



RCH1000

Supporting Research
at The Royal Children's Hospital



NEWSLETTER 2020

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Chairman's note



As I approach my fourth year as RCH1000 Chairman, I feel increasingly fortunate to be able to serve The Royal Children's Hospital (RCH) and the community in this capacity. The absolute dedication to excellence for which our great hospital is internationally renowned continues to be reflected in its truly cutting edge research and clinical practice.

RCH1000 provides a significant contribution toward large scale research projects which aren't fundable through other resources. Our most recent contributions to the HAPPI Kids II study continues to yield critical information about age-specific 'healthy' references for blood samples to paediatricians and surgeons around the world.

As our membership and additional donations from our members have increased, we look forward to being able to address another grant application before the close of 2020 to celebrate the 150th anniversary of the RCH.

During the past year, our Committee has enjoyed a membership renewal with the addition of Greg Lowe, Simon Feldman and Ben Walker. At the same time we extend appreciation to Diane Gerrard, Colin Wise, Alexia Routley and Ruth Kurc who have tendered their resignations after varying terms on the Committee.

Thank you for your continued support. We look forward to working together over the coming year to excel research and innovate patient care at the RCH.

Sincerely,

A handwritten signature in black ink, appearing to read 'Barry Novy', with a long horizontal stroke extending to the right.

Barry Novy OAM
Chairman of RCH1000

2020 Calendar RCH1000 events

Event	Date	Additional comments
Annual Dinner	Wednesday 7 October Port Melbourne Yacht Club	A dinner to celebrate the research funded at the RCH and the people who make it possible.
Grand Rounds	Every Wednesday 12.30pm - 1.30pm Streaming online	The Grand Rounds seminar series is the flagship educational meeting of the RCH campus. Over the course of the year, the series is expected to broaden our experiences and understanding of child and adolescent health, regardless of whether we come from a clinical, research, academic, or other background.

For more information on these events, please contact Erin Davidson at rch.1000@rch.org.au or (03) 9345 5901



Meet an RCH1000 Committee Member:

Ben Walker



My name is Ben Walker, I'm a 39 year old husband to Petalyn and father of two young boys Lachlan aged eight and Sebastian aged three. My younger brother was born with a genetic liver disorder in 1987 and so I spent a lot of time at the RCH as a child and teenager. The care and treatment provided to my brother saved his life. As I've now become a father myself (with one particularly accident prone son who has already had four trips to the RCH!), the importance of what the hospital does to support families has become evident. Now that I'm able to donate to the RCH1000 both financially and with my time, I find there isn't a greater cause than supporting an institution that improves the lives of our children.

1. In five words tell us why you're passionate about supporting the RCH.

There's no more noble cause.

2. How did you become involved in the RCH community?

The RCH has been a part of my life since I was seven years old as a number of family and friends were treated there. I have always been grateful and appreciative of the amazing work and miracles that occur in the four walls of the RCH. As I've aged and become a father myself, the services the hospital provide to children has made me immensely proud of the RCH being in our city, state, country and backyard.

3. How have you supported the RCH over the years?

Previously my support to the RCH had been piece-meal. I'd donated to the Good Friday Appeal every year and participated in the Run for the Kids every so often. As my family has grown and my career afforded me the opportunity to donate my time and money, I decided to become involved with RCH1000 last year.

4. What's your favourite RCH memory?

A number of years ago I was undertaking the Run for the Kids event. As I was halfway through the 15km run and coming over the top of the Bolte Bridge, I could see the RCH in the distance. As my aging legs and body were failing me, I motivated myself by imagining all the young kids who would have been in the hospital wishing they could be outside running. I remember a fellow runner next to me had a slogan on their shirt as motivation for why they were running so I asked them to tell me the story of the person that they were running for. Their stories and the thought of the kids in the RCH spurred me on. I certainly didn't set any records, but I know for a fact that the amazing stories of the RCH and the patients certainly made the last few kilometres of the Run for the Kids a lot easier!

5. What would you say to someone thinking of joining RCH1000?

If you can, do. If you are able to afford the outlay it's worth it. It's about a cup of coffee a day. I would happily forego that second coffee of the day knowing that my funds are going to help support such a great cause. If you have children yourself, you never know when the amazing work of the RCH might help someone you love.

UPDATE: HAPPI Kids are healthy kids



Thanks to the dedicated support of RCH1000 members, Professor Paul Monagle and his team are continuing their vital research on age-specific references for blood samples in children and young people with the HAPPI Kids II pathology study.

HAPPI Kids I

Blood tests are vital in diagnosing whether an individual is sick, monitoring the progress of their illness and treatment, or confirming if they are, medically speaking, 'normal'. Normal is considered as a reading in the range where 95 per cent of the population lie when in good health and is what blood tests are measured against. However, the normal range changes with age and what is a normal reading for an adult is very different to that of a child.

The HAPPI Kids I study, funded by RCH1000 addressed this dilemma by collecting blood samples from 'normal' healthy babies and children from birth to 18 years old and used this data to build a new paediatric-centred database. Researchers can now measure the blood tests of sick children against data that is more relevant to what is normal for their age. This research is a significant step forward in understanding the clinical use of these tests in children not only at the RCH, but in the wider medical community in Australia and abroad.

