

# four seasons

Season after season,  
the Sydney Children's  
Hospital Foundation  
provides assistance  
to the Sydney Children's  
Hospital, Randwick  
ensuring the future  
looks bright  
for our children.



The Sydney Children's Hospital Foundation aims to provide financial assistance for the support of equipment, research and clinical services at the Sydney Children's Hospital, Randwick, which is a leader and centre of excellence for children's health in New South Wales and beyond.

## CONTENTS

Chairman's Letter	02
Executive Director's Letter	03
Chief Executive's Letter	04
The Foundation	05
Operational Chart	05
Winter Diary '02	06
Spring Diary '02	12
Summer Diary '02/'03	20
Autumn Diary '03	28
Winter '03 Diary	36
Completed Fellowships	38
Completed Research Grants	39
Current Fellowships	40
Current Research Grants	47
Abridged Financials	50
Thank you to Donors	52
Thank you to Volunteers	60



## THE CHAIRMAN

The theme of this year's Annual Report, the four seasons, shows how the Sydney Children's Hospital, Randwick provides care for many children with different illnesses and injuries and how the number of these patients can change given the season. It also highlights fundraising opportunities for the Sydney Children's Hospital Foundation, that occur rain, hail or shine, to benefit these patients.

Despite our success in the past year, there are still so many services and disciplines within the Hospital that require financial assistance. Therefore, the Foundation's role is pivotal to ensuring the Hospital can provide the most specialised and sophisticated health care possible.

I wish to express my gratitude to the organisations, companies and individuals that gave so generously this year to support the Sydney Children's Hospital and the extraordinary work they do. Your ongoing support will continue to help improve the quality of life and survival time for many brave young patients.

I would also like to take this opportunity to thank the dedicated staff and volunteers of the Sydney Children's Hospital Foundation and the Foundation Board for giving so much of their time and energy.

Jack Ford

Chairman  
Sydney Children's Hospital Foundation



CHAIRMAN

JACK FORD

## THE EXECUTIVE DIRECTOR

Dear Friends and Supporters,

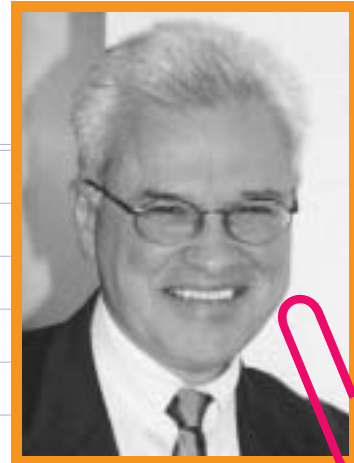
The dedicated staff of the Sydney Children's Hospital, Randwick have delivered another year of excellent service, outstanding performance and leadership in the health system. In addition to the usual achievements in highly specialised services, research and education, there has been increasing emphasis on community outreach and networking. Our patients, families and other consumers have been engaged in planning, delivering and improving both access to and quality of our services. Symbolically, we opened the new Sydney Children's Community Health Centre, Randwick bringing together teams covering all aspects of behavioural, developmental and community child health.

In setting goals for next year, these themes will be further developed and formalised. We will open our new, specialised Child Protection Unit as well as our Inpatient Child and Adolescent Mental Health facility. We will strive to be not only national, but also world leaders in our child and family friendly service, consistent with our philosophy of compassionate and comprehensive care. We will blend these commitments with initiatives in new technology, expanding knowledge and the growing scientific base of our practice.

Our two-way community relationship remains the corner stone of our achievements. While our commitments to the community are exemplified above, it is support from the community that makes such progress achievable. The Sydney Children's Hospital Foundation has been an essential partner in the projects of both the current and the next financial year. Our success depends on our friends and supporters and we thank you most sincerely.

Professor Les White

Executive Director  
Sydney Children's Hospital, Randwick



EXECUTIVE DIRECTOR

PROFESSOR LES WHITE



## FROM THE DESK OF...

### THE CHIEF EXECUTIVE

Throughout each season of the year, the Sydney Children's Hospital Foundation is committed to meeting the vital needs of the Sydney Children's Hospital, Randwick through important fundraising initiatives.

In addition to the many serious illnesses, diseases and injuries treated at the Hospital every day, we also see children presenting for treatment for a range of problems, which are often exacerbated by seasonal conditions.

Although the seasons change, one thing remains the same all year round - the need for funds to enable the Hospital to continue to provide the best care possible for children and their families. The Foundation provides financial support for clinical fellowships and initiatives; research; medical equipment; services and departments, to mention but a few.

Thank you to all our loyal and generous donors who have supported us over the past year and helped us reach our goals for the Hospital.

We are overwhelmed and privileged to have your continued support, which makes such an enormous impact on tens of thousands of seriously ill children, every day and every season, this year and for years to come.



Elizabeth Crundall

Chief Executive  
Sydney Children's Hospital Foundation



CHIEF EXECUTIVE

ELIZABETH CRUNDALL

The Sydney Children's Hospital Foundation is the principal fundraising body for the Sydney Children's Hospital, Randwick and is dedicated to working with the community to improve the quality of life for seriously ill children. The Foundation works together with organisations, companies and individuals to make a difference to seriously ill children from all over NSW and beyond.

The Foundation helps the Hospital continue to purchase state-of-the-art medical equipment, to financially support life saving services and training programs as well as medical and child health research.

There are many ways that the Foundation raises funds. Below is a description of our operations and how we can help individuals or organisations raise vital funds to benefit patients treated at the Sydney Children's Hospital, Randwick.

The **Accountant** has responsibility for all financial management for the Foundation, the Star Café and the SCHF Gift Shop. This includes monthly reporting and controls, reporting to external Auditors and investigation and control of taxation issues.

The **Arts Program** was created to further enhance the stay of patients treated at the Sydney Children's Hospital. Dedicated to providing an environment that is as free from stress as possible and where the child and their family feel comfortable, safe and secure, the Arts Program aims to improve the healing process and provide a positive impact on ill children – now and in the future.

The Foundation's **Bequest Officer** manages inquiries about making a will, planned giving and is responsible for developing ongoing relationships with the community through talks and visits.

The **Chief Executive** manages the overall day-to-day operations of the Foundation and its strategic direction, in line with Foundation Board policy. This includes liaison with major sponsors, donors, community groups, the Hospital Management Committee and the Area Health Service. The Chief Executive is the Foundation's media spokesperson and attends major fundraising and media events and actively pursues partnerships with the community.

The **Donations** Department's primary role is to receipt all donations through a sophisticated database, provide relevant reports for the Accountant and the Board and ensure adherence to the Privacy Amendment (Private Sector) Act 2000. They also advise on direct marketing campaigns, manage the print and distribution of the 'News' newsletter as well as manage the in-memory and in-celebration donations.

The **Media Manager** works with all media outlets to provide exposure for the Foundation's donors. Media exposure is obtained by publicising

events, special sponsorship partnerships and managing exclusive media fundraising events. The Media Manager also sources and writes articles for newsletters and other publications.

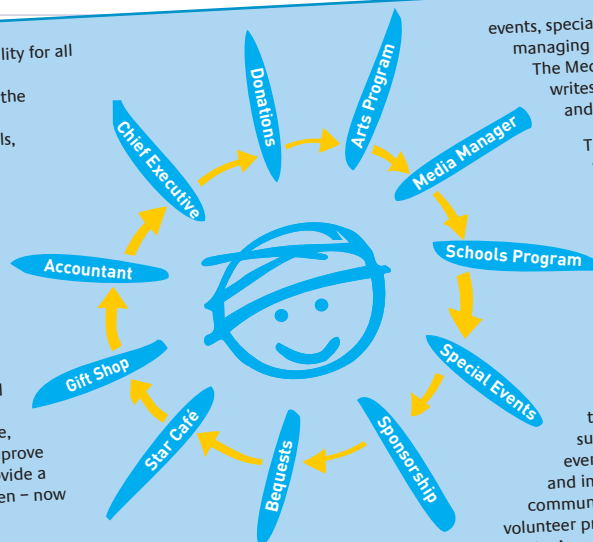
The **Schools Program** works with students from Kindergarten to Year 12 through the Department of Education and Training, the Catholic Education Commission and the Association of Independent Schools, to engender support for fundraising and awareness campaigns – such as **FOR KIDS 4 SICK KIDS**.

The **Special Events** Department develops the Foundation's in-house events and provides professional advice to support the Hospital through organising an event. They assist with the design, planning and implementation of corporate and community events. They also co-ordinate the volunteer program, which forms a valuable part of the Foundation's operations.

The **Sponsorship** Department works with companies and individuals to highlight how they can help the Sydney Children's Hospital. The Hospital has a range of medical services, items of equipment, wards, wings, fellowships, clinical initiatives and research projects in need of urgent sponsorship. The sponsorship team works with sponsors to understand their specific marketing objectives, current interest in meaningful corporate community involvement and how best to find the special 'fit' for the individual, company and staff.

The Foundation's **Star Café** provides delicious food for the patients, parents and visitors to the Hospital with all profits supporting special research programs at the Hospital. The Café is supported by many dedicated volunteers who, each week, give up their time to work in the café.

The Foundation's **Gift Shop** stocks all the essentials for a hospital stay plus newspapers, magazines and a wide range of special gifts.



Winter:  
skiing, snow, open fires,  
jumpers, scarves and gloves,  
doona's and blankets, roast  
dinners, home-made soup,  
toasted marshmallows...





# WINTER

JULY '02

01 **Event** BMW Rushcutters Bay - Hair Growing Competition

01

02

03

04 **Event** Unlimited Advantage - Golf Day

04

05 **Bequest** Late Alan Vincent Usher

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06 **Party** Kate Buxton

06 **Event** National Insurance Brokers Association - Raffle

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09 **Event** Double Bay Bowling Club - Charity Day

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## AMBER JADE FARLOW PATIENT



Amber Jade Farlow was born with no division between her windpipe and trachea and urgently required an operation to split the large common airway into two tubes – one for breathing, the other for swallowing. She also had a very large cleft palate, which required surgery to correct.


