Donation Form

If you'd like to make a donation to the NNU, please fill out this form and post or fax your details, thank you!

The dedication NNU team and concerned parents are working together to create a world-class facility within the next 3 to 5 years that provides:

- Additional intensive care beds
- Additional ventilators
- Better facilities for families of admitted babies
- More floor space
- Research facilities to enhance and improve methods of treatment

The are several options outlined to help us realise the vision of creating a new and improved facility for Victoria's future babies and their families.

We wish you wish your family well, and hope to hear from you soon.

You can make a BIG difference to a lot of small people.

Your donation to the Royal Children's Hospital Neonatal Unit is greatly appreciated

Method of payment (please tick)

☐ Cheque ☐ Credit

***Please make cheque payable to A Celebration of Life**

Credit Card details

☐ Visa ☐ Bankcard ☐ Mastercard ☐ Amex

☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐

Expiry date ☐☐ / ☐☐ Total amount $

Cardholders name

Cardholder signature

Personal Details for Tax Receipt (plaese print)

Name

Postal Address

Phone

Please forward to
to A Celebration of Life

C/-Royal Children s Hospital Foundation
Flemington Rd, Parkville, Vic, 3052
Ph 9345 4510 **Email** donna.aranyi@rch.org.au **Fax** 9345 6900

All donations to the Neonatal Unit at The Royal Children's Hospital are greatly appreciated. Donations over $2 are fully tax deductible.
' A Celebration of Life' is the sole fundraising entity specifically established to support the Neonatal Unit at the The Royal Children's Hospital, Melbourne.

neonatal news

the royal children's hospital, melbourne

ROYAL CHILDREN'S HOSPITAL

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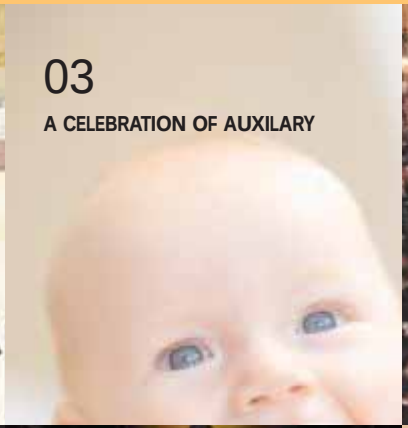

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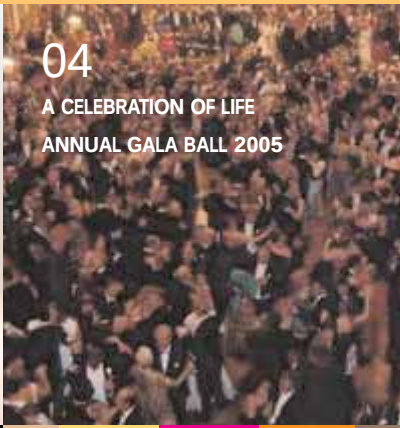

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'A CELEBRATION OF LIFE' OUR HISTORY

A Celebration of Life was created in 2002 by parents Chris and Sophie Clarke.

Their daughter, Madeleine, was born with a severe case of Strep B and given only a 1% chance of survival when admitted to the Neonatal Unit (NNU) at The Royal Children's Hospital, Melbourne. Maddie defied the odds, thanks to the skill and dedication of the Neonatal Medical Team and is now a beautiful and happy three year old and big sister to brother James.

On honor of their gratitude to the NNU, A Celebration of Life was created by Chris and Sophie to assist specifically with the fundraising requirements of the NNU and hopefully make possible the equipment, resources and research that helps to make it one of the premier NNU's in Australia, if not the world.

The major fundraising event for the NNU is the Annual Celebration of Life Gala Ball. Now in its fourth year, this event has helped to raise thousands of life saving dollars for the NNU.

A Celebration of Life is recognized as a fundraising entity for the NNU at The Royal Children's Hospital, Melbourne and comprises a Committee consisting of NNU & RCH staff, parents and supporters. The NNU is deeply grateful to the Clarke Family for their commitment, dedication and invaluable support, which are ongoing.

A Celebration of Life is more than just a namesake – it is a statement of truth shared by the NNU team and all those it exist to support today and for the future.

A WORD FROM OUR CHAIRMAN - Phillip Grant

My involvement with the Neonatal Unit of the Royal Children's Hospital began when my clients, Chris and Sophie Clarke established "A Celebration of Life".

Being the proud father of two young healthy children, my continued and ongoing commitment to such a worthwhile cause remains imperative to me.

I know how important it is for all of us to have healthy, vital children. As parents they are our most precious and cherished gift. All parents fear complications that may arise from birthing - t is vital that this amazing service and all its highly trained staff and unparalleled expertise, remains available to anyone needing it.

Together with the rest of the "A Celebration of Life" Committee, my involvement remains committed to ensuring the unsurpassed facilities and resources of the Royal Children's Hospital Neonatal Unit are funded to the highest level possible.

Contributing to "A Celebration of Life" is not a question of why I am involved, but why not? To me, supporting "A Celebration of Life" is not a choice; it's my own non-negotiable commitment to ensuring excellence in Neonatal Child Care.

Wishing you and your families a very peaceful, happy, healthy and successful 2006.

HOW WE ARE DIFFERENT FROM OTHER NEONATAL INTENSIVE CARE UNITS

The Royal Children's Hospital Neonatal Unit provides highly specialized care to the sickest newborn infants from all over Australia and the Pacific Islands.

It supports and treats a UNIQUE group of babies with UNIQUE needs and is the only Unit of its kind that can assist babies who require treatments not available at other Neonatal Units in Victoria and in some cases, Australia.

Each year

- Over 600 babies are transferred to the NNU by the Newborn Emergency Transport Service (NETS).
- Over 40% of the babies undergo major surgery.
- Over 300 babies receive artificial ventilation via mechanical respirators.
- Most of the babies are seen by specialist doctors from the many medical disciplines available only at the Royal Children's Hospital – Melbourne.
- The highly complex pediatric investigative services including MRI, CT scans, digital angiography, fluoroscopy, endoscopy, electroencephalography, metabolic and laboratory tests, echocardiography and cardiac catheter are not available at other hospitals.

OUR ACHIEVEMENTS

In the last decade there have been many achievements in the care given to babies in the Royal Children's Hospital Neonatal Unit.

Some of the highlights are:

High frequency oscillatory ventilation (HFOV) is a highly sophisticated form of artificial respiration in which very sick babies are ventilated at breathing rates of up to 900 breaths per minute. The Neonatal Unit was the first Intensive Care Unit in Australia to introduce this technology in 1992 and this was the result of a careful and strategic research and training programme. We now run training courses for other intensive care units around the country.

