Eunice Lee knows grief better than most.

The Victorian grandmother lost two sons to the bleeding disorder haemophilia, one at 11 weeks and the other at 16 years.

This month, she got to meet the Royal Prince Alfred Hospital doctor has spent more than two decades developing a world-first cure using gene therapy. Professor John Rasko’s breakthrough was published in The New England Journal of Medicine and heralds a treatment for the life-threatening condition which has plagued Mrs Lee’s life for more than 50 years.

“[Professor Rasko]’s created a miracle for me and for Mark,” she says. “I have dreamt of everything I would say to him when I see him. I wish my other sons could be here to see what can happen when you get someone like him who puts their heart and soul into something like this. It’s incredible.”

Haemophilia is an inherited disorder where blood does not clot properly due to missing or defective clotting factor. Haemophiliacs experience a wide range of bleeding episodes, usually into the joints or muscles, and episodes can often occur spontaneously, without an obvious cause, or as a result of trauma or injury. Over time, bleeding can cause severe arthritis, chronic pain and disability.

Many people with the disorder have to undergo infusions of a synthetic clotting agent up to three times a week.

In Professor Rasko’s trial, 10 male adults with severe haemophilia B were given a single injection of a harmless virus containing a manufactured gene. “The viral agent ferries the gene into the liver where it takes up residence and hopefully produces Factor IX for the rest of the patient’s life,” Professor Rasko says. “We’re confident this therapy is life-changing for our patients and, without doubt, this is the best outcome to date for haemophilia gene therapy in the world.”

The participants were followed for 52 weeks. Eight out of 10 did not require factor infusions and nine out of 10 did not experience any bleeding following gene therapy. There were no serious adverse effects recorded.

For Eunice’s son, Mark, the trial has been life-changing. From birth, he has been “in and out of hospital like it had a revolving door” but since receiving the experimental gene therapy, he has not had any bleeds. “I have two daughters who could be carriers for haemophilia, but now I know that if they have affected children, it will be one injection and they can live normal lives. This goes beyond our little family currently. It will have a positive impact on all generations to come.”
Executive Messages

DECEMBER 2017/JANUARY 2018

Message from the Chief Executive

Dr Teresa Anderson
Sydney Local Health District
Chief Executive

We have come to the end of another year and what an amazing year it has been.

This year, we secured funding for a $341 million redevelopment of Concord Hospital; we won the prestigious NSW Premier’s Award for driving public sector diversity for the Employ-my-ability program; and we celebrated the 135th anniversary of Royal Prince Alfred Hospital.

We also had a world first breakthrough in the treatment of the blood disorder haemophilia. This amazing gene therapy was the culmination of more than two decades of work by Professor John Rasko and his team, and will allow people with haemophilia to have a one-off injection rather than infusions up to three times a week and life-threatening bleeds. It was an honour to meet Mark Lee and his family whose lives have been irrevocably changed by Professor Rasko’s work.

This year, we also experienced the busiest winter since the 2009 influenza pandemic and I’d like to take this opportunity to thank you all for your hard work and commitment throughout this time. Every one of you went above and beyond – with a smile on your faces – to ensure our hospitals continued to run smoothly and our patients received excellent clinical care.

I hope many of you will take a well-earned break over the festive season, to spend time relaxing and with loved ones and friends.

I’d also like to thank our staff who will be working over the holiday season, providing excellent care to our patients who will be away from their families at Christmas.

Merry Christmas. May we all have a happy and healthy 2018.

2017 has been another incredibly busy year with Sydney Local Health District continuing to provide excellent health care to an ever-increasing population, both within our catchment and beyond.

I am very proud that we have again been named the best performing district in the state – a testament to the hard work put in by each and every staff member and volunteer. It is a privilege to be the chair of an organisation which takes such pride in the delivery of healthcare 24 hours a day, seven days a week.

We have achieved so much this year – from winning major awards to growing our services. We won two Premier’s awards for our Transfer of Care program, which gets paramedics back on the road faster by allowing them to hand over their patients to a team of experienced nurses in our emergency departments, and our Employ-my-ability program for job seekers with disabilities. We also received a Prime Minister’s award for the successful roll out of eHealth NSW’s electronic medication management (eMeds) program.