The pioneering operation to reconstruct Amber Jade's trachea was 12 hours long. This high-risk operation, which could have resulted in the loss of her vocal cords, was a huge success and within only four weeks she was breathing on her own.

Although Amber Jade is not out of the woods yet and will still require more operations to improve her condition, her family can't wait for the day she can be taken home and have a normal life.

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Event	Boxing Works - Karaoke Night	19
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Transfer of Funds	to Hospital	21
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Cheque Presentation	Actrol Parts	23
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Donation	Allens Arthur Robinson - Neurology Fellowship	26
		27
Events	'Heroes from Heaven' - Karaoke night for Cystic Fibrosis	28
		29
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**OUR BOARD**



Mr Ford is Managing Director of Sony Pictures Television. He has been a practising lawyer for over 20 years and has BA/LLB degrees from the University of Sydney.

**JACK FORD**  
CHAIRMAN



# WINTER

AUGUST '02

**Fundraiser** AIYAH  
**Event** Wetherill Park Chemist - Raffle

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**City to Surf** Nathan Catts & friends, Wendy Logan & friends  
Judy Ang & friends - participating in the City to Surf

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**Cheque Presentation** Uncle Toby's

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**Event** Ansett Worldwide - Staff Activities  
**Donation** Duke Energy - Mural in Play Therapy

15

**Snowy River Ride**

16

**IN BRIEF**

**PAINT CHALLENGE** On Thursday, South Sydney rugby league players will paint the front of Mascot Hardware store green as part of its conversion to Bunnings warehouse. Commemorative tins of paint from the Charity Paint Challenge will be on sale, with all proceeds going to Sydney Children's Hospital at Randwick. There will be plenty of fun activities, including a jumping castle, face painting and stilt walkers. The event will commence at 7:30 pm on the corner of Bourke and Gardeners roads.

REBECCA COOKE

PATIENT



Last year, 13-year-old Rebecca Cooke was diagnosed with Medulloblastoma. Representing 15-20% of paediatric brain tumours, Medulloblastomas are always located in the cerebellum (the portion of the brain, which helps coordinate movement). Fast growing and invasive, this tumour frequently spreads to other parts of the central nervous system via the spinal fluid. Luckily, this was not the case for Rebecca.

Rebecca was admitted to the Sydney Children's Hospital, Randwick to undergo an operation to remove the tumour - which was a success. The surgeons were able to remove all visible signs of the tumour.

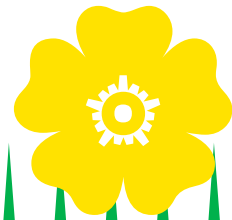
In order to give Rebecca the best chance of cure, she then underwent a course of radiotherapy followed by chemotherapy.

Although Rebecca has now finished treatment, she still has to make three-monthly visits back to the Sydney Children's Hospital for check-ups.



Spring:  
flowers in bloom, baby animals  
warmer days, new leaves on  
trees and plants...





# SPRING

SEPTEMBER '02

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**Cheque Presentation** Coles Supermarkets NSW - Centre for Children's Cancer & Blood Disorders

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**Event** Mallesons in the Community Expo

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**Event** Fishing for Sick Kids 2  
**Bucket Collections** Long Way to the Top Concert

14

**Marathon** Crawl 4 Kids Sydney - Rob Moroney

15



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AUGUST '02

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WILLIAM MONCKTON PATIENT

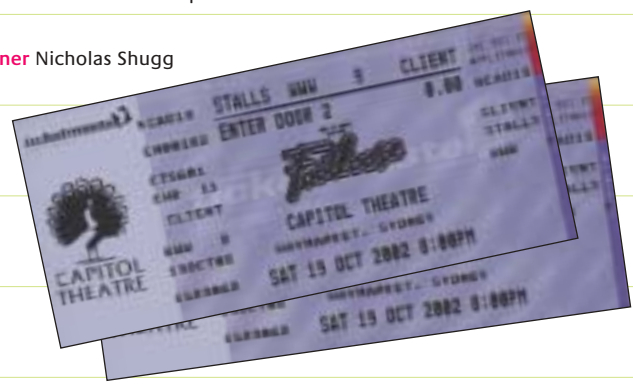
**Cheque Presentation** Sony Foundation - Adolescent Ward

**Event** Ultimo Tafe - Head Shave

**Bucket Collections** Footloose  
**Function** 'Mamma Mia' Charity Premiere SCHF-JHLF

**Event** Fishing for Sick Kids Dinner  
**Event** Comedian Brett Leake 'Fun at Work' - Presentation to Hospital Staff & Sponsors  
**Transfer of Funds** to Hospital

**Dinner** Nicholas Shugg



**Event** Pat Taylor Swim School SCHF - JHLF  
**Bequest** Late Ruby Helen Quinn

**Sponsorship** Duke Energy - Tour of Hospital



Ten-year-old William Monckton was diagnosed with asthma when he started school. One in four children will now develop asthma during childhood. This makes it the most common chronic disease of children – and the incidence of asthma in Australia is one of the worlds highest, doubling in both incidence and severity in the last generation.

The Sydney Children's Hospital has one of the largest asthma assessment centres in the country and also runs a High Risk Asthma Clinic, the only one of its kind in Australia which manages children with this potentially life-threatening disease.

William keeps his asthma in check with medication and makes sure he comes back to the Sydney Children's Hospital every month for a check up.

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OUR BOARD



Mr Allen is Managing Director of Allen Capital Pty Limited. He has a Bachelor of Economics degree from the University of Sydney and a Master of Applied Finance degree from Macquarie University. Mr Allen is a member of the Institute of Chartered Accountants in Australia.

**PETER ALLEN**  
TREASURER



# SPRING

OCTOBER '02

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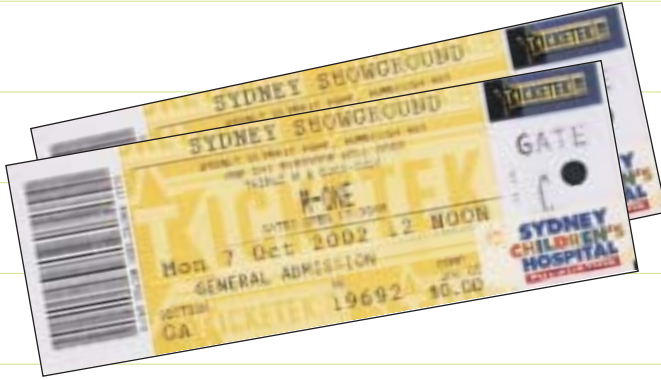
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**Bucket Collections** M One Concert

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**Campaign**  **FIT KIDS 4 SICK KIDS** consulted Foot Cone Belding (FCB) to develop logo.

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**Event** Corporate Express - Golf Day

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**Cheque Presentation** Big W Big Heart Campaign

12

**Event** Greek Glendi Fair

13

**Event** EyeCorp - Golf Day

14

**Christmas Newsletter**

15

16



SEAN DELPRADO

PATIENT



At 15 months old, Sean Delprado was admitted to hospital with a temperature of 41.3 degrees. He underwent a chest x-ray and a blood test - which showed his white blood cell count was very high.

Sean's temperature remained high and a second chest x-ray showed he had pneumonia- so he was transferred immediately to the Sydney Children's Hospital, Randwick for specialist care.

Sean was then operated on and fluid was drained from around his left lung. Two days later he had a MRI (Magnetic Resonance Imaging) scan, which showed that he now had an abscess (collection of pus) in his left lung. He also needed a blood transfusion to help his deteriorating condition.

Over the next week, Sean regained his strength and was finally allowed to go home.

Sean is still more prone to colds and pneumonia but is an energetic 4-year-old who loves spending time with his brother, mum and dad.

SEPTEMBER '02 M T W T F S S

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**Event** Rainbow Ball - YCRC (Sydney Kids Committee)  
**Bucket Collection** Footloose continued  
**Fundraiser** CSI - Garden Sale  
**Transfer of Funds** to Hospital



**Bequest** Late Richard Mayo Sargent

**Event** Australian Hotels Association - Video filming in Hospital



**Bequest** Late Ruby Helen Quinn

**Fundraiser** Botany Golf Club - Charity Evening

**Event** Woollooware - Golf Day  
**SCHF Annual General Meeting**

OUR BOARD



The Honourable Justice Annabelle Bennett is a Judge of the Federal Court of Australia and is currently the Pro-Chancellor of the Australian National University. Prior to her appointment to the Federal Court, Justice Bennett was a Barrister (Senior Counsel) specialising in intellectual property (Bsc (Hons), PhD, LLB) and has also been a past member of the Board of Eastern Sydney Area Health Service.

**ANNABELLE BENNETT**

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# SPRING

NOVEMBER '02

**01** **Fundraiser** Venture Creek - Auction  
**Sponsorship** Sydney Cove - Rotary Regatta

**02**

**03**

**04** **Meeting** Leslie Stevens Fund for Newborn Care Advisory Committee  
**Sponsorship** Corporate Express - Tour of Child Protection Unit

**05**

**Donation** Our Lady of the Sacred Heart School  
**Cheque Presentation and Tour of Hospital** - Johnson & Johnson

**06**



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**Meeting** Tucker Seabrook Gold Dinner Sponsor

**12**

**13**

**Bequest** Late Isabella V Pike  
**Donation** Big W Big Heart Campaign

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CLAIRE SCHANZER

PATIENT



Claire Schanzer's parents took her to see the family GP as they thought she was having problems with her asthma. However, after performing tests, the doctor found she had a chest infection and was given the appropriate medication to treat her condition.

However, a month later, the wheezing returned so Claire was taken to the Sydney Children's Hospital, Randwick where she underwent a MRI and chest x-ray - the results showing she had a bronchogenic cyst, a growth in her trachea that was affecting her breathing.

