

# under the microscope

## Features

Support for Bright Sparks	2
Rett Syndrome	3
Jeans for Genes	4
Liver Disease Therapy	5
Dates for your Diary	6

## Today's scientists for tomorrow's children

The Children's Medical Research Institute (CMRI) is an independent organisation committed to unlocking the mysteries of disease. Our scientists investigate conditions such as birth defects, cancer, and epilepsy. Our philosophy is that major advances in prevention and treatment come from research into the fundamental processes of life. Our work is made possible by our community of supporters and Jeans for Genes®.

50 YEARS OF  
**DISCOVERY**  
CHILDREN'S MEDICAL RESEARCH INSTITUTE

Produced by the Fundraising & Community Relations Department, Children's Medical Research Institute

Locked Bag 23  
Wentworthville NSW 2145  
Tel 02 9687 2800  
Fax 02 9687 2120  
Freecall 1800 GENIES (436 437)  
Email [info@cmri.org.au](mailto:info@cmri.org.au)  
Website [www.cmri.org.au](http://www.cmri.org.au)

© CMRI 2008



## A massive *denimstration* of support in 2008

From Hobart to Darwin and Perth to Sydney, Jeans for Genes Day Genies were across the nation on Friday August 1. The weather was perfect for the thousands of Genies selling badges and merchandise from 6am on the streets, at stations and in shopping centres.

Thousands of schools and businesses registered for the day and showed their support by wearing their jeans and giving a donation. Many organised events in their local area with even our politicians getting on board. We were inundated with online donations too this year, which was fabulous.

With thirty live music venues and over sixty musicians playing for the Jeans for Genes campaign, it was no surprise that Jamm for Genes 2008 was also a rocking success.

*Little genies Ruby 3, Grace 4, and Phoebe Hamilton 2, from the Wagga region  
Photograph kindly supplied by The Daily Advertiser/Riverina Media Group*

# Director's desk



Friends of the Children's Medical Research Institute very often tell us that a major reason they support us financially and in so many other ways is that we are an **independent** research organisation. We are independent of government. We choose the direction of our own research. We have an independent Board, and even made some changes to the CMRI Constitution recently to make it clearer how completely independent we are.

But at the same time we are **connected**. We work together with the Children's Hospital at Westmead, with Westmead Research Hub, with the University of Sydney, and with a wide range of outstanding researchers throughout Australia and around the globe to help us achieve the best possible results.

This newsletter contains an article about the development of new drugs for epilepsy. CMRI's independence has allowed us to support Professor Robinson's research in this area for a decade, regardless of the decisions of external funding agencies. The success of this research has also been critically dependent on a long-term partnership with the University of Newcastle. We are expecting huge benefits for epilepsy sufferers from this work.

Independence.  
Global connectedness.  
We treasure them both.

Professor Roger Reddel

# Vital support for bright sparks

Eight bright sparks at the Children's Medical Research Institute (CMRI) are particularly fortunate to have behind them generous teams and benefactors with a common desire to change the future of child health.

In the mid 1900s, Australian scientist Sir Norman Gregg made significant contributions to children's health worldwide with his work on the link between maternal rubella infection and birth defects. A generation later Sheila Gregg, sharing her father's passion for child health, left a bequest that allowed CMRI to re-establish the Sir Norman Gregg fellowship. Dr YongJuan Chen is awarded this fellowship for research into genetic eye disorders such as cataracts and anophthalmia (no eyes).