We are the only intensive care unit in the country that employs High Frequency Jet Ventilation. This technology is a life saver for babies with the most severe forms of lung disease.

Together with our colleagues at the Royal Melbourne Hospital we have led the way in the management of a rare form of cerebral aneurysm
(an abnormality of arteries and veins in and surrounding the brain) by interventional radiology thus providing both survival and favorable outcomes to many babies who in other centres would have died.

Our craniofacial surgeons have pioneered a form of jaw lengthening operations for babies born with facial abnormalities such as Pierre Robin Sequence. This surgery has produced stunningly successful outcomes and revolutionized the care of these conditions.

Together with our Neurology colleagues we are investigating ways to improve the outcomes for the sickest babies including those with Post Haemorphragic Ventricular Dilation (commonly occurring in very premature babies) and have pioneered the use of MRI technology and bedside EEG monitoring in a Neonatal environment.

We provide the best outcomes in the country for a condition called Congenital Diaphragmatic Hernia. This is where a baby is born with a large hole in the diaphragm resulting in the intestines being present in the chest thus compressing the lungs. The condition requires the combined skills of neonatologists, nurses, cardiologists and surgeons. Our outcomes for this previously lethal condition are second to none in the world. Survival of this condition provides a normal life for these babies.

Our nursing staff has pioneered the management and prevention of pain in sick babies and has led the way in surgical wound care. The nursing staff is continuing to provide that best care to sick infants round the clock every day of the year.

We have recently appointed the first Professor of Neonatal Nursing Research in Australia.

Our Music Therapist is looking at ways to improve the quality of life on the Intensive Care Unit for the sick babies.

We provide a home apnea monitoring service for babies who are at risk of and for their parents who are worried about Sudden Infant Death Syndrome.

Most of the advances over the years have been made possible by the very strong commitment to Research and Education by all members of the Neonatal Unit. The best care of the sickest infants cannot occur without the valuable achievements provided through Research and Education.

ROYAL CHILDREN'S HOSPITAL NEONATAL UNIT VISION

The Neonatal Unit will become the benchmark of world's best practice for the care of the sickest newborn babies and their families.

ROYAL CHILDREN'S HOSPITAL NEONATAL UNIT MISSION

The Neonatal Unit will improve the health outcomes for newborn babies by:

- Providing the best and full range of tertiary and quaternary specialist care for the sickest babies in Australia and Internationally
- Providing undergraduate and postgraduate education in medical, nursing and allied health disciplines
- Initiating and conducting research to enhance the clinical care of our patients
- Providing information, health promotion, resources, education and advocacy for the families of our patients

In order to maintain our mission and achieve our vision we need to:

- Attract and retain the best medical nursing and allied health professional staff
- Establish world's best practice medical and nursing care of sick newborn infants
- Acquire and maintain essential and cutting edge equipment
- Improve access to and availability of newborn intensive care beds
- Improve the space and the environment in the clinical areas
- Improve the facilities for the families o the babies
- Improve and maintain the infrastructure and facilities for research
- Improve and maintain the infrastructure and facilities for education
- Update and improve the Neonatal Unit website

Funds raised are used by the Royal Children's Hospital Neonatal Unit to:

1 Purchase and maintain essential and cutting edge equipment in order to provide the best possible care for the babies

2 Improve the bed availability in the Neonatal Unit by providing and equipping additional intensive care cots.

3 Assist in building a brand new Neonatal Unit which will provide world's best facilities and environment for the sickest babies and their families.

4 Support ongoing research and education in the Neonatal Unit.

02 UNIT MANAGER'S REPORT

SHERI WALDRON

Greetings and welcome to the first 2006 edition of NNU News.

The NNU has been a very busy place over the holiday season and whilst the care and health of our babies and families are always our first priority, we have also had to consider the upcoming Redevelopment of the Neonatal Unit.

Fifteen years ago, the Neonatal Unit moved to the 2nd Floor of the main building of the Royal Children's Hospital. Whilst this was an improvement on our previous location, over the years it has become more and more apparent that that we have simply "outgrown" our current home!

Physical space particularly in the Intensive Care Room is very restricting for staff and for parents who wish to sit at the bedside to be with their newborn baby.-

In April 2005 we facilitated a Parent focus group, specifically asking parents for their feedback. What would they want us to change given that we have the opportunity to move to the 3rd floor and to a larger area?

The feedback we received - along with input from our multidisciplinary team - has provided us with a new design for Neonates who will be looked after at the RCH.

Whilst we are restricted to building structure we have been able to improve upon design and space to accommodate infants and improve the facilities for their parents and families.

We will be able to increase our total bed capacity from 22 cots to 25 cots and the patient rooms will have a maximum of four infants per room, with double rooms to accommodate two patients and one single room.

This will allow much more space at the bedside for parents and create a quieter environment and hopefully prove more conducive to developmental care.

We are also building a Parent Retreat (separate from the clinical environment) where parents will be able to relax in a quiet lounge, enjoy kitchen & dining amenities and a tranquil outlook over Royal Park.

The Post Natal Mothers Unit will also be located on the same level and there will be overnight rooms for parents who are rooming in with their infant prior to discharge.

We have also designed a private lounge with a private garden for quiet times for parents to use.

The funding for the clinical facility is primarily supported by the Department of Human Services however in order to undertake our increased equipment costs and parental furnishings we will be relying on the special funds raised by "A Celebration Of Life" and other fundraising events.

If you are interested in making a donation towards the future of Neonatal care at the RCH please contact Ms Donna Aranyi our NNU Fundraising Manager on (03) 9345 4510.

We are very excited about the plans for redevelopment, which will ensure our NNU becomes the benchmark of world's best practice for the care of the sickest newborn babies and their families.

DONNA ARANYI

Fundraising Manager

A Celebration of Life – NNU @ the RCH

I am thrilled and excited to have been recently appointed to this position and regard my involvement with A Celebration of Life and the NNU as a great privilege.

I have worked within the not-for-profit sector for more than seven years (specifically within the area of childhood cancer) and posses skills relating to fundraising, sponsorship, marketing, event & project management, program development & support and service delivery.

The thing I love most about my work is the opportunity to meet many inspiring and generous people. I'm not taking about celebrities and philanthropists necessarily, although their contributions are vital but mostly those that ultimately benefit from the services and results of our fundraising achievements, that is our families and especially our babies!

My life is greatly enriched by those I work alongside everyday in an attempt to make a difference to real people's lives. The NNU Team is comprised of an amazing collection of dedicated and incredibly gifted individuals and they deserve our acknowledgement, support, praise and encouragement.