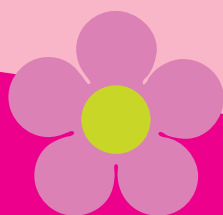
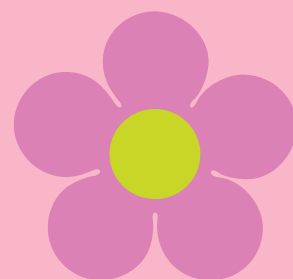
Surgeons at the Sydney Children's Hospital were able to perform the operation endoscopically - causing less injury and pain for Claire and ensuring faster recovery time.

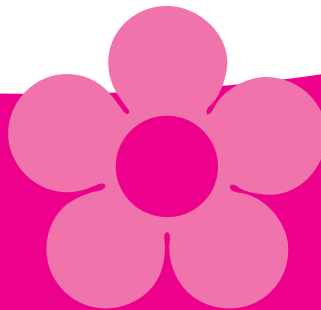
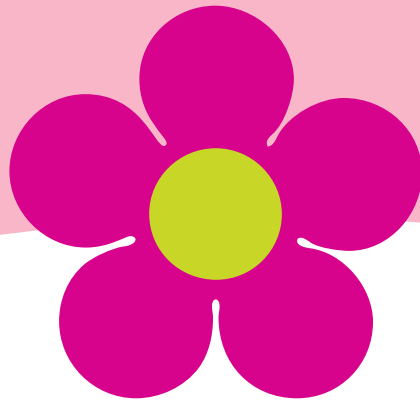
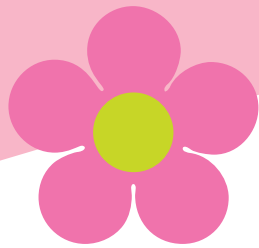
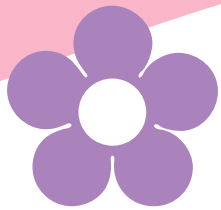
After only one night in the Intensive Care Unit to monitor her condition, she was up and about and allowed to go home the next afternoon.

Since then, Claire has made a 100% recovery and is now a happy and healthy four-year-old and all she has to show for her ordeal are three tiny, unnoticeable scars.



Summer:  
swimming, holidays, presents,  
celebrating with family,  
daylight saving, sunscreen,  
watermelon, ice cream,  
fans and air-conditioning...





# SUMMER

DECEMBER '02

HOLLY WHITTEN

PATIENT



Seven year old Holly Whitten first came to the Sydney Children's Hospital, Randwick last year after an accident at home which knocked the top two vertebrae in her neck out of alignment. Although that injury should have healed long ago, Holly has woken up three times since the accident unable to move her neck. In order to treat her condition, Holly required spending another few days in Hospital on her back in traction.

Holly is back home doing the things she loves most – swimming and ballet.

**Event** Theresa Flacks Fridge Raffle

01

**Event** J & J O'Brien - Christmas Party

03

**Donation** The Gwynville Group - CCC&BD

05

**Event** Coogee Family Fun Day

07

**Event** Helen O'Grady's Drama Academy

08

**Sponsorship** Bloomborgs Kids - Christmas Party

09

**Cheque Presentation** Lakes Hotel - CCC&BD Late Effects Clinic

10

**Event** Rushcutters BMW Gourmet Food & Wine Night

**Cheque Presentation** ING Direct - Telehealth

11

**Cheque Presentation** Gourmet Traveller

**Tour of Hospital & Cheque Presentation** for Ultimo Tafe

12

**Event** Tropicana Café Fundraising

**Event** Ku-ring-gai Council - Carols in the Park

13

**Cheque Presentation** City of Sydney RSL

15

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**Hospital to host charity ball**

On New Year's Eve staff of the Intensive Care Unit (ICU) at the Sydney Children's Hospital, Randwick, will host a fundraising ball at the ANA Harbour Grand Hotel to help raise \$20,000 for the patients treated in the ICU.

Starting at 7 pm, guests will be served a three-course meal and entertained by Popperina Jazz, one of Sydney's most popular cover bands. Guests will also have the opportunity to participate in a silent auction.

The ICU is one of only three specialised level six units providing intensive care for children, from newborns to teenagers, in NSW.

Between 700 and 800 children are admitted to the ICU each year.

For tickets, please call Mary Lou Morriss on 9382 1499 or e-mail [morrissm@scshs.nsw.gov.au](mailto:morrissm@scshs.nsw.gov.au).

Ticket cost \$150 each and include beverages.

**SATURDAY 7 DECEMBER COOGEE**

**FAMILY FUN DAY**

Coogee wants that U2v will hit Coogee beach again for the fourth year in a row to help raise much needed funds for the Sydney Children's Hospital, Randwick. The day will feature over 80 events & stalls, including Markets, Hire and Indie Coats, kids clothes, old time photographs, lambs, jewellery and an all day concert - so head to Coogee and check out the winter party in town.



NOVEMBER '02 M T W T F S S

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Sponsorship Big W Suppliers Dinner

Transfer of Funds to Hospital

Cheque Presentation Grace Bros Charities Fund

OUR BOARD



Ms Entwistle founded the Camp Quality support program for children with cancer in Australia and during the seventeen years she was CEO, extended it to eighteen other countries. She is now a director of Rally for Recovery, a fundraising effort for clinical research in children's cancer. She was awarded the Order of Australia in 1995.

VERA ENTWISTLE

Event CICU NYE Ball

DINING GUIDE

TROPICANA CAFE
This is help for kids
By Barry Turner
These customers...
Nicole's gift to little patients
Soft-hearted Big W staff help children



Soft-hearted Big W staff help children

Big W staff...
Soft-hearted Big W staff help children
The staff...
The staff...
The staff...



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# SUMMER

JANUARY '03

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**Sponsorship** Allens Arthur Robinson Summer Clerks - Tour of Hospital  
**Donation** Big W Big Heart

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**Sponsorship** Coles Supermarkets NSW - Tour of Hospital

15

**Bequest** Late Stanley Roy Rosebery

16

EMMA BYERS

PATIENT



In 1995, two year old Emma Byers was diagnosed with Acute Lymphoblastic Leukaemia (ALL) - where an abnormal cell is present in the blood, and blood-forming organs, in a type of Leukaemia (cancer of blood forming tissue in the bone marrow).

After two years of intensive chemotherapy at Sydney Children's Hospital, Randwick, Emma went into remission. However, at her next check-up, a blood test revealed the leukaemia had returned and once again Emma was admitted to the cancer ward for treatment and a stem cell transplant.

Today, Emma is a happy and healthy nine-year-old. Once again she is able to play soccer with her brothers, ride on her dad's motor bike, and do all the things most kids take for granted.



DECEMBER '02	M	T	W	T	F	S	S
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**Sponsorship** Tenix - Tour of Hospital 17

**Meeting** Sydney Express Couriers Re: Pro Bono Courier Services 18

**Event** 2Day FM / John Edwards Crossing Over Tour ticket auction  
**Transfer of Funds** to Hospital 20

**Bequest** Late Fay Olive Page 21



OUR BOARD



Ms Frost is a Company Director and Business-woman; specialist in people motivational skills and issues management.

GLEN-MARIE FROST



# SUMMER

FEBRUARY '03

01

02

**Sponsorship** Meeting Coles Supermarkets NSW

03

04

**Cheque Presentation** Demolition Contractors Association

05

**Event** Gold Dinner - Volunteer Brief

06

**Sponsorship** Variety Club - Tour of Hospital

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**Cheque Presentation** Sydney Buses

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**Sponsorship** Meeting Allens Arthur Robinson

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Dr Grimes is a medical practitioner and was previously Minister for Social Security (1983 - 1984) and Minister for Community Services (1984 - 1987). Dr Grimes is currently Chairman of the South Eastern Sydney Area Health Service Board and Chairman of AusHealth International. Dr Grimes was awarded an Order of Australia in 1992.

**DON GRIMES**

OUR BOARD

**KRISTY & ALEC  
APOLOSLOLOVSKI**

**PATIENT**

**Sponsorship** Meeting Big W  
**Cheque Presentation** Pauls Milk & Qantas Collect-a-Cap

**17**

**Cheque Presentation** Greek Glendi - Springtime

**18**

**Transfer of Funds** to Hospital

**19**

**Event** Cellarmaster's - 21st Birthday Party

**20**

**Event** Eileen Rogoff - Art Sale

**21**

**Sponsorship** Meeting Gwynville Group

**22**

**Donation** Kids with Cancer Foundation - Australian Stem Cell Facility

**23**

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Kristy, three and her brother Alec, six months old both have Cystic Fibrosis (CF). CF is a genetic disease, which is passed to one quarter of all children whose parents both carry a particular abnormal gene. This gene is carried by one in twenty-five Australians.

The Cystic Fibrosis gene interferes with the transport of water in and out of body cells. This abnormality makes normal secretions unusually thick and sticky, seriously affecting the body's ability to function.

The abnormal secretions affect almost every one of the body's major systems including the lungs. This progressively leads to severe digestive disturbance and malnutrition due to gut blockage as well as a serious and advancing form of lung damage, eventually leading to an untimely death.

In order to treat Kristy and Alec's condition, they require a combination of antibiotics, physiotherapy, high fat diet and enzyme tablets to help digest food.

Kristy and Alec are both happy children and get up to as much mischief as other children their own ages!



Autumn:  
leaves on the ground,  
crisp nights, morning dew,  
Easter buns and chocolate...





# AUTUMN

MARCH '03

HANNAH DODD

PATIENT



11 year old Hannah Dodd was born with a Clubfoot - a deformity of one or both feet in which the patient cannot stand with the sole of the foot flat on the ground and at three months old, she had her first Urinary Tract Infection which led to the discovery of a Horseshoe kidney - a variation in kidney development where both kidneys are joined together.

At 12 months old, Hannah was also diagnosed with Spina Bifida - a developmental defect in which part of the spinal cord and its coverings is exposed through a gap in the backbone and to top it off, Hannah's bladder was also half the normal size, which meant that she would experience long term problems with incontinence.

Hannah has undergone many surgical operations over the years to help her get better. Although she will never be able to run or swim like other able-bodied children, she will run rings around them when it comes to what she does best - riding a horse.