Our annual Sydney Innovation and Research Symposium was another significant success this year, attracting thousands of staff, clinicians and researchers exchanging ideas on the future of healthcare. The inaugural Big Idea and Sydney Robotics Summit also helped put the symposium on the map for clinicians and researchers around the nation.

And next year looks equally as exciting already. I am looking forward to work starting on the redevelopment of Concord Hospital to ensure it continues to meet the demands of the community and our veterans, and we expect the new multistorey car park for staff at RPA to open within the next few months. We are also working on a master plan for Canterbury Hospital so there are interesting times ahead.

The achievements this year from our staff show that they are committed to working together with compassion, respect and integrity to provide services that are relevant, efficient and focused on achieving the best possible outcome for our patients.

Thank you for your hard work and enjoy the festive season.

The Hon. Ron Phillips
Sydney Local Health District
Board Chairman

Message from the Chair, District Board

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Puppy love changing lives

Dani has a sense of hope – for the first time in 19 years.

It’s all thanks to some creative thinking by the mental health team at Royal Prince Alfred Hospital – and a tiny miniature spoodle called Lucy.

Dani is the first participant in the innovative TAILS pilot program funded by the District at the last round of The Pitch.

TAILS, or Therapy Animal Intervention in Sydney local health service, provides a long term patient with a puppy to look after at home, train and bring back into the unit regularly to spend time with other patients.

It is the brainchild of Dr Viktoria Sundakov, Dr Amy McTaggart, registered nurse Michelle Harris, occupational therapist Abby Moran and social worker Kirsten Gridley.

“Mental health units can be restrictive, sterile, lonely, frightening and stigmatising, removing people from their everyday lives and routines,” says Dr Sundakov, RPA’s Director of Psychiatry.

“These problems are worse after hours and on weekends when boredom and a lack of activities can contribute to frustration, worsening of symptoms and aggression. Animal assisted therapy alleviates tension on the ward, promotes social integration and reduces stress-related separation from family and friends.”

In the past few years, Dani has spent an average of 224 nights a year as an inpatient in psychiatric units across NSW.

But since being involved in TAILS, that has dropped to seven nights in the past five months.

“Lessons speaks volumes about the changes that have happened within me as a result of having something meaningful to do and feeling valued,” she says.

For Dr Sundakov, TAILS provides a cost-effective, targeted, innovative solution – with a touch of humanity.

“When you have a long term patient, it’s important to be brave enough to step outside the box and do something different to improve their life.”

Lucy is already attending puppy preschool at the University of Sydney and will undergo training through Delta Therapy Dogs. She will officially be on the job within our wards next year.

$1.4 million mental health step down service opens

A new 10-bed service offering psychosocial support and clinical care for mental health clients has officially opened in Burwood.

Jointly founded by social enterprise New Horizons, NSW Health and Sydney Local Health District, Eurella is a ‘step up, step down’ rehabilitation and recovery service with an emphasis on relapse prevention and residential support following discharge from hospital.

The District’s Director of Clinical Services, Mental Health, Dr Andrew McDonald, said Eurella could ease pressure on mental health inpatient units and help people recover faster.

“It provides a safe and supportive environment in the community for people facing acute mental health problems, by either avoiding hospital altogether or, where hospital care is necessary, stepping back into the community before returning home,” he said.

The Chief Executive Officer of New Horizons, Judi Higgin, said: “Eurella’s unique position is that it provides tailored, holistic support, combining the clinical and psychosocial care to help people recover as quickly as possible.

“This type of ‘step up, step down’ facility is a tried and tested model in Victoria. Opening this successful model in Sydney is a great addition to the existing support, and a real step forward for community-based models of care.”
Royal Prince Alfred Hospital researchers will explore the first 1000 days of life in a bid to determine whether conditions such as obesity, diabetes and cardiovascular disease can be prevented.

The Baby1000 study, which received widespread media coverage this month, will recruit 500 women and their partners for a longitudinal pilot study.