This is a very exciting time to be involved with the NNU and I am working diligently to establish some excellent supporters and sponsors who share our vision to establish a world class facility and centre of excellence within the NNU here at the RCH.

When I am not fundraising or networking, I enjoy spending my time walking and cycling along the beach in Elwood where I live, going to the movies, playing piano and catching up with friends and family. In 2005 I completed a Diploma in Holistic Living Counseling with a special interest in the area of grief and bereavement. I have two adorable cats called "Nelson" & "Lulu" and believe that life, despite its challenges, is for living – having fun and appreciating our blessings.

I would love to meet any parents or interested parties that would like to know more about our fundraising activities, upcoming events or those that have suggestions or ideas that may serve the NNU. My office is located on the Ground Floor, Main Entry Building in the RCH Foundation Offices. You will find me here from 8.30am – 5pm every day and I extend an open invitation to all of you to visit me anytime. Alternatively, I can pop up to the Unit for a chat if that is more convenient – please see Sheri Waldron and she will arrange a time to meet.

I look forward to working with you all, sharing many great experiences and ultimately creating a legacy worth leaving for our children of today and in the future.

Donna

Ph (03) 9345 4510 or donna.aranyi@rch.org.au

03

A CELEBRATION OF AUXILARY

how you can help!

Definition: An Auxiliary is "a group or organization which assists or is supplementary to a larger one. Person or thing that gives aid of any kind; helper".

The Macquarie Dictionary Revised Third Edition.

Auxiliaries have existed at the RCH since 1922 where they have made and continue to make a significant contribution to the overall fundraising endeavors of our hospital.

In 2006, there are now more than 70 Auxiliaries in existence at the RCH, all working tirelessly to raise important funds and awareness for various Units within the hospital or more generally.

The Auxiliaries are made of up volunteers who donate their time, goods or services to assist with fundraising efforts. The stalls that you see as you enter the Main Entry Building on Flemington Road, are manned on a daily basis by various Auxiliaries. Monies raised from sales generated by these stalls are donated to various Units/Departments within the hospital specifically or allocated to a general fund as advised by each Auxiliary.

A Celebration of Life has now been registered as an official Auxiliary of the RCH and we are looking for members to sign up, take an interest and help us run our stalls in 2006.

We are also in need of new, donated goods that can be sold at the stalls to help raise monies for the Neonatal Unit. ALL MONIES raised at COL Auxiliary Stalls will GO DIRECTLY to the NNU to be utilized to purchase equipment, resources or whatever is urgently needed.

Twice a year, the combined auxiliaries gather for two important market days at the RCH:- Paddy's Market on March and Andy's Market in November. These are very busy sales days and we will need to rely on suitable goods being donated to help us raise monies for the NNU, so if you know anyone who may be able to contribute, we'd love to hear from you!

Suitable items can include new toys, plants, new books, craft items (knitted toys & blankets etc), new homewares, new cosmetics, new jewellery, new decorator items – anything really as long as it is new and in perfect condition.

One NNU Mum has kindly made gorgeous new library bags and children's aprons which will sold at an upcoming stall in March – special thanks to Carolyn Gray for her wonderful contribution!

You can also support the COL Auxiliary by selling the RCH tote bags which are given out on consignment. The bags are sold for $2 each and $1 from every sale is allocated to the COL Auxiliary. Many people have had success selling them to friends, family, workmates, kindergartens, schools, sporting clubs, social clubs, Mother's Groups etc…

Please see the list of dates for COL Auxiliary Stalls in 2006 below. We would love to hear from anyone who

- can Volunteer their time to man a stall
- donate items that can be sold at stalls
- wants to become a member of the Auxiliary
- wants to help by selling RCH tote bags

A Celebration of Life (COL) Auxiliary Dates 2006

Hours : 9am — 3pm

Parking Complimentary Parking available for all Volunteers, RCH Main Car Park

Stall various items for sale that are donated or organized by the COL Auxiliary, 100% of sales to COL.

Bags sales of RCH bags and merchandise, 50% of sales donated to COL Auxiliary

CALENDER

17th Mar	Stall (Paddy's Market – Combined Auxiliaries)
29th Mar	Stall
5th Apr	Bags
8th May	Stall
25th May	Bags
June	N/A
10th July	Stall
8th Aug	Bags
Sept	N/A
13th Oct	Bags
14th Nov	Bags
30th Nov	Stall (Andy's Market – Combined Auxiliaries)
7th Dec	Stall

Like most organized committees or working groups, our Auxiliary will only be as successful as the people involved encourage it to be and we really do need as much help as we can get if we are hoping to enjoy such success.

We hope to hear from you soon!

Please contact Donna on (03) 9345 4510 or donna.aranyi@rch.org.au for further information.