**01** **Events** Surry Hills Detectives - Golf Day  
**Events** Freight Forwarding Footy Tipping Competition

**02**

**Sponsorship** **FITKIDS4SICKKIDS**™ Dept of Sport & Recreation - agreed to sponsor

**03**

**Sponsorship** **FITKIDS4SICKKIDS**™ Kelloggs - agreed to sponsor

**04** **Event** Pancake Day  
**Event** Botany Bay - Golf Day

**Presentation** SCHF Research Grants Presentation Evening

**05**

**06** **Bequest** Late Alfred Henry Scoffin

**07**

**CELLARMASTERS CELEBRATION** Bondi Junction-based Cellarmasters celebrated its 21st birthday with a bacchanalian-themed party at the Paddington Town Hall, donating the \$5000 proceeds to Sydney Children's Hospital, Randwick. The night featured an abundance of award-winning Australian wines, a tasty gourmet supper, fantastic lucky DJ and the crowning of surprise celebrity *Bacchus Jeannie Little*.

**08**

**Sponsorship** Corporate Express - Charity Fete Day

**09**

**Event** Gardens R Us - Sale

**10**

**Easter Newsletter**

**11**

**Meeting** Disney Theatrical Productions Re: The Lion King

**12**

**13**

**14**

**Meeting** Goldman Sachs/JBWere Re: Gold Dinner Major Sponsorship

**15**

**16**

**Event** Maroubra Seals - Head Shave

**SATURDAY 8 MARCH** **CLEARANCE SALE TO ASSIST CHARITY**  
Today, over \$1 million worth of office furniture, computer hardware and software, computer supplies and office supplies will be reduced to clear. All monies raised from the day will go to the Sydney Children's Hospital, Randwick to assist sick children. The sale, from 8am to 5pm at Corporate Express, Dolmery Ave, Rosebery, will aim to raise over \$100,000. The event will also feature free entertainment and a bloc.

Event Bondi Diggers - Golf Day

17

Transfer of Funds to Hospital

18

Meeting Rally for Recovery Committee

19

20

21



OUR BOARD



Ms Leckie has been in public relations and marketing for over 20 years, working primarily for a national retail chain and running her own PR firm, Skye Macleod Enterprises. Skye now consults to various companies on marketing. Skye is also a member of the Taronga Park Zoo Foundation.

SKYE LECKIE

Event Lions Club of Sydney - Pacific Ball

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**CHARITY CLEARANCE SALE**

Here's a way to save money and give it away at the same time. Corporate Express is a leading office products supplier and today it is having a massive clearance sale to benefit the Sydney Children's Hospital. CE will sell thousands of quality products at bargain prices, to help raise needed funds for the hospital. All goods must be sold on the day, including office furniture, computer hardware/software and other computer and office supplies. Last year, the charity sale raised \$60,000 but this year the aim is for \$100,000.

You'll also get free entertainment, face painting, a barbecue and drinks.

The one-day sale is under cover, so don't worry about the weather. Buy some paper cups and give the children a hand.

9am-5pm, Dalmeida Ave, Rosebery.  
0295 0000







# AUTUMN

MAY '03

01

**Event** Shout Out with an Open Heart at Kabarett Junction

02

**Donation** B'nai B'rith Bargain Bazaar

03

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**Event** An Amber Affair

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**Meeting** SBA Re: Annual Report Design

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**Event** Actrol - Golf Day

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16



## LITTLE EMILY

## PATIENT



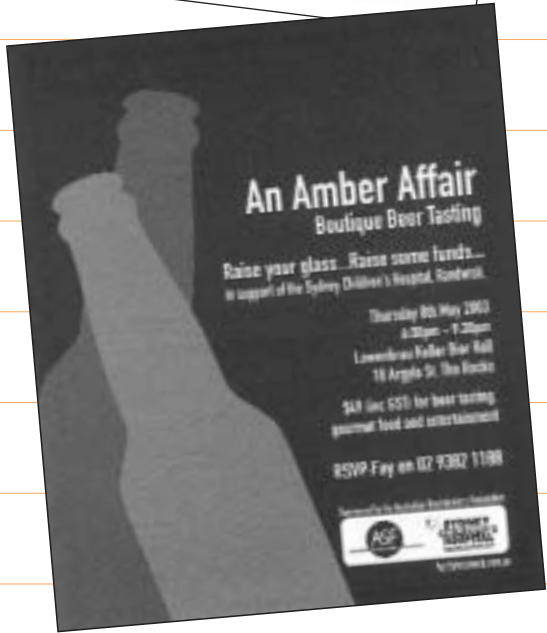
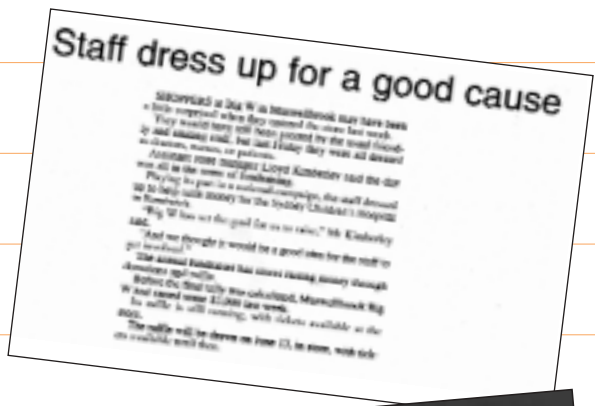
Emily (now eight years old) was born with Congenital Adrenal Hyperplasia (CAH), a rare and life-threatening incurable genetic disorder.

At only two days old, Emily was transferred to the Sydney Children's Hospital, Randwick for specialist care and on arrival, the endocrinology team had to save her life as she went into adrenal crisis. Her family had to learn all about her condition - what medications she needed, what symptoms to be aware of and what action to take when another crisis arose.

Emily has been in a critical condition several times over the years and endured many hospital admissions, especially in her first year. Although admissions are less common now, they are still a part of her life and she accepts that as bravely as an eight-year-old can.

Whilst Emily's condition is incurable, it is manageable. Other than check-ups at the Sydney Children's Hospital every three months, Emily has to take medication three times a day and undertake blood tests at home every month.

		17
		18
<b>End of Financial Year Newsletter</b>		19
		20
<b>Transfer of Funds to Hospital</b>		21
		22
<b>Bequest Late Sarah Williams</b>		23
		24
		25
		26
		27
<b>Events Cronulla Lions - Seafest</b>		28
		29
<b>Events Gold Dinner - Gold Patrons' Drinks</b>		30
		31
<b>Donation AJC Group 1 Jockeys</b>		



OUR BOARD



Mr Walton is Chairman of Walton Enterprises, Deputy Chairman of the Australian Institute of Management, and a Director of Young and Rubicam Australia, Capital Investments and the Prince of Wales Medical Research Institute. He is a past Chairman of the Eastern Sydney Area Health Service. Mr Walton holds a B Ec (Hons) from Sydney University, an MBA from Stanford University and is a CPA. He became a Member of the Order of Australia in 1998.

JOHN WALTON AM



# WINTER

JUNE '03

**01** **Event** John Lloyd begins his 100,000 kms 'Cycle Around Australia for Kids with Cancer'

**02**

**03** **Cheque Presentation** Cellarmaster's 21st Birthday Party

**04**

**05** **Sponsorship** Sydney Art on Paper Fair - Tour of Hospital

**06**

**07**

**08**

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**10**

**11** **Donation** Tenix Emergency Fellowship

**12** **The Gold Dinner**  
**Event** Australian Stockbrokers Foundation - Awards Night

**13**

**14**

**15**

**16** **Campaign**  **FITKIDS4SICKKIDS™** - Major Prize Draw

**HALLE FOSTER**

**PATIENT**



Halle has had it tough since day one. She was born with a hole in the heart - and in order to fix the hole she needed to put on weight, which was a constant battle.

In and out of hospital for six months, Halle finally reached five kilograms, which meant she could undergo the operation.

Halle's operation was a success - the hole was patched without any complications and by the next night she was off the ventilator and allowed home nine days later.

Halle is now so vibrant and full of life and although she might need another operation some time in the future, her parents Dean and Monique know they were in the best hands possible, at the Sydney Children's Hospital.



MAY '03	M	T	W	T	F	S	S
				1	2	3	4
	5	6	7	8	9	10	11
	12	13	14	15	16	17	18
	19	20	21	22	23	24	25
	26	27	28	29	30	31	

Event Rose Bay Rotary - Quiz Night 17

Meeting Sell & Parker 18

19

Transfer of Funds to Hospital

Campaign Susie O'Neill presents FITKIDS4SICKKIDS prizes to winning school St Cecilians 20

Event Bvlgari 21



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Event Opening Sydney Children's Community Health Centre, Randwick 27

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OUR BOARD



Professor Les White is Executive Director of Sydney Children's Hospital and conjointly appointed as Professor in the School of Paediatrics, University of New South Wales. He is a medical practitioner and children's cancer specialist, with a strong research background. He is president of Children's Hospitals Australasia and Chair of the South East Health Child and Youth Network.

PROF. LES WHITE



Sydney Children's Hospital Foundation Endocrinology Fellow  
DR KRISTEN NEVILLE

Network 10 Intensive Care Fellow  
DR AMISH VORA

Tenix Emergency Department Fellow  
DR MERRAN MACKENZIE

Coogee Bay Hotel Surgery Fellowship

Sydney Airports Corporation Ltd Asthma Fellow  
DR LAUREL TEOH

Construction, Forestry, Mining, Energy Union (CFMEU)  
Intensive Care Unit Fellow  
DR SANJAY TAPARIA

Sydney Children's Hospital Foundation Child Protection Fellow  
DR KAREN ZWI

Allens Arthur Robinson Neurology Fellow  
DR HELEN YOUNG

San Diego Foundation Farrell Fund Sleep Medicine Fellow  
DR JIM PAPADOPOULOS


Sydney Children's Hospital Foundation Cardiology Fellows  
DR AARTI HEJMADI – July to December  
DR AZAM MOH'D NOR – January to July

Sydney Children's Hospital Foundation Nephrology Fellow  
DR LEIGH HAYSOM

Sydney Children's Hospital Foundation Cystic Fibrosis Fellow  
DR YVONNE BELESSIS

Sydney Children's Hospital Foundation –  
Joshua Holland Leukaemia Fund Fellow  
DR STEPHEN LAUGHTON

Gold Dinner Gastroenterology Fellow  
DR FRANCES CONNOR



In addition to the Hospital's dedication to service and caring, it also has a duty to advance knowledge for future generations through training fellowships. Each year the Foundation awards sponsored and competitive fellowships which provide opportunities for the Sydney Children's Hospital staff to further specialise in various disciplines of paediatric medicine and surgery.