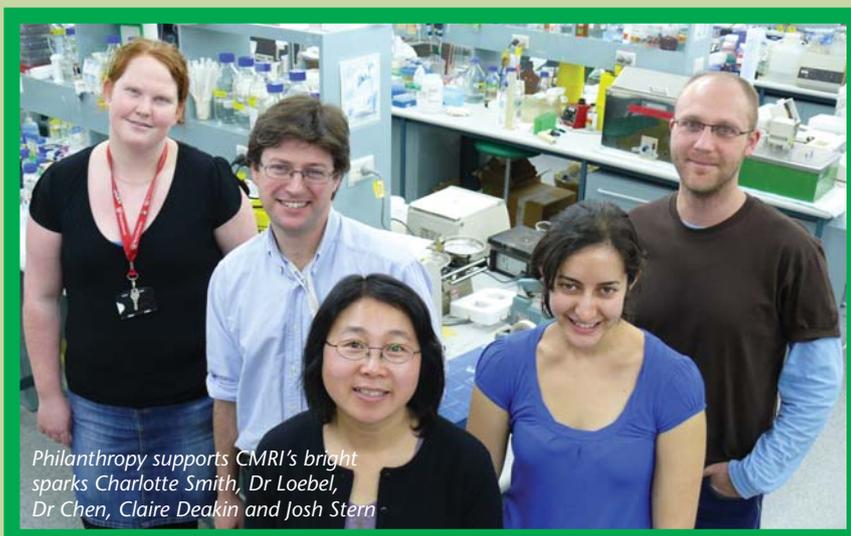
Judith Hyam, former Lady Mayoress of Parramatta, passed away in 1990 from cancer. Soon after, a small band of friends established a cancer research trust fund in her memory and in 2007 they celebrated \$1 million of funds raised. This year two Judith Hyam Memorial scholarships are awarded to PhD students Josh Stern and Zeenia Kaul who are studying the mechanisms of cancer.

Claire Yass, the daughter of a successful fabric manufacturer, had a particular drive to improve the lives of children and when she passed away in 1995 made a bequest to the CMRI. A scholarship in her honour is awarded to Claire Deakin who is undertaking a PhD to create viruses that can be used to treat the genetic immune disorder "boy in the bubble" disease.

The Douglas and Lola Douglas Scholarships are awarded to LingShan Chan and Charlotte Smith who are both beginning their PhDs. LingShan and Charlotte are investigating proteins that may be involved in epilepsy and cancer.

The Denise Higgins Scholar is Allison Dane whose PhD studies are focussed on developing new gene delivery techniques to treat genetic liver conditions.

Kimberly-Clark Australia have been partners with the CMRI since 1994. A major component of their support is the Kimberly-Clark Australia Fellowship, which is awarded to Dr David Loebel. Dr Loebel is identifying the genes involved in early embryonic development, which can cause defects in the liver, pancreas and intestines of newborn babies.



Philanthropy supports CMRI's bright sparks Charlotte Smith, Dr Loebel, Dr Chen, Claire Deakin and Josh Stern

# Our Supporters



Earle Page College's annual Fashion Extravaganza was very entertaining with college Headmaster David Ward beating Armidale Mayor, Cr Peter Ducat, in a push-up competition. But Blake Shuttleworth, head of the 2007 fundraising committee, beat them both and still had the strength to present a cheque for \$30,000 to the CMRI.

*Stuart Croft gives an outrageous performance on the catwalk at the Earle Page College Fashion Extravaganza*

Twenty original photographs by CMRI scientists were exhibited at the Arthouse Hotel in August. Printing and framing of the artworks was generously supplied by Sun Studios Australia and the Art Scene.



The Central Coast Creative Craft Group, established in 1980, sell their unique, quality, hand-made crafts on the second Saturday of every month at the Gosford City Arts Centre. Since they began supporting the CMRI, the Group has donated over \$60,000.

*Members of the Central Coast Creative Craft Group Vicki Gleeson, Gwen James, and Jean Miller*



*Samantha, Kath, Ella and Dave Furney*

Kath and Dave's 4 year old daughter Ella was born with a liver hemangioma, a large vascular tumour that needed to be removed. Inspired by Ella, Kath ran in the Gold Coast Marathon to raise money for research that can prevent childhood illness. Thank you to all the supporters and especially to Kath, who has raised almost \$20,000 for the CMRI.

# Possible treatment for Rett Syndrome

Rett syndrome, a devastating genetic brain development disorder that primarily affects young girls, may be helped by a simple treatment for the first time.

Using a mouse model of Rett syndrome developed by the Children's Medical Research Institute (CMRI) in Sydney, researchers from the Howard Florey Institute in Melbourne found that giving the mice a range of toys to stimulate mental activity greatly delayed the onset and reduced the severity of coordination and movement problems.

"We also found that a brain chemical called BDNF, which plays a role in the birth and survival of new neurons as well as modifying connections in the brain, was at similar levels in both normal mice and the Rett syndrome mice that had been given toys," says Prof Patrick Tam, head of the CMRI team.