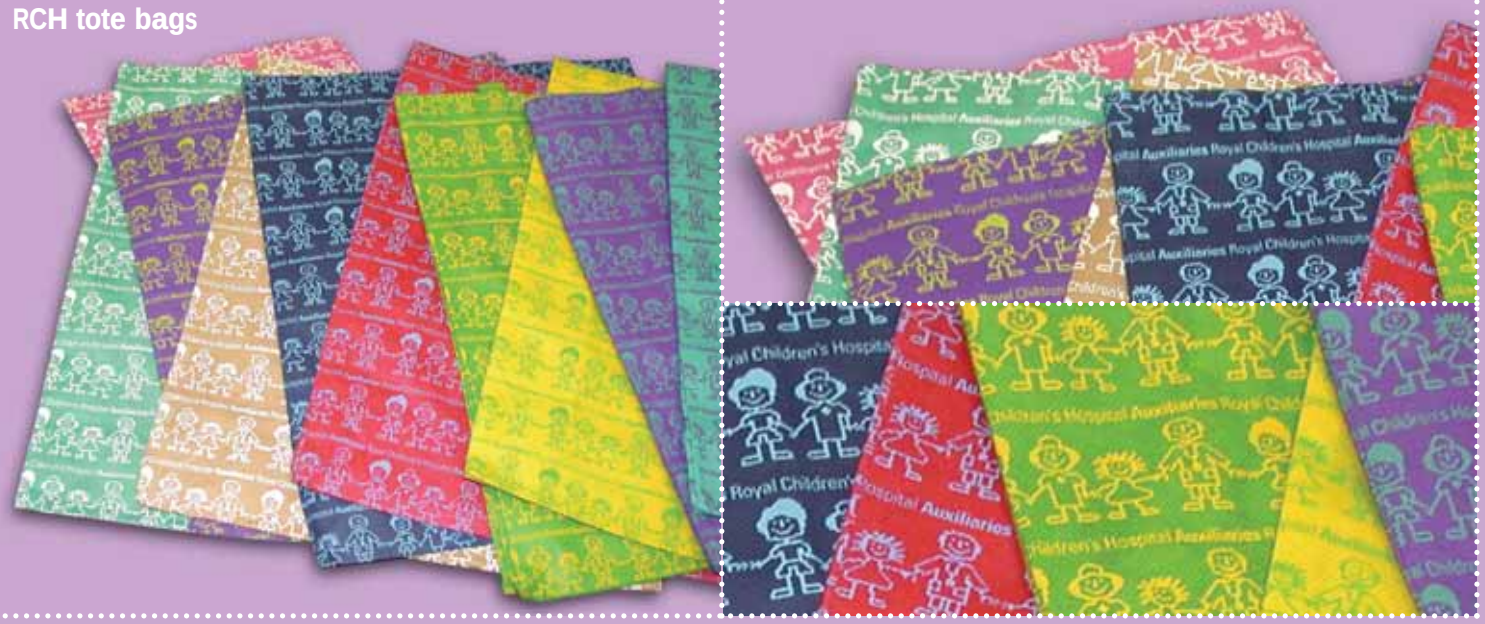
Fundraising Appeals Act

On the 1st July 1999 new fundraising legislation was approved for Victorian "Not for Profit" organizations – The Fundraising Appeals Act 1998 (no.78/1998).

To ensure A Celebration of Life does not breach the legislation we need our supporter's assistance. Legal implications not withstanding it is extremely important that we always protect the name of A Celebration of Life in the community.

It is imperative that we know in advance about ALL fundraising that is being conducted in the name of A Celebration of Life. If you have any queries about fundraising for A Celebration of Life please phone **Donna Aranyi** (03) 9345 4510 – thank you!

RCH tote bags



04

A CELEBRATION OF LIFE ANNUAL GALA BALL 2005

The Neonatal Units' 3rd annual fundraising event, 'The Celebration of Life Ball' was held at Crown Palladium Ballroom on May 12th, 2005.

This black tie event was a huge success, with over 1100 guests attending and raising $500,000.000 for the NNU!

Entertainment was provided by Tania Doko, Jimmy Barnes and The Scared Weird Little Guys, with a special guest appearance by Peter Fonda (son of Henry) who was in Melbourne shooting the film 'Ghost Rider'.

Peter not only added a touch of Hollywood glamour to the evening, but also auctioned off his MV Agusto motorbike and leathers raising $60,000!

Another highlight of the night was the 'Sparkling Bar', proudly sponsored by Moet and Chandon. Guests who purchased a Moet piccolo went into the draw to win prizes which included gorgeous jewellery and a five star getaway at the Golden Door Health Retreat to name a few.

The main and silent auctions were also fabulous this year with a great variety of goods on offer.

Special thanks goes out to all our sponsors and the ex-NNU parents who generously supported the night by purchasing tickets and attending the event with family and friends, donating goods or services to the main and silent auctions or working as volunteers doing various jobs that made the night run smoothly.

We're hoping to keep this very special event going, but to do so it takes a lot of organizing and we need your help. If you're interested in going on our email/mailing list to get information about ticket purchase for the next event or how you can donate goods or be a volunteer, we'd love to hear from you.

Please contact Donna Aranyi at The Royal Children's Hospital Foundation on (03) 9345 4510 or email donna.aranyi@rch.org.au

We hope to see you at the next one!

Kimberley Mannix

GALA BALL 2006

The date for this year's COL Gala Ball is Thursday 14th September 2006, The Palladium – Crown Entertainment Complex.

This event forms the major fundraising effort for a COL and will again be another night not to be missed!

More details to come but if you are interested in attending please contact Donna to reserve your tables/tickets asap to avoid disappointment – this year's event is going to be HUGE!

Speaking of HUGE, we have the monumental task of securing suitable prizes for our Main and Silent Auctions on the night. Generally speaking, items with a value up to $1000 are suitable for the Silent Auction. Main Auction items tend to have a higher value and we would welcome any offers from corporate sponsors or those in a position to donate something priceless or that "money can't buy"!

As a guide, here are a few suggestions of items that often attract good bidding at charity auctions:-

Silent Auction Items

Dining Vouchers, Accommodation Vouchers, Vouchers of any kind (skydiving, massage, beauty, hairdressing, personal training etc) , Homewares, Jewellery, Wine, Artworks, Fragrance & Cosmetics, Fashion Items, Hats, Sporting Memorabilia, CD's & DVD's, Fine Food Hampers, Sporting Goods, Plants, Gardening Equipment, Tools, Electrical Appliances, Furniture, Linen etc…

Main Auction Items

Cars, Holidays, Artwork, Boats, Diamonds, Sporting Memorabilia, Garden Landscaping, Money Can't Buy Experiences i.e. fast laps in a Ferrari etc.., Large Scale Dining Packages (10+ guests), Big Boys Toys i.e. Jet Ski etc…

ALL ITEMS MUST BE NEW AND IN MINT CONDITION.

So, if you have employers, friends or family members that may be in a position to donate something suitable for our Auctions or would like to attend this year's event, please start "spreading the word"!

Official Pledge Forms for Auction Prize Donors are available from Donna at the office – please call 9345 4510 or email donna.aranyi@rch.org.au to have some posted or emailed to you.

CALLING ON ALL VOLUNTEERS!

Volunteers often form the backbone of any great charity organization and A Celebration of Life is no exception.

So we are calling all Grandparents, parents, Aunts and Uncles, Brother and Sisters and basically anyone over the age of 18 years to consider becoming a Celebration of Life Volunteer!

We are in need of Volunteers who can help:

- Man a stall at the RCH for our COL Auxiliary
- Volunteer for a variety of tasks associated with our Annual Gala Ball
- Attend NNU events in a volunteer capacity

Volunteers do not need any specific experience related to fundraising but if you have ever volunteered at a charity event or auction, this would be advantageous but is NOT essential as training and support will be provided where necessary.

If this sounds like you or someone you know, please contact Donna asap and she will be happy to discuss with you how your support can and will make a difference.

COL FOUNDER CHRIS CLARKE

SPECIAL THANKS TO OUR COMMITTEE

DIRECTOR NNU DR. PETER McDOUGALL

05

'TOUR DE BEBE' 2006

Moonee Valley Rotary Club

Charity Bike Ride for The Neonatal Unit of The Royal Children s Hospital, Melbourne
And support a NNU Dad at the same time!

Robert Greenberg, father of Georgia - who spent just over three months in the NNU in 2003 – will join fellow Rotarians and ride 1100kms in support of the NNU as part of this year's "Tour de Bebe" charity bike ride.