Cognition, language and quality of life in Benign Childhood Epilepsy.

DR ANNIE BYE AND DR ANDREW BLEASEL

Cure is not enough: long term adjustment in survivors of childhood cancer.

DR RICHARD COHN, DR BELINDA GOODENOUGH AND PROF. MARK CHESLER

Development and validation of an instrument to measure adherence in school-aged children with asthma or diabetes.

DR JACKIE CRISP, MS VICKI BARON, MS MARY ELLEN HARROD, PROF. HELVI KYNGAS, MS ROBYN ROSINA, MS SANDRA WALES

Development of an in vitro explant culture technique to study olfactory axonal targeting mechanisms.

PROF. ANNE CUNNINGHAM

Determining how human cells respond after infection with the bacterium *Helicobacter pylori*.

DR ANDREW DAY

Paediatric oncology end of life context: the basis and impact of the decision to die at home.

MS DONNA DREW, DR BELINDA GOODENOUGH, DR SUSAN TRETHERWIE, MS SUSAN HIGGINS

Healing of Skull Defect without the use of Bone Graft.

DR MARK GIANOUTSOS

Comparison of methotrexate levels in patients undergoing treatment for Acute Lymphocytic Leukaemia.

MR PHILIP GRANT, MS MARY ELLEN HARROD, MS ANNE SENNER

Snoring or sleep apnoea and asthma – is there a link in young children?

PROF. COLIN SULLIVAN

Reliability of physiotherapists using the Pirani Assessment of Clubfoot.

MS ANITA MUDGE, MS SUSAN SIMS

Fine mapping of an autosomal dominant ASD locus.

DR EDWIN KIRK, DR MICHAEL BUCKLEY

Factors causing resistance to spontaneous tumour regression in Neuroblastoma.

PROF. GLENN MARSHALL, MS LOEN HANSFORD

Research represents a major investment in the future of our children. It is vital to the mission of the Sydney Children's Hospital, Randwick. The Sydney Children's Hospital Foundation's Scientific Advisory Committee comprises: Professor Bernard Stewart (Chairman), Professor Eugenie Lumbers, Professor William O'Sullivan, Professor Denis Wade, Professor Graham MacDonald, Professor EH Bates, Professor GJ Morgan and Professor Sue Nagy.

Bedside placement of Transpyloric Feeding Tubes in the Paediatric Intensive Care Unit using Gastric Insufflation.

MS MARY LOU MORRITT

Spinal Muscular Atrophy Carrier testing study.

DR DAVID MOWAT, DR MICHAEL FIELD

Localisation of genes responsible for autosomal dominant and x-linked Retinitis Pigmentosa.

DR ANNE TURNER, DR MICHAEL BUCKLEY

Normal ranges for markers of Syndrome X and other disorders in childhood and adolescence.

DR JAN WALKER

The relationship between dietary fibre intake and functional constipation in children and adolescents.

MS KYLIE WHITTEN

A molecular analysis of the role of Long QT Syndrome in Sudden Infant Death Syndrome (SIDS).

DR GARY WILLIAMS, DR YAN LIN KAO

Antidiuretic Hormone (ADH) secretion during rehydration therapy for gastroenteritis and diabetes mellitus in children.

DR KIRSTEN NEVILLE, DR MATTHEW O'MEARA

The effects of sensory experiences at or after birth on subsequent infant pain responses to a subsequent immunisation injection.

MS TIINA PIIRA, A/PROF. DAVID CHAMPION, DR KEI LUI

Genetic control of Hirschsprung's Disease and Neuroblastoma.

DR EDWARD SHI

What stops us: why don't drug and alcohol workers notify?

DR DIMITRA TZIOUMI, MS DEB ARTHUR, MS SARAH HARRIS



### The Sydney Children's Hospital Foundation Gastroenterology Fellow

DR AVI LEMBERG

The Gastroenterology Department at the Sydney Children's Hospital provides a consultative and procedural service in gastroenterology, hepatology and nutrition. The department was the first paediatric endoscopy unit in Australia (1977) and now manages a wide range of gastrointestinal, liver, feeding and nutritional disorders.

The department has a particular focus in the management of children with Inflammatory Bowel Disease (IBD), establishing the first multi-disciplinary IBD clinic in Australia in 2001. Research endeavours have led to international recognition for pioneering work.

The Gastroenterology Department has received great benefit from the addition of a Fellow. The Fellow is available daily for calls from parents, GP's and Paediatricians regarding (as well as review of) any current in or out patients of the department or new referrals, including after hours calls. The Fellow is also available 24 hours, seven days a week to perform or assist with out of hour's procedures. In addition, the Fellow has allowed for an increase in the number of patients seen in clinic each week.

During my tenure as the Gastroenterology Fellow, I will commence five projects including: a joint project with the Australian Paediatric and Adolescent Inflammatory Bowel Disease Database, a pilot trial of the usefulness of Probiotics as an adjunct in the treatment of children with IBD and an analysis of the usefulness of Upper Gastrointestinal Endoscopy when diagnosing children with Crohns Disease.



### Novo Nordisk / City of Sydney RSL Endocrinology Fellow

DR MONIQUE STONE

The Endocrinology Department cares for children with disorders of their hormones and metabolism. The most common condition we see is Type 1 Diabetes. We also look after children with short stature, delayed and early puberty, adrenal disorders, thyroid disorders, osteoporosis, obesity and ambiguous genitalia. We see children with endocrine complications of brain tumours, cancer and its treatment (chemotherapy/radiotherapy), renal failure, genetic disorders and other chronic illnesses.

Most of our workload is outpatient based. The endocrinology team consists of staff specialists, clinical nurse specialists, fellows, diabetes educators, a dietician and a social worker - there is also a rotating Registrar and Resident attached to the team.

I also participate in the on-call roster (a 24 hour, 7 day a week service to provide assistance to families and medical staff in managing diabetic or other endocrine emergencies), in outpatient clinics and ward rounds.

#### p.40 AVI LEMBERG

"The Gastroenterology Department at the Sydney Children's Hospital was the first paediatric endoscopy unit and now manages a wide range of gastrointestinal, liver, feeding and nutritional disorders."

#### p.40 MONIQUE STONE

"Adolescence is a time when diabetes is difficult to control..."

#### p.41 LAUREL TEOH

"I have been actively involved in providing in and outpatient care to children and their families with a range of sleep and related disorders."

#### p.41 KRISTEN NEVILLE

"Having a fellow in the department has allowed us to both enhance these services and conduct substantial research."

#### p.41 STEPHEN LAUGHTON

"The research revolves around how a person's genetic make up influences both their chance of getting cancer and their likelihood of cure."

The Fellow assists in the teaching and supervision of the junior medical staff, takes FRACP candidates for two hours each week and is involved in regular presentations at clinical meetings.

My research project aims to improve the control of Type 1 Diabetes during puberty. The study involves using an oral medication, in conjunction with insulin, to improve insulin resistance in teenagers with Type 1 Diabetes. We have had a lot of positive feedback from patients keen to be involved. We hope to publish the results of this trial in a reputable peer review journal.



**San Diego Foundation Farrell Fund  
Conjoint Sleep Medicine Fellow**

DR LAUREL TEOH

I wish to express my gratitude to the San Diego Foundation Farrell Fund for the support of the Sleep Medicine Fellowship. I feel privileged to have been appointed to this position as it has allowed me to further develop my interest in paediatric sleep disorders.

As the Sleep Fellow, I have been actively involved in providing in and outpatient care to children and their families with a range of sleep and related disorders. This is with the aim of reducing morbidity, mortality and optimising the quality of life of each child.

The Sleep Unit cares for children with obstructive sleep apnoea (OSA), craniofacial abnormalities, neuromuscular problems, and complex lung disorders, such as Cystic Fibrosis and non-respiratory sleep disorders including night terrors, sleepwalking and other parasomnias. As part of my training, I have acquired diagnostic skills in paediatric sleep disorders and skills in the initiation of continuous/variable positive airways pressure (CPAP/VPAP). These are new techniques of non-invasive ventilation.

I will be presenting a project on OSA in infants at the World Congress on Sleep Apnoea in Finland and at the National Sleep Conference in Auckland this year. Another research project in progress is a study of near missed cot-death babies. Presenting at hospital conferences and teaching of medical students, junior medical and paramedical staff is also an integral part of my activities.

**Sydney Children's Hospital Foundation Conjoint  
Endocrinology Research Fellow**

DR KRISTEN NEVILLE

I have been privileged to hold the position of Fellow in Endocrinology at Sydney Children's Hospital in 2002 and am currently the Foundation Research Fellow. Our department looks after children with diabetes and hormone problems and also provides an outreach service to other areas of NSW.

I have been involved in several research projects over the last year – one looking at hormonal and electrolyte changes with different intravenous fluids for rehydration of children with gastroenteritis. Our results indicate a need for change from current management to a more salt rich fluid containing dextrose. These studies have been presented at both local and international conferences and are currently being prepared for publication. They are likely to change fluid therapy both in Australia and internationally.

We are also involved in a collaboration study with the Centre for Children's Cancer and Blood Disorders at the Sydney Children's Hospital, investigating the risk of 'Syndrome X' in long term survivors of childhood cancer and are presently screening all survivors. 'Syndrome X' is a collection of metabolic abnormalities that has been shown to be associated with a high risk of adult type diabetes, heart disease and stroke. Early identification of those affected or at risk will allow us to implement prevention strategies and early treatment.