"The next step is for us to look at the effects of environmental enrichment on anxiety and cognition in the mice, as these are common problems in Rett syndrome," said Prof Tam.

"This discovery shows that gene-environment interactions may be important for all brain diseases" said Prof Tam.

Prof John Christodoulou from the Children's Hospital at Westmead also contributed his clinical expertise to the team.

This research was published in the *European Journal of Neuroscience* and is the first published paper on the effects of environmental enrichment in a Rett syndrome model.

*The photo in the "O" on the front cover shows the 'Purkinje' brain cells from a mouse with Rett syndrome. Typically these cells show less branching in the brains of girls with Rett syndrome.*

*Prof Patrick Tam, Dr Rania Kairouz, Abid Mohamedali and Dr Greg Pelka, part of the team of researchers who may have found a first treatment for a genetic mental disorder*



# Jeans for Genes®

The Jeans for Genes Denim Gold Dinner, proudly sponsored by Toyota Financial Services, was attended by over 400 people in July. Key celebrity supporters included pop star Ricki-Lee Coulter – the face of Jeans for Genes, Chris Bath from Channel 7, and Ray Hadley 2GB radio host and auctioneer on the night. The highest selling jeans were from the band *The Police*, painted by Alison Coulhurst, and sold for \$22,000. Thank you to The Leading Hotels of the World, Vietnam Airlines and the Sample Group for donating exciting travel and accommodation prizes, and to House of Fraser for donating a beautiful 18ct gold and diamond helix necklace.

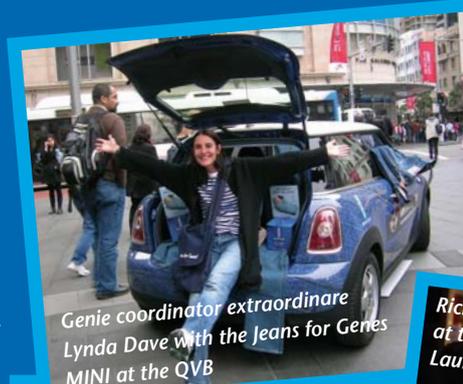
Budding designers of fashion and furniture made denim creations to the theme of "50 years of celebration" for our Do it with Denim Design Competition. Congratulations to Dragana Tepsa of St George TAFE NSW for the fashion outfit and to Jacob Wong of Lidcombe TAFE NSW for the furniture piece. For more information go to [www.doitwithdenim.org.au](http://www.doitwithdenim.org.au)

Jamm for Genes events included an office-band performance in the Sydney office of Allens Arthur Robinson, a massive line-up of 15 country music artists including *The McClymonts* held gig goes enthralled at the Canterbury-Hurlstone Park RSL, with the support of Hotsource. By far the most futuristic and unique Jamm event to date was the virtual Jamm for Genes online, put together by Matthew Davies aka "Oh My Kidd" from *The Pocket*. Thank you to everyone who was involved. Visit [www.jammforgenes.org.au](http://www.jammforgenes.org.au) for all the stories behind this year's most successful gigs.

Special thanks must go to our 28 official retailers and Gene-uine Deal supporters. Their ongoing support through the month of July enables customers to buy our merchandise or support us through a percentage of their sales. We would also like to thank the MINI Garage Sydney and Decently Exposed for providing us with a denim-look MINI which was a fabulous talking point with media and the public.

On behalf of the staff and scientists at the Children's Medical Research Institute, the Jeans for Genes team would like to thank everyone who supported this year's event. Your support is very important for us to continue our on-going research into children's diseases.