HAPPI Kids II

Building on the vital data gathered in HAPPI Kids I, the second stage of this study is expanding to support the diagnoses, monitoring and treatment of more complex blood conditions.

Using the same methods as HAPPI Kids I, highly trained pathology collectors are working in collaboration with The Royal Women's, Sunshine and Northern Hospitals to obtain samples from 'healthy' newborn and prematurely born babies to those aged up to 18 who are visiting hospital for minor day surgery.

"The study involves all the campus partners and is logistically challenging to administer. For each sample we collect from a child of a certain age we need to determine what tests we need on that age group. Each of the tests requires samples in a different medium and so our collectors have to know which mediums to collect in, then samples have to go to the right labs for processing," said Professor Paul Monagle.

"Before HAPPI Kids I it was argued that doing reference ranges in children the way we are doing it was not possible. A part of what we did with HAPPI Kids I and what we're currently doing with HAPPI Kids II is demonstrating that it is possible no matter the complexity. We are so appreciative of RCH1000 support because this study is fundamental to the care of our children."

HAPPI Kids II: How it works

Blood collected from medically “normal” children from birth to 18 years old to build a database of age-specific blood samples

Birth ————— **18yrs**



Blood samples go through age-specific tests



IMMUNOLOGY CELLULAR TEST

A complex test which is used in the diagnosis and management of immunity deficiencies.



TELOMERE LENGTH TEST

Telomeres are caps at the end of each strand of DNA. There are three different tests conducted. Measuring telomere length is important for the diagnosis of blood cell and bone marrow diseases.



PLATELET FLOW CYTOMETRY TEST

This test helps with the diagnosis of bleeding disorders.



AGE-SPECIFIC BLOOD DATABASE

results are published in journals and provide a reference range for the RCH and the community.



IMPACT ON KIDS

The RCH and other institutions can now measure the blood tests of sick children against data that is more relevant to what is normal for their age.



Pocket rocket Matilda's brave oncology battle

The HAPPI Kids II study will have a significant impact on the diagnosis of complex diseases and allow for individually tailored treatment for children like Matilda with acute lymphoblastic leukaemia (ALL).

Words by Brigid O'Connell, Herald Sun

Matilda Hutton-Latham is known for being a cheeky prankster. With her twin brother, Patrick, by her side, the pair are natural born sidekicks.

So when the four-year-old started limping a month before Christmas, parents Ivan and Belinda thought their sassy daughter was mimicking her dad, who was also hobbling after injuring his leg.

An X-ray showed there was nothing structurally wrong with her leg. A blood test was next. Within an hour, doctors gave her parents an envelope with the results.

The doctors had already phoned The Royal Children's Hospital (RCH). The couple were told the hospital was expecting them. Matilda was diagnosed with acute lymphoblastic leukaemia (ALL).

"We just told her she has a bad germ and it will take a long time to get rid of it," Mr Hutton-Latham said. "She was a bit scared of the other kids in the oncology unit who had no hair. We've just told her she'll be all right and her hair will grow back thicker and stronger."

More heartbreaking than the upheaval Matilda's illness has caused for her family, and the toll the treatment has taken on her little body, is how common this type of cancer is.

The RCH sees about 40 children a year with ALL, making it the most common cancer the hospital treats.

These children all face at least two years of treatment, and that's if things go to plan.

Oncologist Françoise Mechinaud said while the types of chemotherapy they used were decades old, they were now much better at adjusting the dose depending on the disease risk of the patient.

They use a set formula to work out the intensity of treatment needed, entering the child's age, the number of infection-fighting white blood cells in their blood, the genetic and biological make-up of the disease, and finally — and often most importantly — how well the child responds to the first month of therapy.



Photo by Jay Town, Herald Sun

"This risk-adjusted treatment has been a significant progress, so there is a scale in what we do and not one size fits all," Dr Mechinaud said. "Because Matilda responded well, but not very well, she is in the intermediate risk."

"We know that with very standard treatment we can cure up to 90 per cent of the kids with medication that has been used for many, many years."

One of the hardest parts of cancer treatment has been separating the twins, who recently turned five. "She's a non-stop little pocket rocket, and Paddy is very similar," Mr Hutton-Latham said.

"Tilly will be saying, 'I want to go home right now,' to my wife when they're in hospital. At the exact same time, Paddy will be at home saying pretty much the exact same thing, right down to the same words. You get a bit of that separation anxiety."

"Paddy just says he hates the germ. That he wants it to go away."

"I just hope she has a full recovery in the next couple of years, without any relapse so she can move on and put it all behind her."

RCH1000 Luncheon and tour

The RCH1000 tour and lunch gives members a fascinating insight into the incredible work undertaken at the hospital and how philanthropy drives innovation in medical research.

The annual RCH1000 tour and lunch was held on Saturday 4 May 2019 with 35 members and guests attending. Hosted by Simon Harvey, Principal Specialist in the Neurology Department, the tour initially covered the hospital's ground floor facilities. Participants were then taken to the Neurology Department, where discussion covered a range of conditions treated and an explanation of the on-site diagnostic equipment including the electroencephalogram (EEG).

