$5 helix jeans badge has taken on a celebratory sparkle and you can also buy a cool \$3 'Cosmic Baby' patch – Aussie designer, Jeremy, generously donated his skills for this one. The \$10 badge this year revisits the beautiful jeans of Cathy Freeman, painted by Bronwyn Bancroft, from our 1995 Art Auction.

You can also buy badges from our wonderful network of retail supporters, including major jeans outlets (see our website for a complete list).



Channel 7 stars have fun and show their support. L-R Ben Hewett (Big Arvo), Jenni Baird (All Saints) holding Oliver Mann, Thomas Simeon, Mel Symons (Ground Force) and Georgie Shew (Always Greener). All are wearing Jeans for Genes apparel.



\$5 Badge



\$3 Patch



\$10 Badge

Superstars Unzipped A Jeans for Genes Retrospective

As part of our 10th birthday celebrations we are holding a Retrospective Exhibition of painted celebrity jeans from earlier years. Some jeans capture the essence of the celebrity, others the essence of the artists personal style. Justin Miller of Sotheby's has generously given his time to select the jeans which will be exhibited in Melbourne at The Arts Centre, and in Sydney at the Town Hall, the Sydney Opera House and The Arthouse Hotel.

The exhibition will feature the jeans of Gianni Versace, Elizabeth Taylor, Cathy Freeman, Ian Thorpe and John Travolta, to name a few.

Superstars Unzipped is proudly sponsored by Jeans West.

Associate sponsors include Avant Card and the exhibition spaces below.

**The Arts Centre,
Melbourne**
100 St Kilda Road
4 June – 27 June

**The Arthouse Hotel,
Sydney**
275 Pitt Street
7 July – 27 July
(Open to guests 18
years and over only)

Sydney Town Hall
Kent Street entrance
16 July - 3 August

Sydney Opera House
Studio Foyer
Bennelong Point
28 July - 15 August
(Open to Opera House
Patrons only)

Jean Look 2003 Competition

Are you interested in winning great prizes and an introduction to a model agency? Well here is your chance. All you have to do is fill out the entry form for Jean Look 2003, which is located at www.jeans4genes.com.au, and send in your entry fee and a recent photograph. 300 people will be chosen to enter the finals, which will be held at Indooroopilly Shopping Centre, QLD, Castle Hill Towers Shopping Centre, NSW and Chadstone Shopping Centre, VIC.

Re-Designed Jeans 2003

Jeans Look will be held in conjunction with the TAFE Redesigned Jeans competition, where TAFE students display wonderful jeans they have designed. You can help to select the winning designs too. There will be spectacular fashion parades and presentations by dancers from selected local dance institutes.

Jeans for Genes Art Auction 2003

The Jeans for Genes Art Auction traditionally marks the launch of Jeans for Genes Day, and of course, this year the elegant gala dinner will take on a celebratory theme. The event will be held on Thursday 24 July at Dockside one of Sydney's most dazzling locations with panoramic views of Cockle Bay Wharf.

Celebrity Jeans from around the world will be auctioned at the dinner, including Michael Jordan's and Baz Lurhman's jeans. All the jeans will be beautifully painted on by our ever-generous Australian artists. And the gala raffle, drawn on the night, offers the chance to win a fabulous all-inclusive holiday for two to Los Angeles, flying business class and staying at The Leading Hotels of the World.

Dinner tickets - \$200,
or a Table of Ten - \$1800
For bookings call Kelly on: 02 9687 2800

The Art Auction is proudly sponsored by Sydney Prestige Properties.

Want to find out more?

Call Toll Free 1800 677 260
Visit www.jeans4genes.com.au
or Email genie@jeans4genes.com.au

Workplace Giving now even easier!

Recent changes made by the Tax Office have made it even easier for people to donate to charities through their pay.

The Tax Office and the Australian Charities Fund worked together to create workplace giving programmes that will allow donations to be pooled from many employees and sent directly to eligible charities, such as CMRI, in a single transaction. This will provide a significant saving in administrative costs to charities and the employees will receive an immediate tax benefit. Employees can nominate their preferred charity from a selection provided by their employer.

If you would like to find out how you can help CMRI through this scheme, please call Stephen Ryall on 02 9687 2800 or visit the Australian Tax Office website at www.ato.gov.au.



Honours student Nicole Vlahovich receiving her Scholarship award from Blacktown City Mayor Alan Pendleton

Local honour for Honours Student

Every year, as part of its commitment to train the next generation of young scientists, the CMRI welcomes a clutch of University students who will complete their Honours degree projects in the Institute's laboratories. This year Dr Peter Jeffrey, Head of Developmental Neurobiology, picked a winner in Nicole Vlahovich, who's potential has been recognised by her local Blacktown City Council.

Each year the Council awards eight tertiary scholarships to support promising students. "It is a big compliment to be recognised in this way, and the award will really lighten the financial load," Nicole said.

Nicole is studying for a BSc in Biomedical Science at the University of Western Sydney's Hawkesbury campus. Her Honours project is aimed at identifying the protein partners that work together with the Doublecortin protein to help control brain development.

A neuron stained to show the doublecortin protein is shown in the 'O' on the front cover. Photograph by fellow honours student Macarena Rodriguez.



Prevention is better than cure...

And the key to prevention lies in research.
It's as simple as that!