Jeans for Genes is a major fundraiser of the Children's Medical Research Institute



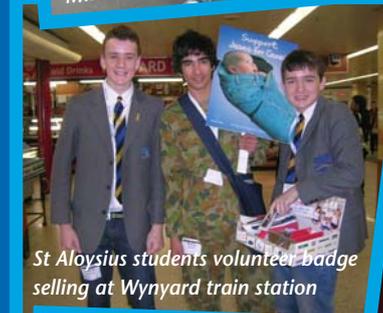
Genie coordinator extraordinaire Lynda Dave with the Jeans for Genes MINI at the QVB



The Pocket online Jamm for Genes gig



Ricki-Lee Coulter and Jackie Facaris at the Jeans for Genes Day Media Launch



St Aloysius students volunteer badge selling at Wynyard train station



Ray Hadley taking the winning bid for The Police jeans at the Denim Gold Dinner



Volunteer Jack Brewer demonstrating at Hyde Park station



Model Sahra Tohow on the catwalk in the Do it With Denim winning fashion piece by Dragana Tepsa



Volunteers from Sydney Girls High School with Ricki-Lee selling badges at Pitt St Mall



Rare Spares denimning they care on Jeans for Genes Day





# Committee Power

**The Mothers' Day Luncheon** held at the Hilton Hotel was a spectacular success with Georgie Gardner as guest of honour and the debonair John Mangos as MC in particularly good form. Keep Friday May 8, 2009 in your diary for next year's secret guest.

**The Strathfield Committee's** anniversary dinner for 170 people at 'La Mirage' was a golden way to celebrate our 50 years with a splendid dinner, music and dancing. Professor Reddel gave a thoughtful address and Stephen Ryall acted as MC.

**Coffs Harbour Coast Committee's inaugural Gala Dinner** was an unequivocal success thanks to the great organisation by the committee. Over \$18,000 was raised.

Children were spellbound and adults mystified when the best of Australia's magicians performed at the Glen St Theatre. Over \$20,000 magically appeared after a great deal of excellent organisation by **Thumbelina Committee**.

Four unique quilts have been donated by **Turramurra Quilters**. To purchase raffle tickets and enter the draw to win a quilt, contact Kathleen Stokes-McKeon on 02 9416 2413.

50 years of fund-raising was celebrated by the **Kangaroo Valley Committee's Anniversary Dinner** with a Jeans for Genes theme. Old friends, long time supporters and the local community packed out the venue and a wonderful evening was had by all.

**Port Hacking Committee** organised a Chinese Banquet on 8/8/8 in conjunction with the Opening Ceremony of the Olympic Games. Ex-Olympians reminisced and the yabbee marathon raised gales of laughter and donations.

# Dates for your Diary

**Saturday 20 September** Jeans for Genes Race Day at Rosehill Race Course. Enjoy a spectacular day at the races with prizes, raffles etc. Everyone is a winner! Contact Patti Payne 0418 867 784.

**Monday 22 September** Charity Golf Day at Cronulla Golf Club. Shotgun start at 12:30pm, get a mixed team together. Contact Jenny Degnan 02 9523 0268.

**Saturday 18 October** "The Super Supremes" in the Pavilion, Quirindi. Contact Pam Lord 02 6747 3917.

**Friday 31 October** Luncheon with Crime Writer Michael Rowbotham at the Monash Country Club, Powderworks Road. Contact Maureen Botha 0402 021 739.

**Friday 7 and Saturday 8 October** The annual Wagga Christmas Fair, a feast of stalls full of Christmas goodies at the Murrumbidgee Turf Club.

**Friday 7 – Sunday 8 November** Gerringong Quilt Show at the Gerringong Town Hall. Grand opening 6pm Friday.

**Wednesday 12 November** The Canberra Luncheon, at The Lodge is bound to be spectacular. Limited numbers so book early. Contact Celia McKew 02 6273 7977.

*Top to bottom:*

*Mrs Tanny Mangos, John Mangos with 18 month old son Kostas, and Georgie Gardner at the Hills Committee Mothers' Day Luncheon;*

*Trevor and Joyce Thiele, Prof Reddel and Bruce Scott-Smith at 'La Mirage' for the Strathfield Committee's 50th anniversary dinner;*

*(L to R) CMRI's Jennifer Philps with Coffs Harbour Coast Committee members Christine Harding, Julie Brighton, and President Rachel Howell;*

*Michele and John Seckold, organisers of the Thumbelina Committee's "Magic at the Glen";*

*Quilters (back row) Jessie McKinlay, Eleanor Buckle, Judy Eastman and Elizabeth Sinclair, with CMRI's Jennifer Philps and Thumbelina Committee's Naomi Stokes in front;*

*Members of the Kangaroo Valley Committee celebrating 50 years of fundraising.*