The Rotary Club of Moonee Ponds aims to raise $70,000 for a new Jet Ventilator through their 7 day 'Tour de Bebe' charity bike ride which will be coming to a town near you in March 2006.

Currently the NNU at The Children's Hospital is the only facility in Australia with a ventilator of this type, which is a life-saver for babies born with certain types of lung disease.

The ride involves over 30 cyclists who will ride1100kms throughout country Victoria, each of them raising sponsorship money and giving freely of their time to help save babies' lives.

We'd very much appreciate your assistance in helping us raise public awareness of the life saving work done in this specialized unit of the hospital. To do this we're asking families in the towns and surrounding areas that the riders are cycling through, if they would be willing to assist with some local media coverage.

Also if your family or friends or the local businesses you have dealings with are interested in sponsoring a rider or for media queries please contact Donna Aranyi on (03) 9345 4510.

Georgia is now a happy, healthy and beautiful two year old, thanks in part to the expertise and care of the NNU Team. Her Daddy's participation in this event is yet another great example of how many of our parents willingly choose to continue to support the vital work of the NNU. Well done Robert, Kimberley and Georgia!

Tour de Bebe – Ride Itinerary

DAY 1 Saturday 25th March 2006
RCH, Melbourne – Euroa

DAY 2 Sunday 26th March
Euroa – Echuca

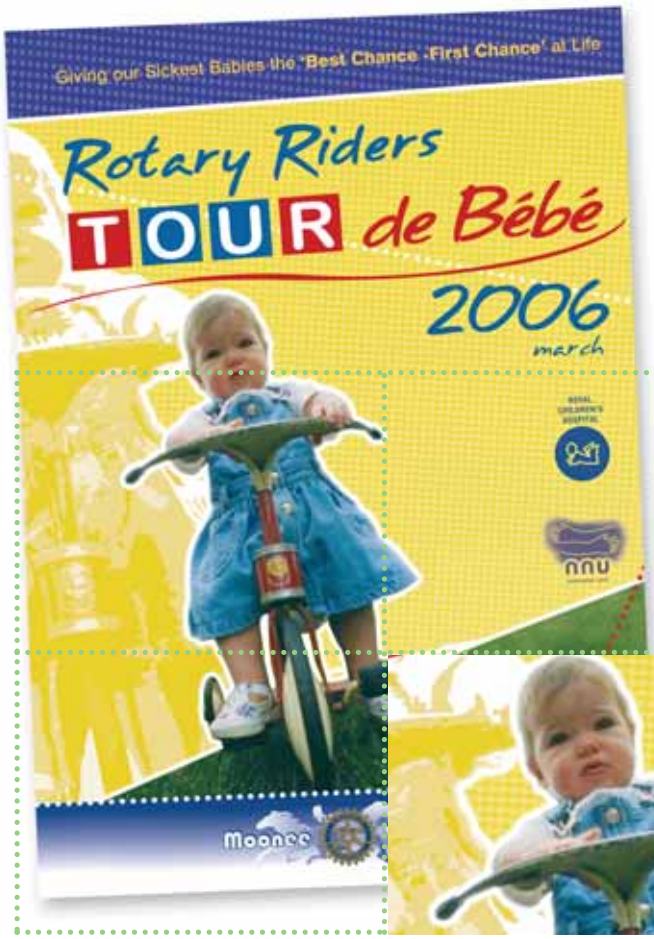
DAY 3 Monday 27th March
Echuca- Bendigo

DAY 4 Tuesday 28th March
Rest Day in Bendigo

DAY 5 Wednesday 29th March
Bendigo to Ballarat

DAY 6 Thursday 30th March
Ballarat to Lorne

DAY 7 Friday 31st March
Lorne to Queenscliff



06
JACK'S STORY

Jack was born at 2:38pm on Sunday February 23rd 2003 at the Freemasons Maternity hospital in Melbourne. Jack is our second child and brother to Harry (5yrs old). Jack was an absolute delight and weighed at a healthy 9lbs.

I went home late on Sunday after noon a very confident new father of two boys, I picked up Harry from friends and started to think about life ahead with two gorgeous kids. I went into work the next day after dropping Harry off at his regular Monday family day care and then planned to take Harry into hospital that afternoon to meet his new brother and see mummy. Cindie told me how Jack had been very sleepy during the day and had had some little green vomits that were diagnosed as just clearing his system since his delivery. He was beautiful.

At about midnight on Monday the 24th our lives changed for good. Jack had a large vomit of green bial and his abdomen had blown up, the nurses immediately contacted Cindies Obstetrician who quickly diagnosed Jack to have Hirschsprungs disease and asked for further tests and contacted the ward Paediatrician. Cindie called at 2.30am and awoke me with the news that our perfect new baby was about to be transferred to the Intensive Care department of the Royal Childrens Hospital. What a wake up call !! I immediately packed some things for Harry, woke him and again dropped him at friends and proceeded to drive into the Freeemasons hospital. I was greeted by Cindie and the Paediatrician looking at Jack plugged into machines and awaiting the arrival of the NETS team to transport Jack. What we witnessed next was something that no parent of a newborn wants to see or even imagines exists.

In came the NETS team with the mobile life support system and proceeded to pack Jack inside. He ended up resembling a little doll packed into this big machine looking out at Cindie and myself through a glass porthole.

I went with the NETS team for the 20minute journey across town and arrived at the NeoNatal intensive care unit. What an absolute wonderful bunch of people who are totally dedicated to their little charges. Poor Cindie was left at Freemasons by herself, she was unable to leave as she had only given birth 36 hours earlier. The nurses "unpacked" Jack and talked to me about what the prognosis was for Jack and the process from here. They kindly directed me to the parents room and told me to try and get a few hours sleep. I remember walking into the room and curling up on the cold vinyl couch and looking out across and sleeping Melbourne city skyline, no one else out there except for Cindie and the hospital staff knew anything about our poor little Jacks problem!!! We spent the next 10 days in the neo natal intensive care unit until Jack had all the tests to confirm his Hirshsprungs disease. Cindie moved between hospitals after a day.

We had an accelerated learning curve in those days and a lot about a disease we had no idea even existed less than two weeks ago !! Jack was diagnosed with about 10cm of bad bowel as a result of the barium Xray and was scheduled for surgery at 5weeks of age for a suave procedure. During this 10 days we learnt about enemas and diet etc for young Jack so we could be confident with our little gem at home until the surgery.