We are also exploring other factors, which may alter treatments and improve long term outcomes in these patients. These studies are currently being analysed for presentation and publication.

**Sydney Children's Hospital Foundation - Joshua Holland  
Leukaemia Fund Haematology / Oncology Fellow**

DR STEPHEN LAUGHTON

I have been fortunate to continue as the Sydney Children's Hospital Foundation – Joshua Holland Leukaemia Fund (SCHF- JHLF) Fellow this past year. The Fellowship is for a senior paediatric trainee to undertake clinical research in the broad field of molecular epidemiology and childhood cancer. The research is conducted at the Centre for Children's Cancer and Blood Disorders at the Sydney Children's Hospital (SCH).



The research revolves around how a person's genetic make up influences both their chance of getting cancer and their likelihood of cure. This important information could then be used to tailor therapy to a child that maximises cure potential while minimising toxicity. A study initiated last year examining these possibilities has revealed a biologic marker that predicts relapse in children with Acute Lymphoblastic Leukaemia. Clearly this has clinical application if confirmed.

While exposures to environmental toxins have been extensively investigated as causative agents in childhood cancer, no particularly strong associations have been found. Using molecular techniques to determine genetic make up allows the examination of gene-environment interactions. I am currently involved in a case-control study looking at a number of genes and correlating these with environmental exposure questionnaire data.

This Fellowship has been funded through the generosity of a group of families who have been personally affected by childhood cancer. By providing such support, valuable experience has been gained in this important area of research.

#### Rob Maroney "Nappy Man" Infectious Diseases Fellow

DR EMMA BEST

Infections represent a major reason for consultations and hospitalisation in children. I am currently employed as the Paediatric Infectious Diseases (ID) Fellow at the Sydney Children's Hospital. As the ID Fellow, I fulfil a number of roles which include:

- Infectious diseases advice and education
- Best management of infectious diseases e.g. meningitis
- Tropical diseases or travel related illnesses
- Immunisation clinics
- Infection control and public health Issues
- Policy decisions for the hospital to ensure minimal infection risks for patients and staff
- Notification about diseases (e.g.: meningococcal). This enables the quick detection of local epidemics and control measures to be put in place.
- Member of the national Paediatric HIV service
- Care of children affected with this illness in New South Wales
- "Camp doctor" at the national Paediatric HIV camps

In addition, the Fellowship provides a very important opportunity for me to pursue research in areas within infectious diseases. I am currently chief investigator on two important research projects. The first project is establishing the safety of a common antibiotic used in critically ill children in hospital. The second project (via the nationwide Australian Paediatric Surveillance Unit) is establishing the incidence, management and outcome of a rare bacterial infection in children. The position of ID Fellow is accredited as a specialist training position in Australasia and has enabled me to continue my specialist Paediatric training in this area.

#### AT A GLANCE

##### p.42 EMMA BEST

"Infections represent a major reason for consultations and hospitalisation in children. The fellowship provides a very important opportunity for me to pursue research in areas within infectious diseases."

##### p.43 JULIAN AYER

"The cardiologists are involved in in-outpatient assessment, assistance with post operative intensive care management of cardiac patients, sedated echocardiography, trans-oesophageal echocardiography, post graduate and under graduate teaching and research."

##### p.43 MICHAEL FAHEY

"The position of neurology fellow is essential for continuity of care for patients with neuro-logical problems and also for its role in training child neurologists from around Australia."

##### p.43 JANIS CHAMBERLAIN

"My clinical responsibilities include caring for children currently undergoing bone marrow and cord blood transplant for a variety of diseases including cancer, metabolic disease and blood disorders."

## BIG W

### Big W Cardiology Fellow

DR JULIAN AYER

The Department of Paediatric Cardiology at the Sydney Children's Hospital provides cardiac services to the children of Sydney and NSW. There are four cardiologists and two cardiothoracic surgeons associated with the department. The cardiologists are involved in in-outpatient assessment, assistance with post operative intensive care management of cardiac patients, sedated echocardiography, trans-oesophageal echocardiography, post graduate and under graduate teaching and research. As Cardiology Fellow, I am also involved with all these activities.

The training program is coordinated by the Cardiology Specialist Advisory Committee of the Royal Australian College of Physicians and the position is by secondment from the Adolph Basser Cardiac Institute.

My work within the department includes: assessment of newborn infants with suspected congenital heart disease in order to diagnose the condition and assist in the institution of immediate care, consultations on inpatients not admitted under the cardiac service, preoperative and post operative assessment of children requiring cardiothoracic surgery, two outpatient clinics per week where I undertake assessment of new patients and also the follow-up of old patients.

This work involves performing and/or interpreting echocardiograms, electro-cardiograms and x-rays. I have regular on call responsibilities with the support of the cardiologists in the department. I am also involved in under graduate and postgraduate teaching.

Allens Arthur Robinson 

### Allens Arthur Robinson Neurology Fellow

Dr Michael Fahey

I am currently working as Neurology Fellow at the Sydney Children's Hospital. I have moved to Sydney from Melbourne to take this post as no equivalent training position in child neurology exists in Victoria, South Australia or Western Australia.

My work includes management of acute neurological emergency cases such as new onset seizures,

headaches, encephalitis and meningitis. I also care for children with more chronic conditions such as cerebral palsy, epilepsy, brain tumours and muscular dystrophy.

I am first on call to see inpatients referred on a consultative basis from other specialities and I also work on a one in two on-call roster to cover neurological patients after working hours.

I take part in 2-3 outpatient clinics per week. Two of these clinics are for general neurology and epilepsy patients. I also participate in a weekly specialist neuromuscular management clinic. This is a statewide multidisciplinary clinic, which aims to provide complete care for children with neuromuscular problems such as Duchenne Muscular Dystrophy (DMD).

I also take part in outreach clinics in Campbelltown and Newcastle, assist with reading EEG's and also in performing nerve conduction studies, an essential tool in the diagnosis of children with neuromuscular disorders.

The research project I am currently working on is to validate a questionnaire of sleep disordered breathing in boys with DMD - the most common inherited muscle disorder affecting 1 in 3000 males.

I believe that the position of Neurology Fellow is essential for continuity of care for patients with neurological problems and also for its role in training child neurologists from around Australia.



### Coles Supermarkets Haematology / Oncology Fellow

DR JANIS CHAMBERLAIN

This year I have been privileged to care for children and their families as a Fellow in Paediatric Oncology, Haematology and Stem-Cell Transplantation for the Centre for Children's Cancer and Blood Disorders (CCC&BD). The Fellow's roles have both clinical, and research components.

My clinical responsibilities include caring for children currently undergoing bone marrow and cord blood transplant for a variety of diseases, including cancer, metabolic diseases and blood disorders. I actively manage newly diagnosed patients, and assist in educating patients and families about complex diseases and necessary therapies during times of great stress.

In my role as conjoint Associate Lecturer in Paediatrics with the University of NSW, I participate in undergraduate medical education and examinations.



In addition, I contribute to the extensive clinical and research meetings conducted by the CCC&BD.

My main research interest has important clinical ramifications. I have been instrumental in designing a clinical trial to be conducted by the CCC&BD. The role of Amifostine, an agent aimed at protecting children from the toxicities of chemotherapy and radiotherapy, will be examined in the transplant setting. If the trial indicates a positive outcome for children treated with this drug, then children undergoing similar transplants in the future will be spared a degree of pain and suffering associated with the transplant procedure.

#### Mario Fenech Book Launch Respiratory Fellow

DR BRADLEY MARTIN

The Respiratory Medicine Department is involved in the management of children with short-term problems such as pneumonia and other respiratory infections as well as the long-term management of children with diseases such as asthma, Cystic Fibrosis and chronic lung disease due to prematurity. The department has a number of doctors, nurses and scientists who are heavily involved in clinical work but are also active in several areas of research.

Asthma is a very common, but often underestimated disease in which reliable, consistent long-term care is essential. The support of this Fellowship allows us to provide such care through our clinics. This is particularly important for children who have had life-threatening episodes of asthma and required admission to the Intensive Care Unit.

My major research project in 2003 involves assessing respiratory function in children who have had surgery for tracheal stenosis (narrowing of the windpipe). Before the development of an effective operation, this unusual condition was often fatal and long-term outcomes have not been well documented in the past. This study will give us the opportunity to assess how these children have progressed since their surgery and also allow us to give better advice to families of children who may require similar operations in the future.

#### The Sydney Children's Hospital Foundation Rehabilitation Fellow

DR MARIA KYRIAGIS

The Rehabilitation Department at the Sydney Children's Hospital manage children with many different conditions including acquired traumatic brain injury, cerebral palsy, spinal cord injury, limb deficiency and spina bifida. My role as the Rehabilitation Fellow includes managing the direct medical care of inpatient rehabilitation patients, the majority of which have an acquired brain injury. I participate in a variety of outpatient clinics every week including a general rehabilitation clinic, brain injury follow up clinic, botulinum toxin clinic (spasticity management), limb management clinic and spina bifida clinic run through the Rehabilitation Department.

#### AT A GLANCE

**p.44 BRADLEY MARTIN**

"Asthma is a very common but often underestimated disease in which reliable, consistent long-term care is essential. The support of the Foundation allows us to provide such care through our clinics."

**p.44 MARIA KYRIAGIS**

"My role as the Rehabilitation Fellow includes managing the direct medical care of inpatient rehabilitation patients, the majority of which have an acquired brain injury."

**p.45 SANJAY TAPARIA**

"I have had alternating responsibility on a weekly basis as the principal medical officer, running the ICU by day."

**p.46 YVONNE BELESSIS**

"At Sydney Children's Hospital we have been actively researching the early years in Cystic Fibrosis children, investigating the impact of respiratory infections. We have a research programme whereby our young patients have an annual broncho-scopic aimed at identifying lung infections early and then treating them appropriately and effectively."

Another aspect of my appointment is to develop the trauma rehabilitation service within the hospital. Currently, I am the chair of the Trauma Rehabilitation Working Party, which has recently instituted a daily trauma ward round to review all new trauma admissions. The purpose of this ward round is to promote good communication between the various teams and health professionals involved in the care of these children both in hospital and for their discharge planning.