There are over 10,000 known genetic disorders. To correct these and many other disorders research is needed to find the causes.

Here is my gift:

\$100 \$75 \$50 \$25

Other \$

Please find enclosed my cheque

Please charge my credit card:

credit card number

cardholder's name

cardholder's signature

expiry date

name

address

postcode

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Please send me:

- More information about CMRI
- Christmas catalogue
- Information on my nearest fundraising committee
- An annual report
- Information on how to make a bequest
- Please update your records for my contact details

All donations are tax deductible



I would like to join the Automatic Credit Card Donor Program

Automatic Direct Debit Amount to be donated:

\$

Please complete the Credit Card Details at left.

Frequency: Monthly Quarterly Other

Commencement Date:

Please complete this coupon, enclose it with your donation in the envelope provided and mail to:

Children's Medical Research Institute
Locked Bag 23, Wentworthville NSW 2145 Australia
Tel 02 9687 2800 Fax 02 9893 9166

Thanks for your help.



Clockwise from far left:

Len Gauci, Secretary of the Rotary Club of Glenhaven proudly presents the proceeds of the Charity Golf Day to CMRI's Dr Peter Jeffrey;

Guest speaker Joanna Savill of SBS (left) with CMRI's Jennifer Philps and Susie Zicat, President of the Ku-ring-gai Committee, at the annual luncheon;

Thumbelina Committee members show off the latest fashions from Jan Jolly at their annual luncheon, left to right, Jean Lever, Moira Wood, Lynne Wilson, Robbie Nicholson, Lesley Pitts and An Shenstone with President Naomi Stokes (seated);

Jessamy gets a 'Gone with the Wind' addition to her wardrobe, authentic down to the hooped petticoat and pantaloons, from Mrs Melissa McWhite of South Carolina, USA.



Committee Power

Happy 20th Birthday - Wagga Wagga Committee

More than 100 people gathered together to meet with old friends, reminisce and celebrate two decades of fundraising fun. The celebratory lunch was attended by CMRI Director Professor Peter Rowe who congratulated the committee on their wonderful efforts to raise over \$400,000 over the past 20 years.

Strathfield Committee

'A Special Luncheon' was enjoyed with glorious views of the Parramatta River at Dede's Restaurant in the Sydney Rowing Club. Guest speaker, Ita Buttrose AO OBE, former editor of Women's Weekly, entertained all with tales of her life as a journalist. Her wit, natural style and practical approach to life left everyone feeling uplifted.

Thumbelina Committee

A delicious luncheon was enjoyed by a sell out crowd at the annual Fashion Show. The catwalk display of the winter fashions by Jan Jolly received a warm welcome, due in no small part to the fun being had by the wonderful models – Thumbelina's very own Committee ladies!

Ku-ring-gai Committee

SBS food writer and commentator, Joanna Savill, was guest speaker at the annual lunch at Killara Golf Club. Joanna entertained nearly 200 guests with her world-wide experiences of how the ceremony of cooking and sharing meals can form great bonds, above and beyond language.

Rotary Club of Strathfield

Nearly 500 people sat down to a splendid dinner at La Montage and danced the night away at the Children's Charity Gala Night. Thank you to Rotary Club of Strathfield for their handsome donation.

Rotary Club of Glenhaven

Congratulations to the Club on their magnificent efforts to raise a stunning \$15,000 from their Charity Golf Day. Thank you to the Castle Hill Golf Club who were most generous with their sponsorship of the event.

Jessamy's travels

Jessamy is a handmade doll who is travelling the world to acquire an international wardrobe. She was sent on her way by Robyn Corbett of Brisbane who meets via the Internet with a group of dedicated sewers in the USA, New Zealand, Australia and UK to swap sewing and family stories. Jessamy will be visiting the members of this group to be fitted for her new wardrobe and along the way she is writing her journal and collecting souvenirs, photos and memorabilia. So far Jessamy has been to the USA and the UK and is now spending time in New Zealand. At the end of her trip Jessamy will be set to work to raise funds for CMRI. Bon voyage!

Apologies to tireless charity worker, Mrs Pat Wikner, whose name was incorrectly spelled in the previous issue of Under the Microscope. Many thanks to Mrs Wikner for her wonderful efforts in support of CMRI.

Dates for your Diary

Northern Beaches Committee

Jeans for Genes Country and Western Ball, St Ives Showground, 1 August

Port Hacking Committee

Denim Theme Bush Dance and auction, Pavilion in Gunnamatta Park, Cronulla, 1 August. Call Jennifer 02 9687 2800

Thumbelina Committee

'A Taste of France' - Grand Raffle and Cabaret Supper – Win a trip to France for two staying in 5 star luxury hotels courtesy of The Leading Hotels of the World. Tickets will be drawn at a Parisian Café style supper, with cabaret entertainment from Anna Weaving et 'Ses Deux Amis', Saturday 26 July at Pavilion on the Park, Art Gallery Rd, Sydney. For Raffle or Supper tickets call Lesley or Ossie Pitts on 02 9417 1160

Adelaide Committee

The inaugural event of the new Committee will be a Masquerade Charity Ball with a three-course dinner, entertainment from Planet Square and special guest Kelly Nestor from Channel 10 News, 28 June, The Semaphore Palais, Semaphore. Call 08 8341 6333 for tickets.