We went through twice daily saline enema's at home and in hindsight managed very well. Jack was a very robust boy at birth and stood out like a 900lb gorilla compared to the premature babies in the intensive care ward. This was a major benefit to Jack and I believe greatly helped him to start his journey toward surgery. Cindies parents were staying with us from Brisbane and were a great support during this time looking after Harry and allowing us to just focus on Jack and keeping him alive. Thanks Beverley and David.

It was time for Jack to have his surgery, we had to be at the Royal Childrens Hospital at 7am on the Monday morning and was expecting about 4 hours of surgery, at 2pm Jack had completed his marathon surgery and had 30% of his large intestine removed (about 30 cms). The surgery went perfectly. This was a stressful time as Cindie and myself sat in the waiting room from 7am until 2pm watching other parents as their children came and went from surgery, when was our little Jack going to finish his surgery ?? Cindie and Jack then stayed in hospital for the next 5 days, this was absolutely amazing considering what had just happened to him.

He was discharged on the Friday afternoon and allowed to come home to begin the rest of our lives. Little did we know that he would be back in hospital the next day, the doctors left a swab inside Jack to prevent extra 'poo' coming down his bowel and where unable to retrieve it, they thought it would be discharged. We took Jack in to the emergency department on the Saturday night for X-Rays and then back in for emergency surgery on Sunday morning. He was out within a couple of days and a much happier baby. My parents stayed with us from the Gold Coast for two weeks, again another great help for us allowing us to focus totally on little Jack. Thanks Mum and Dad.

For the next few months we progressed and then were hit by Gastro !! I remember receiving a call from Cindie on a Friday afternoon at work saying that she had taken Jack to the Paediatrician and was about to be admitted to the Cabrini hospital. I left work immediately. I took Harry home and had a "boys weekend" with him while Cindie and Jack stayed in hospital. Monday came and Jack was to be discharged, the complication was that Harry was scheduled for hospital on Monday to have his fourth set of grommets and his adenoids removed. So I picked Cindie and Jack up just before lunch, dropped them home and took Harry straight into hospital for his day procedure. But off course Harry didn't come out of his General Anaesthetic too well and we had to stay the night !! We then proceeded to be in and out of the Royal Childrens hospital about another 7 times averaging 1 visit every 5 weeks.

This was a nightmare time and really drained our energy and confidence. The last time Jack was in hospital was our 6th wedding anniversary in October 2003. By this time Harry had a direct relationship in his mind with hospital and Jacks bottom !! We have been through a course of regular dilatations, ranging from every day to once a week and a point now where we no longer need to apply this invasive procedure. While it is invasive it is clearly did Jack the world off difference in assisting the scare tissue to expand without the need for further surgery. During this time Jack also has had to go into the Royal Childrens on a monthly basis to be dilated under General Anaesthetic.

We spent a great but still pretty nervous Christmas in QLD with our families always aware that Jack may have to go into a hospital we didn't know and we would have to deal with surgeons and doctors we were not familiar with. We didn't and all had a fantastic time. We have since had a 1 month driving holiday through the east coast. We won't venture outside Australia and too far from medical care until Jack is over his 5th birthday.

It is now almost Jack's 3rd birthday and he is preparing to go to kinda. Jack has grown into a independent strong minded little man. Most of his medical problems seemed to stabilise at around 1 year of age, Cindie reckons that he woke up one morning just after his first birthday and was a changed and much happier baby. We put this down to his bowel maturing at around the age of 1. We are now seeing a gastroenterologist who has taken Jack off all dairy and requested that we give Jack an enema every two days to try and get his bowel used to being empty and then full rather than semi full all the time and just passing stool continuously. This seems to be working with Jack having full urine control and being able to wear just underpants without a nappy most of the time with few "accidents". While bribery of goodies is probably not the best thing for a kid it quickly focuses his mind on trying bowel control. Total control will always be a problem because of his Hirschsprungs but we are hopeful that he will gain some form of control.

Jack is an absolute bundle of joy and has an extremely strong personality. He is always busy and is learning so quickly that Cindie and myself are in total amazement on a regular basis due to the new things that he has picked up and seems totally at ease with the first time he does or says something. I often think and describe Jack to people as the future King of the World, his confidence is high, he doesn't take no for an answer and is always busy learning. We are hoping that his strong personality will help him to overcome any issues caused by his Hirshsprungs later in life.

For any new parents out there who are starting off on the Hirshsprungs or any other paediatric medical journey just stay strong and look at what an absolute bundle of joy you have created. Every time I look at Jack I am blown away by how much he has been through but yet how happy and strong he is. He is an absolute champ…

Thanks to the wonderful work that the NeoNatal Intensive Care staff performed in Jack's early days, the NETS team and the professional and caring support of all doctors, surgeons and emergency room staff that have been involved in Jack's care over the last 3 years. You have given our little Jack the gift of life.

I would also like to acknowledge Cindie and the amazing job she has done with Jack to help him get to a point where he is strong, growing and very happy. Her love and devotion to Jack has made all the difference.

I think Jacks favourite saying sums it all up :
Daddy (or Mummy) I'm your friend !!

Andrew Littleford (Dad)

Melbourne

February 2006

06

ANTHONY MEZZATESTA'S STORY

Our little star was born on 19th of October 2004.

He was 2 weeks early due to abnormal fluid in his abdomen being identified pre-natally at 34 weeks. He spent 5 days in the special care nursery at St Vincent's Private and after numerous tests x-rays and checks was allowed to come home. His abdomen remained abnormally distended and got worse so 10 days later our pediatrician sent us to the NNU at the RCH for further investigations.

After several days of high emotions and endless tears we learned his condition was "Chylous Ascites". It was rarely seen in children's abdomen without a known cause so once again Anthony was put through numerous tests, scans, x-rays and an MRI. The tests revealed that his lymphatic system was not working for him from the chest down and this was the cause of the problem. The course of treatment for him was no oral food for an extended period to allow his lymphatic system to rest and hopefully sort itself out.

We waited patiently for signs of improvement as around us in the NNU we saw so many children undergoing complex treatment and fighting their way to good health and eventually off home.

We wondered when our turn would come. As his condition worsened he continued to swell up with fluid and become more uncomfortable. Emotions became unbearable as the crib we had so carefully prepared at home remained empty and our hearts shattered at the thought he may not come home.

After 4 weeks of being fed intravenously (TPN) and no improvement our doctor identified his concern that no improvement had been seen. We decided to start searching for surgeons overseas who had successfully treated this condition as we wanted to be prepared for the final option if required.

On Monday 6th of December Anthony recommenced feeding orally. We watched him cautiously as we hoped that it would not have an adverse reaction. A few days later we saw a dramatic shift in his condition. The fluid in his abdomen began to reduce and he continued to increase his intake of the formula. We were excited to see this change and waited anxiously for news that we could get him off all the beeping equipment which tied him to his cot and take him home.