I have had two research proposals passed by the Ethics Committee of the South Eastern Sydney Area Health Service. The first research project is to examine the prevalence of phantom limb pain and sensation in children with a limb deficiency and, the second research project is to examine the long term functional and rehabilitation outcome of sporting injuries in school aged children.



#### Construction, Forestry, Mining, Energy Union (CFMEU) Intensive Care Unit Fellow

DR SANJAY TAPARIA

During my time as the Intensive Care Unit (ICU) Fellow at the Sydney Children's Hospital, I have had alternating responsibility on a weekly basis as the principal medical officer, running the ICU by day. This involves the morning rounds, supervision of the Registrar's inpatient allocation, patient assessment, technical procedures, discussion and/or assistance in emergency procedures or elective procedures. I am also responsible for consultations in the inpatient wards of the Hospital, the Emergency Department and respond to cardiac arrest and trauma calls. I am responsible for discussions concerning retrievals, co-ordination of admissions and discharges with the supervising nurse of the shift.

I am involved in selectively pairing registrars to work in the ICU in discussions concerning their confidence, learning and progress and involved in feedback discussions to them with one of the Directors (Clinical Supervisor). I collaborate with the Medical Director in formulation of the Junior Staff Roster, attend Quality Assurance Meetings and provide feedback to registrars about decisions made in this forum. I have shared

responsibility for preparations and presentation of morbidity and mortality discussions and provide daily data relating to the relative dependence of patients in the ICU. I am also responsible for a weekly tutorial on cardiopulmonary resuscitation of infants and children.

I am responsible for supervision of and involvement in communication with other medical teams and outside agencies concerning the progress of patients in the ICU and the bed availability requests for intensive care post operatively.



#### Coogee Bay Hotel Surgery Fellowship

This Fellowship incorporates the development of foetal surgery where pre-birth (antenatal) conditions are diagnosed and assessed at the Sydney Children's Hospital. In the case where an operation is required, the foetus may be operated on with the development of minimally invasive (laproscopic) instruments.

This work is at the forefront of paediatric surgery and is only performed at a few centres around the world. The support of the Fellowship in Paediatric Surgery specialising in Foetal and Laproscopic Surgery assists in developing a team of specialists in a growing field which allows in utero operations to be performed which could result in saving the lives of babies otherwise beyond help.

Coupled with this ground breaking work is the establishment of a joint initiative with the Royal Hospital for Women in foetal diagnosis and treatment which continues to strengthen the work conducted by the Fellow to benefit future generations of paediatricians and families and children who need their help.



**Tenix**

#### Tenix Emergency Department Fellowship

The Sydney Children's Hospital is accessed by approximately 28,000 children every year from babies to 16-year-old adolescents.

Paediatric Emergency staff are required to have a range of very special skills that enable them to deal with the



vast number of different problems which present to the Emergency Department.

These highly trained and dedicated staff care for children who may have anything from minor cuts, broken bones, major trauma from car accidents, asthma or life threatening diseases as well as children who may have complications of chronic illness such as leukaemia or epilepsy.

Amongst other responsibilities, the Tenix Emergency Fellow is on call to provide treatment for children rushed to the Emergency Department by parents or ambulance. The Fellow also works as an integral member of the State Retrieval System for the helicopter and aircraft transfer of critically ill children who require specialist care.

The funding of the Emergency Fellowship has allowed us to conduct and implement research findings, ensure junior doctors and nurses receive ongoing training and most importantly, helped to extend the highest level of care to children in emergency situations.

#### Heroes From Heaven / Mario Fenech Book Launch Respiratory Fellow

DR YVONNE BELESSIS

I have been very fortunate to be the recipient of the "Heroes from Heaven" Cystic Fibrosis Fellowship. This fellowship, proudly donated by the families and friends of children with cystic fibrosis (CF), has helped to continue the excellent care of children with CF and to make possible high level research into the mechanisms and progression of the disease.

CF is a life-limiting genetic condition that can manifest at birth and then progressively affect the lungs and many other organs of the body. About one hundred new patients are diagnosed every year and the child and family are faced with a chronic condition characterised by unremitting respiratory infections, poor nutrition and growth and recurrent hospitalisations.

The outlook for children with CF is improving but a cure is still remote. Most patients succumb in their thirties, at the brink of their adult life.

We have been actively researching the early years in CF children, investigating the impact of respiratory infections. We have a research programme whereby our young patients have an annual bronchoscopy aimed at identifying lung infections early and then treating them appropriately and effectively. More recently we have been able to measure their

lung function and correlate this with the results of their bronchoscopy.

The Fellowship in CF has enabled the bronchoscopy programme and measurement of lung function to continue. It has also enabled further investigation into other possible conditions impacting on lung function such as reflux aspiration. The prevalence of infection now appears to be decreasing in our younger patients and we believe this is one result of our research programme. The Fellowship has also provided the opportunity to measure lung function in normal Australian children and therefore establish healthy reference data, which currently does not exist for children less than five years of age.

We have been invited to present some of this work at the Australian and New Zealand Cystic Fibrosis Conference later this year. This would not have been possible without the support of the families and friends of our CF kids and the unfailing support of the Foundation.

**p.47 MARIA CRAIG**

“The aims of this study are to: find out how commonly enterovirus infections occur in pregnant women; determine whether there is a link between enteroviruses and the first signs of diabetes in infants who are at genetic risk of developing diabetes; and describe how enteroviruses might be involved in diabetes.”

**p.47 ALISON KINGSLEY**

“This research study will review the accessibility of the usual toilet/bathroom used by children and adolescents with physical disabilities gather relevant anthropometric data, to provide evidence for guidelines on which to base recommendations for toilets/bathrooms”

**p.48 JOHN LAWSON**

“We will compare SPM with other established methods of epilepsy localisation and if effective, SPM could be used to identify more children who could benefit from epilepsy surgery and improve their outcome.”

**p.48 DIMITRA TZIOUMI**

“Although abuse in infants is the most life-threatening, under-referral exists in all age groups of children seen at the Emergency Department of SCH.”

**p.48 MARK GIANOUTSOS**

“The aim of the proposed research project is to augment bone healing so that distraction can be carried out at a faster rate, reducing the morbidity associated with the procedure.”

**p.48 JILL HUMMELL**

“Goal Attainment Scaling (GAS) is an individualised criterion-referenced measure designed to evaluate change in student outcomes after a period of intervention”

## Leslie Stevens Fund for Newborn Care (LSFNC)

This fund was established by the Stevens family to acknowledge and commemorate the contribution to paediatrics of the late Professor Leslie Stevens, particularly in the field of neonatology and over more than 40 years of clinical care, teaching and research at Sydney Children’s Hospital (formerly known as The Prince of Wales Children’s Hospital) and the Royal Hospital for Women.

The aim of the fund is to make a contribution to the health and wellbeing of children at the outset of life through monetary support in the field of neonatology, broadly and flexibly defined to encompass the periods before, during and after birth. The Fund is to promote advances in research and clinical care in the field of neonatology generally.

## Enteroviruses as triggers of autoimmunity in utero and in infancy

DR MARIA CRAIG

The number of children developing Type 1 Diabetes is increasing in NSW and the reasons for this are unknown. There is mounting evidence that infection with a common group of viruses, called enteroviruses, is associated with the development of this form of diabetes. The initial step in this process may occur during pregnancy. The aims of this study are to: find out how commonly enterovirus infections occur in pregnant women; determine whether there is a link between enteroviruses and the first signs of diabetes in infants who are at genetic risk of developing diabetes; and describe how enteroviruses might be involved in diabetes. The team conducting the research will characterise in detail the viruses involved and investigate whether they have specific features that may account for their ability to induce diabetes.

Accessible toilet facilities for children and adolescents:  
enhancing the evidence base.

MS ALISON KINGSLEY

Providing accessible buildings and amenities for people with disabilities is a legislative requirement for all organisations. Minimal guidelines exist on which to base the dimensions for a toilet/bathroom in public buildings including Sydney Children’s Hospital, which will enable it to be accessible for children and adolescents with physical disabilities. This research study will review the accessibility of the usual toilet/bathroom used by children and adolescents with physical disabilities gather relevant anthropometric data, to provide evidence for guidelines on which to base recommendations for toilets/bathrooms which will be accessible to the majority of children and adolescents with physical disabilities.



### Evaluation of a new brain-imaging tool in the assessment of severe epilepsy caused by brain malformations.

DR JOHN LAWSON

Children with malformations of the brain can present with very severe epilepsy that can be difficult to treat with medications. Identifying the extent of the brain malformation on an MRI scan can be difficult. We are testing a new technology (called SPM) that may be able to automatically detect these abnormalities. Such information can be used to guide surgical removal of abnormal tissue in an attempt to cure epilepsy. We will compare SPM with other established methods of epilepsy localisation and if effective, SPM could be used to identify more children who could benefit from epilepsy surgery and improve their outcome.

### Improving detection of child abuse

DR DIMITRA TZIOUMI

We know from previous studies at Sydney Children's Hospital (SCH) that we are "missing" cases of child abuse. Only one quarter of children aged under one year with a fracture are referred to the Child Protection Unit for further assessment. We estimate that an additional thirty infants per year are at risk of child abuse but are not identified. Although abuse in infants is the most life-threatening, under-referral exists in all age groups of children seen at the Emergency Department of SCH. This research has two components: firstly, to develop a culturally component training module to improve referral of children of all ages to the Child Protection Unit and, secondly, to evaluate a policy of referral of all children under one year old presenting with a fracture. We will evaluate whether these interventions result in improved detection of child abuse as compared with current practice.

### Improved healing when stretching the facial bones

DR MARK GIANOUTSOS

Distraction of the facial bones is a common procedure for a number of paediatric congenital conditions. However, it has significant morbidities associated with the long-term aspects of the procedure. The aim of the proposed research project is to augment bone healing so that distraction can be carried out at a faster rate, reducing the morbidity associated with the procedure.

This will have significant social and economic implications for the patient, family and hospital.