Simon also spoke at length about the diagnosis and treatment of paediatric epilepsy and the very significant improvement in treatments and outcomes which have been achieved during recent years.



Simon Harvey, Principal Specialist in the Neurology Department.



Photo by Jason Edwards, Herald Sun

2019 RCH1000 Annual Celebration Dinner

The annual RCH1000 dinner is an opportunity for members to come together to celebrate their support of the RCH and to showcase the impact of research to new supporters. The 18th dinner was held at the Port Melbourne Yacht Club on Tuesday 24 September 2019.



Many thanks to long standing RCH1000 Patron, Peter Hitchener OAM who continued his generous support as the Master of Ceremonies for the evening.

Guests were treated to a truly inspiring presentation from RCH surgeon, Dr Liz McLeod, who shared the good news story of the successful separation of Bhutanese conjoined twins, Nima and Diwa.

Dr McLeod prefaced the story by saying that, “without research into this incredibly rare condition and without the sharing of that information by colleagues around the world, we would not have been able to consider performing the surgery. A huge proportion of this research is made possible only with philanthropic investment.”

While reflecting on the importance of teamwork in the surgical field, Dr McLeod said that, “human beings work best as collectives. There is nothing new about this – this is primate evolutionary biology 101. We are strongest together.”

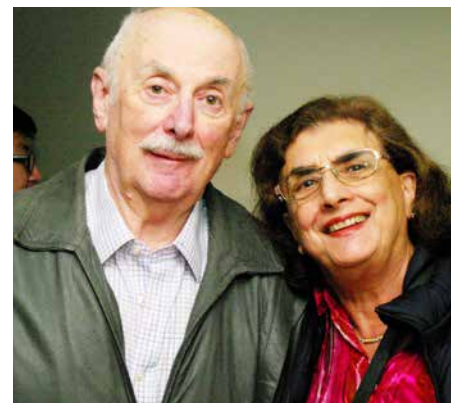
Similarly, RCH1000 has significant impact by bringing people together to support the hospital, rather than working as individuals.

The dinner was a great success with 16 new members joining the RCH1000 family on the night. As we grow, the difference we can make to the lives of some of the most vulnerable children grows with us.

Our goal is to become 1000 members strong.

Will you join us in 2020?

The 2020 RCH1000 Annual Celebration Dinner will take place on Wednesday 7 October.



*"Research is
designed to explore
truth, and to inform
action."*

Dr Liz McLeod





Meet an RCH1000 Member:

Regina McInnes



Regina McInnes has been a member of RCH1000 since 2004 and sat on the RCH1000 Committee for a number of years. As the director of her own real estate company, Regina knows Melbourne and understands the importance of the RCH through the difference it makes to so many lives.

I think it's important to support the hospital as a way to give back and recognise the amazing work that all the teams at the hospital do," she said.

Regina's support through RCH1000 has helped fund numerous projects. One of these is the neuroimaging analysis laboratory that performs various diagnostic imaging tests to assess different organs and systems of children with brain tumours, epilepsy, stroke, head trauma and neurometabolic disorders.

"When you meet the staff, their passion and dedication is inspiring," continued Regina. "The research means we are finding ways to make lives better for those with an illness and their carers and families."

Committee Members 2020

Peter Hitchener OAM
PATRON

Barry Novy OAM
CHAIRMAN

Efrem Goldhammer OAM
CHAIRMAN EMERITUS

Ben Walker (Deputy Chair)

Geoff Kliger

Richard Leder OAM

Michelle Olinder ESM

Joseph Carbone

Sue Hunt

Anthony Mercuri

Regina McInnes

Simon Feldman

Melanie Super

Sid Gaddie

Sara Gold

Michael Lewin

Les Thomaidis

Jeff Slabe

Peter Stach

Greg Lowe

Celebrating 150 years of care



2020 marks 150 years of care at the RCH, an incredible milestone that encompasses ground-breaking clinical innovation, cutting-edge medical breakthroughs and the best in patient centred care, placing the RCH as one of the world's leading paediatric hospitals.

To celebrate this momentous milestone, the hospital will present RCH150, a year-long program of community events, through-provoking seminars and historical exhibitions.

RCH150 features opportunities for the whole community to be involved; whether it's exploring our Hospital Heroes Gallery or the MCRI Medical Milestones on campus, going on a Healthy Adventure with Ari on your mobile device, or exploring Melbourne and Geelong as part of Me and UooUoo: RCH150 Anniversary Art Trail. This year we will also welcome two new permanent artworks on campus by First Nations artists as part of Celebrate. Create. Connect, the Aboriginal Art Project.

The anniversary is also our opportunity to thank you, the hospital's community of supporters for the significant role you've played in making the RCH a world leading paediatric hospital and creating a future of bright possibility for sick children.

We hope that you will be part of the RCH150 celebrations, please visit rch150.org.au to learn more.





RCH1000

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Thank you for your continued support

Are you interested in becoming an
RCH1000 member?
Please contact Erin Davidson at
rch.1000@rch.org.au or
(03) 9345 5901



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