Anthony came home on the 17th of December just enough time to set up our tree and share our first Christmas together. Since then Anthony has continued to surprise doctors with his improvements and is now an active toddler with a great smile and appetite!

As parents of a child cared for in the NNU we are thankful to h0ave been able to sit with our child everyday and participate in his care. The nurses in the NNU are gifted in taking care of the parents as much as their patients. The commitment of doctors and nurses of that ward is truly admirable. We can only imagine the difficult tasks they face everyday as they carefully reassure anxious parents and treat very ill little babies. A big thank-you to you all and we are sure that like us ,a lot of parents at home think of the staff and parents in that ward every day, as they enjoy sitting and playing with their healthy babies at home.

Giosy Maio & Pat Mezzatesta

06

ELLEIGH JOY UNDERWOOD'S STORY

Elleigh Joy Underwood was born 9th of May 2004 at the Mercy Hospital, East Melbourne. Elleigh was born 14 weeks premature (week 26) and weighed 750 grams. Elleigh is the sister of her twin brother Ben, who regretfully was lost earlier during pregnancy at week 14.

Elleigh was transferred from the Mercy to the Royal Women's Hospital NICU at birth and at 20 days of age developed sepsis and was diagnosed with a serious bowel infection, Narcotizing Enterocolitis (known as NEC) and suspected perforated bowel. She was transferred to the Royal Children's Hospital for urgent surgery on 29th May 2004 where she underwent removal of 50 per cent of necrotic small intestine along with a small amount of large intestine. The remaining small intestine of 57cm was deemed healthy and a Stoma was created.

Elleigh underwent further surgery on 7th of July 2004 involving the closure of the Stoma. She developed a stridor during recovery from surgery and a granuloma was identified in Elleigh's throat in close proximity to her vocal chords. A tracheotomy was performed with tube inserted on 6th of August 2004. Elleigh's recovery was further marred by a stricture requiring surgery on 12th September 2004. She had a further 4cm of bowel removed along with some surgical shaping of the bowel to enhance reattachment.

At 45 weeks gestation, Elleigh suffered a further setback with a severe bout of Bronchiolitis and necessary mechanical ventilation for a number of weeks. Throughout the many procedures Elleigh endured, she was constantly supported with intravenous drugs to cover for infections and life support. Her veins were tiny and often were not suitable for the necessary insertion of catheters. A broviac line was inserted prior to surgery for the stricture and this helped support the need for intravenous drugs.

There were many times we would leave the hospital with a sense of joy and achievement and there were days we would be devastated and wonder about the future for our little girl. Our precious girl endured 186 days of intensive care treatment and five surgeries and was discharged 10 November 2004. She came home to her loving family and has warmed our hearts with her beautiful sense of awareness and wonderful smile. Our deepest thanks to Dr Peter Dobson, Dr Michael Stewart, Dr Joe Crameri, the team of resident doctors at the unit and of course the nursing staff. Elleigh would not be with us without your skill and dedication.

Elleigh is now nine months old (uncorrected) and weighs around 9lb (approx 4.2Kg). She will remain with her tracheotomy until her body size is adequate to enable surgical removal of the granuloma (estimate around 2 years of age). Her general health is very good and she is on solid foods and has steadily increased her weight.

Elleigh's discharge home was welcomed with a celebration and fundraising event. The event was a great day and an opportunity for us to give something back in acknowledgement of the support we received whilst at NICU. The function raised $9,350 for the ward. Dr Peter Loughnan attended our function and accepted our thanks and that of many family and friends. We sincerely thank our wonderful friends and family for their support and also recognize the generous donatory contributions of: Doug & Sarah Golden, Colin Parkes and staff at Burton & Parkes, Katrina Andrulis, Will Lockett and staff at Specialist Mortgage, Castrol Oils Australia, Leigh Kennos of Confectionery Link for donating lollies for our function and Barry Michael former IBF World Boxing Champion for donating a pair of signed boxing gloves for our auction.

07
NNU STAFF SPOTLIGHT

Robyn Smith
Care Manager NNU

My name is Robyn Smith and I am the full time Care Manager on the Neonatal Unit. I share this role with my colleagues, Jane Williamson and Lisa Hawley.

The role of Care Manager can be quite challenging. There are often many people involved in the care of our babies and I hope that with our assistance, your stay as parents can be made just that little bit easier.

I commenced working on the Unit in 1990 when we were still on the 10th floor. I spent 1994 at the Royal Women's Hospital doing the Neonatal Intensive Care Course and returned to the Royal Children's in early 1995. During my time on the Unit, I have worked as a Registered Nurse, Clinical Nurse Specialist, Associate Unit Manager and now Care Manager. I have even spent time as Acting Unit Manager, relieving Sheri Waldron for her well-deserved holidays.

The role of Care Manager is one of diversity. We essentially assist parents during their stay in hospital by being a constant person on the Unit to whom they can turn to for questions and advice. We plan the day-to-day care of the babies so that general housekeeping cares such as when to change a naso-gastric tube or an isolette don't be forgotten. We also contact, with parents permission, the local GP and Maternal Child Health Nurse [MCHN] with information about the baby and reason why they are in hospital. MCHN and GP's are valuable community resources that can offer parents advice and assist once they have taken their baby home from hospital and we try to utilize their service as much as possible.

Our other important role is to co-ordinate meetings between parents and the various medical/surgical teams that may be involved in their child's care. This can be a difficult process as I am sure everyone is aware of how hard it can be to arrange meeting times that suit all individuals involved.

Facilitating parental education is also important so that when a baby is ready for discharge home, the parents feel capable and confident to perform all the necessary duties that being a parent requires. This may be something simple like changing a nappy, but can also be quite complex such as learning care of a tracheostomy or naso-gastric tube.

In my spare time I organize the Units golf tournaments, usually twice per year depending on golfers rosters and availability. I also run a Unit Book Club for 12 intrepid readers; am a Committee Member for The RCH Ski Club and regularly attend movies, dinners and enjoy meeting friends at the pub, especially on Friday night after a busy week at work!

Dr John F Mills
MB BS, FRACP, M Med Sc, Ph D
Neonatal Paediatrician

I am one of the nine neonatal paediatricians in the Neonatal Unit, Royal Children's Hospital. I came to Australia in 1991 for a one year break from the rigours of training as a heart specialist in London. Fifteen years later I'm still here although working with babies rather than adult patients which is much easier (they can't talk back!).