### Inter-rater reliability of Goal Attainment Scaling

MS JILL HUMMELL

The School Therapy Team for Students with a Physical Disability – Northern Sector (STTSPD) which is based at the Sydney Children's Hospital provides a service for students with a physical disability who are mainstreamed in local schools. As identification of student's goals forms the basis of ongoing assessment and management, an assessment tool that is reliable and responsive in detecting change is required. Goal Attainment Scaling (GAS) is an individualised criterion-referenced measure designed to evaluate change in student outcomes after a period of intervention. Whilst one study has indicated that the GAS has high inter-rater reliability when used in infant therapy programs, no comparable studies have been undertaken with school-aged children or adolescents. This research study will address the inter-rater reliability of the GAS with school-aged children and adolescents who have a physical disability and receive services from the STTSPD.

### A study to investigate the cause of an inherited disorder characterised by liver disease and immune deficiency

DR ROBERT LINDEMAN

Hepatic Veno-occlusive Disease with Immune Deficiency (VODI) is an inherited disorder affecting the liver and immunity. The syndrome was first described in families of Lebanese extraction at the Royal Alexandra and Prince of Wales Children's Hospitals. The gene for this disorder is unknown. This application is to establish the genetic basis of this disorder, to improve our understanding of this condition and of veno-occlusive disease, which frequently occurs after bone marrow transplantation.

This research will benefit the affected families by identifying healthy carriers, giving accurate recurrence risk and allowing prenatal diagnosis in later pregnancies. Benefits to the broader community may include treatments for post bone marrow transplantation complications.

**The use of Neuromuscular Electrical Stimulation with Botulinum Toxin and therapy to improve the function of the upper limb in children with Cerebral Palsy.**

DR KEVIN LOWE

This project represents the start of an ambitious collaboration between the Sydney Children's Hospital, the Spastic Centre, the University of NSW, University of Western Sydney and Royal North Shore Hospital. Each of the teams' members brings to the project significant expertise in the areas, respectively, of paediatric rehabilitation medicine, Botulinum Toxin Therapy, traditional therapy, biomechanical measurement, qualitative assessment and functional electrical stimulation. The aim will be to combine these skills for the purpose of determining whether electrical stimulation is effective with Botulinum Toxin therapy in reducing upper limb spasticity in children with cerebral palsy.

**The influence of preparation on children's distress during aversive medical procedures: a randomised treatment study.**

DR JOHN PEREIRA

In ongoing work, we have found that distraction reduces children's distress during an aversive medical procedure (MCU, x-ray of the kidneys). Not all children benefit from distractions, however, some remain highly distressed. This study evaluates preparation as a means of enhancing the impact of distraction during the MCU. Children aged two to seven years will receive the distraction intervention with one of two types of preparation (directed at the parent and child, or the child only). We will compare their impact on children's distress, parental behaviours, and child adjustment after one week. The findings have implications for helping young children manage aversive procedures.

**The identification of a new gene for hereditary blindness.**

DR ANNE TURNER AND DR MICHAEL BUCKLEY

We have studied a large family that clearly demonstrates x-linked Retinitis Pigmentosa, a form of inherited visual disability. Considerable time and money has already been spent on characterising this family and collecting DNA samples from 20 extended family members. A scan of the X chromosome revealed that the likely causative gene may lie in a region, which has not previously been reported to cause Retinitis Pigmentosa.

The aim of this project is to use molecular genetic techniques to localise and identify this novel gene for x-linked Retinitis Pigmentosa.

**DAIR (Diabetes in Adolescence and Insulin Resistance).**

DR CHARLES VERGE AND DR MONIQUE STONE

Type 1 Diabetes is the most common life-long disorder with onset in childhood. Patients must have insulin injections, measure their blood sugar levels several times daily, and adhere to a strict diet. Adequate control of blood glucose levels is vital to prevent long term eye and kidney complications that may result in blindness and kidney failure. Adolescence is a time when diabetes is difficult to control, due in part to high growth hormone levels causing insulin resistance (a state in which the body does not respond strongly to insulin). This study will test whether treatment with rosiglitazone (used frequently in Type 2 Diabetes) will reduce the insulin resistance of adolescence and improve the control of Type 1 Diabetes during puberty.

**The role of Lung Clara cell in inflammation – an in-vitro cell culture experiment.**

DR HE WANG AND DR KEI LUI

Very premature babies often develop a debilitating lung condition called Chronic Lung Disease (CLD). Evidence suggests that lung Clara cells produce a protein that secretes (CC16) that has lung protection properties in infections and other lung diseases. We want to study in laboratory mice, how the lung Clara cells would respond to inflammatory stimulation, whether they secrete CC16 and reduce the production of inflammatory substances from inflammatory white cells. We will isolate mice lung Clara cells and stimulate them with the group of inflammatory mediators commonly found in lung fluid of CLD babies. This will establish an experimental model for our subsequent experiments investigating the differences in using newborn and fetal mice lung Clara cells.



## ABRIDGED FINANCIALS

### STATEMENT OF FINANCIAL PERFORMANCE for the year ended 30 June 2003 SYDNEY CHILDREN'S HOSPITAL FOUNDATION

STATEMENT OF FINANCIAL PERFORMANCE for the year ended 30 June 2003			STATEMENT OF FINANCIAL POSITION as at 30th June 2003		
	2003	2002		2003	2002
	\$	\$		\$	\$
<b>INCOME</b>			<b>CURRENT ASSETS</b>		
Bequests	381,980	328,136	Cash Assets	1,063,890	2,343,393
Donations/Fundraising	5,216,085	5,457,647	Receivables	196,766	218,133
Investments	1,109,505	910,913	Inventories	42,112	43,958
Shop & Café Operations	1,158,408	1,063,444	Other Financial Assets	12,318,025	11,112,131
Proceeds on sale of investments	123,398	158,267	<b>TOTAL CURRENT ASSETS</b>	<b>13,620,793</b>	<b>13,717,615</b>
<b>TOTAL INCOME</b>	<b>7,989,376</b>	<b>7,918,407</b>	<b>NON CURRENT ASSETS</b>		
<b>LESS EXPENSES</b>			Other Financial Assets	3,154,231	3,379,976
Fundraising	438,344	513,183	Property, Plant & Equipment	931,412	940,198
Depreciation	40,768	38,610	<b>TOTAL NON CURRENT ASSETS</b>	<b>4,085,643</b>	<b>4,320,174</b>
Operational	945,649	748,279			
Shop & Café Operations	961,403	863,944	<b>TOTAL ASSETS</b>	<b>17,706,436</b>	<b>18,037,789</b>
Investments	756,503	577,168			
<b>TOTAL EXPENSES</b>	<b>3,142,667</b>	<b>2,741,184</b>	<b>CURRENT LIABILITIES</b>		
<b>NET PROFIT FROM ORDINARY ACTIVITIES</b>	<b>4,846,709</b>	<b>5,177,223</b>	Payables	654,671	185,806
			<b>TOTAL CURRENT LIABILITIES</b>	<b>654,671</b>	<b>185,806</b>
Add: Capital and Reserves brought forward	17,851,983	14,919,194	<b>TOTAL LIABILITIES</b>	<b>654,671</b>	<b>185,806</b>
			<b>NET ASSETS</b>	<b>17,051,765</b>	<b>17,851,983</b>
Less: Grants Distributed/ Distributable	(5,646,927)	(2,244,434)	<b>EQUITY</b>		
			Contributed Equity	100	100
			Reserves	17,051,665	17,851,883
<b>TOTAL EQUITY/ FOUNDATION FUNDS</b>	<b>17,051,765</b>	<b>17,851,983</b>	<b>TOTAL EQUITY</b>	<b>17,051,765</b>	<b>17,851,983</b>

## STATEMENT OF FINANCIAL POSITION

### AUDITORS' REPORT TO THE MEMBERS OF THE SYDNEY CHILDREN'S HOSPITAL FOUNDATION

We have audited the Abridged Statement of Financial Performance and Statement of Financial Position for the year ended 30 June 2003 in accordance with Australian Auditing Standards.

The abridged financial report is derived from the Foundation's full annual financial report. In our audit report to the members dated 2nd September 2003 on the full annual financial report, we expressed an opinion, subject to the qualification described below, that the final report presented fairly the financial position of the Sydney Children's Hospital Foundation as at 30 June 2003 and the results of its operations for the year then ended.

The qualification referred to above relates to the impracticability of the Foundation establishing control over the collection of cash donations prior to its entry into the Foundation's financial records. Accordingly, as the evidence available to us regarding revenue from this source was limited, our audit procedures with respect to cash donations had to be restricted to the amounts recorded in the financial records. We therefore were unable to express an opinion whether cash donations the Sydney Children's Hospital Foundation obtained were complete.

In our opinion, the information reported in the abridged financial report is consistent with the full annual financial report from which it is derived and upon which we expressed the qualified audit opinion referred to in the previous paragraph. For a better understanding of the scope of our audit, this report should be read in conjunction with our audit report on the full annual financial report which may be obtained from the Foundation at: Locked Bag 5, Randwick NSW 2031.

Horwath Sydney Partnership  
Level 10, 1 Market Street  
Sydney NSW 2000

Michael Kaplan  
Partner



## THANK YOU TO DONORS

### Thank you to all our generous donors

Our sincere thanks to all our donors. Collectively your commitment has enabled us to meet our goals. We are determined that the Sydney Children's Hospital, Randwick will provide the best available health care for the children of Sydney, NSW and further afield. Your generous and ongoing support has made a difference to this and future generations of sick children treated at the Hospital.

To all our donors who have given up to \$500, thank you. Your generosity has assisted the Hospital and its vital work enormously. Thank you also to everyone who has donated goods in kind – everything from auction prizes to services. Donors \$500 and above are listed below. Your generous commitment to our needs is deeply appreciated.

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Our volunteers play a major role in undertaking a diverse range of tasks from assisting with food preparation and customer service at our Café and shop, to support at special events and administrative duties. We sincerely wish to thank our volunteers for their energy and commitment and look forward to their ongoing support.

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