I trained as a 'baby' doctor in Brisbane and then came to Melbourne in 1998 to get more experience in looking after babies that need surgery. After spending three years doing research into high frequency oscillatory ventilation (a special breathing machine that vibrates the lungs rather than imitating the natural breathing pattern), I started working as a full time specialist in the Unit in 2001.

At home I'm kept busy with two 'babies' of my own - Charlotte 6yrs and Eliza 4 yrs. I spend most of my time away from the hospital with my wife Helen and our wonderful girls. In the rare moments by myself I listen to music, read, tinker with my computer, and enjoy a glass of good red.

My ambition is to learn to surf, although my colleagues think that, at 40, I may have left it a bit too late to learn!

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Robyn Smith

Care Manager NNU

Helen Shoemark
MME BMus RMT

I run the Neonate and Infant Program for the Music Therapy Unit at RCH. The program provides live music therapy and recorded music services to families with infants anywhere in the hospital. Not surprisingly, this means that I spend a lot of my time in the Neonatal Unit, but also on the cardiac unit which has an increasing number of families with newborns there for several months at a time.

I've been a music therapist for 24 years and in that time I've worked and studied here and in the United States. For 14 years I worked as a clinician with children who had multiple disabilities and in early intervention with families whose young children were experiencing difficulties due to long hospitalisation or longer term issues. I also taught in the music therapy program at the University of Melbourne for four years. I came to RCH in 1995.

In 2002 we were pleased to team up with the MARCS Labs from the University of Western Sydney to accept an Australian Research Council Linkage Grant totalling nearly a quarter of a million dollars. The 'Music Therapy for Vulnerable Infants' study examined the impact of live singing for infants who were on the Neonatal Unit for more than four weeks. We were very grateful for the generosity of families who allowed their infants to participate in the study.

Because we had tricky requirements for collecting data (like the room being quiet!) in the end we were able to use data for just 20 infants.

The infants in the experimental group had music therapy sessions three times per week for four weeks. The intervention protocol was contingent singing – this means responding to the infant's behaviours using either soothing or stimulating singing.

The first round of results, using the Neurobehavioral Assessment of the Pre-term Infant (NAPI), showed a significant effect. The NAPI evaluates features of neonatal motor development, state regulation, and level of response to stimuli. After the four-week intervention period we found that NAPI scores for our control group (who received regular care) deteriorated, while scores for the infants in the experimental group improved slightly. The scores which influenced these outcomes most were for crying and irritability. There are other assessment results to be analysed in the coming months and then we will publish the results.

In the meantime I am doing a PhD in which I am using qualitative analysis to really examine the components of the intervention. This is a very new field, and very few music therapists anywhere in the world do the face-to-face work I do (I guess 24 years does make a difference). So it is important to provide articulate descriptions of the protocol I used so that other music therapists around the world can also use it successfully.

Before Music Therapy, I was a Cub Scout leader for several years. I gave that up to pursue my PhD, which hardly rates as a hobby! I'm married to Greg Shoemark, an automotive and industrial PR consultant. We have a 17 year old son who keeps us on our toes, and is a daily reminder that babies grow into healthy admirable young people!

< **Dr John F Mills**
MB BS, FRACP,
M Med Sc, Ph D,
Neonatal Paediatrician

< **Helen Shoemark**
MME BMus RMT

08
CHERUBS

WHAT IS CHERUBS?

Dawn Torrence, the mother of a little boy born with CDH in 1993, founded CHERUBS in 1995. After struggling to find the information and support that she needed during critical times in her son's life, she made it her goal to try to prevent other families from feeling alone and overwhelmed. CHERUBS is named for all the children born with CDH that do not survive.

What Is CHERUBS Australia?

CHERUBS Australia was founded in 2001 after Australian members of CHERUBS found that a lot of information provided by the International group, such as certain medical terminology and treatments, was not always relevant to them. We have membership spread throughout Australia. Our group consists of families expecting children with CDH, families who have surviving CDH children and families who have lost their babies to CDH. CHERUBS Australia maintains strong ties with the International group.

WHAT IS CDH?

Congenital Diaphragmatic Hernia (CDH) occurs in approximately 1 in every 3,000 births. The cause is not yet known. The diaphragm is formed in the first trimester of pregnancy and controls the lungs' ability to inhale and exhale. CDH occurs when the diaphragm fails to form or to close totally and an opening allows abdominal organs into the chest cavity. This inhibits lung growth.

Every patient diagnosed with CDH is different. Survival rates depend on the types and number of organs involved in the herniation and the amount of lung tissue available. There are many surgical procedures and complications that may or may not occur with each individual. The overall survival rate has been estimated at 50%, although this number is relating to all patients in general and not necessarily in accordance to each patient (information adapted from the American Medical Association Home Medical Encyclopedia; 1989; Random House).

WHAT DOES CHERUBS AUS. OFFER ITS MEMBERS

We offer our members support in a number of ways. These include:

- Quarterly newsletters with experience from other parents, stories and photos of our cherubs and group updates.
- Website full of information, links, photos, poems and stories.
- Listservs (group mailing lists) for both grieving families and families of survivors.
- Parent-to-parent matching – helping families who have experienced similar CDH situations get in contact with each other.

On-call volunteers are available throughout Australia.

CONTACT DETAILS
Danielle Kessner
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T (03) 5135 6999
W http://au.geocities.com/ozcherubs/

FINANCIAL SERVICES FOUNDATION AND VARIETY'S SUPPORT OF THE NNU

- more than a "Monetary Affair"

Over the last three years, the Financial Services Foundation has conducted an Annual "Monetary Affair" Gala Ball and chosen the NNU at the RCH as its nominated charity for this event.

In 2005, Variety – The Children's Charity joined with the Financial Services Foundation in their fundraising efforts and together raised $20,000.00 for the NNU.

Recently, Dr Rod Hunt met with Financial Services Group Associate Director - Michael Randall, Variety Events & Administration Manager – Janette Connolly and Gary Suckling from Smith Barney Citigroup to receive their outstanding donation of $20,000.00 which will help to purchase a new VIP Bird Gold - infant/paediatric ventilator for the NNU.

We also extend our deepest thanks and gratitude to Julie Baxter at Events Australia and to all those that helped to make this gift and event possible.

Without the support of friends such as these, the NNU would be unable to update and maintain it's highly specialized equipment. We are honored by this gesture and belief in our work and hope that the 2006 "Monetary Affair" Gala Ball is another great success!

(Insert pic – from left to right Michael Randall, Janette Connolly, Dr Rod Hunt & Gary Suckling)

Left to right > Michael Randall > Janette Connolly > Dr Rod Hunt > Gary Suckling