“Obesity is one of the most serious global health crises of the 21st century, and the greatest rise is among women of reproductive age,” says neonatologist Dr Adrienne Gordon.

“At the time of conception, the health and lifestyle of the parents — including their diet, body weight, stress levels and whether or not they smoke — play an important role in the development of the foetus and in determining the future health of the child,” Dr Gordon said.

“This study offers an invaluable opportunity for intergenerational prevention. A deeper understanding of how these parental factors impact on children and long-term health could lead to improved health for future generations.”

Women who are less than 13 weeks pregnant or are planning a pregnancy are invited to apply to take part. Participants will need to attend study visits at the RPA clinic at the Charles Perkins Centre in Camperdown before, during and after pregnancy.

Throughout pregnancy and beyond, researchers will collect general information on lifestyle, nutrition, body composition, pregnancy weight gain and mental well-being. A wide range of biological samples will also be collected.

Collections will be stored at the recently launched NSW Health biobank at RPA, the largest storage bank for human biospecimens in the southern hemisphere.

Participants will also receive two extra free ultrasounds later in their pregnancy normally only available for high-risk pregnancies.

For more information, please contact cpc.baby1000@sydney.edu.au

Dr Adrienne Gordon, left, hopes to unlock chronic disease.

Getting sleepy

Mental health inpatients could soon be wearing these futuristic glasses to improve their sleep patterns and reduce their need for sedative medications.

Developed by researchers at Adelaide’s Flinders University, the Re-Timer glasses shine glowing green-blue light into the eye of the wearer to help manipulate their production of melatonin — the hormone the body uses to induce sleep.

“The biggest driver of your body clock is light and the light on the ward, even a brightly lit ward, is one-thousandth the intensity of outside on a cloudy day,” RPA’s Professor Nick Glozier. “We are not augmenting the body clock of our patients, enabling them to get good circadian rhythms.”

The glasses were worn by several Socceroos to combat jet lag on their flight home from Honduras during the World Cup qualifications.

Professor Glozier, a clinical academic at the Professor Marie Bashir Centre and the University of Sydney, was awarded $46,500 at the latest round of The Pitch to roll out the program over 12 months.

Judges Chief Executive Dr Teresa Anderson, Associate Professor Vicki Taylor, Associate Professor Victor Storm and RPA’s acting general manager Nobby Alcala also funded the purchase of Saebo orthosis treatment kits for use at Balmain and Royal Prince Alfred hospitals at a cost of $41,187.

The kits are used to improve hand and arm mobility and function in people with neurological injuries, including stroke.

Professor Nick Glozier demonstrates the Saebo.
Water therapy ticket to health

For Kerri Thorne, Royal Prince Alfred Hospital’s hydrotherapy pool has been a ticket to mobility.

The 52-year-old from Glebe developed severe rheumatoid arthritis at the age of seven, and has undergone multiple joint surgeries, including fusions and joint replacements. She’s one of many patients who find land-based activities difficult due to joint instability, pain and weakness.

At RPA, hydrotherapy, where patients exercise in a heated pool with physiotherapists, is used to provide people like Kerri with a weightless environment to improve muscle strength, reduce pain, lose weight, improve function and reduce disability.

Hydrotherapy is also used to help obese patients lose weight as it reduces the need for joint replacement surgery, and for those still requiring surgery, weight loss can lower surgical risk through improved cardiovascular function and result in shorter hospital admissions.

Unlike other community pools, the RPA hydrotherapy pool has specialised equipment, staffing and emergency protocols in place to allow our most disabled patients to safely access and undertake hydrotherapy.

“Accessibility is different for everyone because we all have varying needs, but I spent months trying to find a community pool that I could use and none of them worked for me,” says Kerri. Now, a few months into weekly sessions with a physiotherapist at the RPA pool, she is already experiencing improvements in her strength and balance.

“My musculoskeletal system is very weak and I get injured very easily, but I can move much better in water and already I’m more steady standing and a lot less stiff.”

Work is also starting soon on a new wheelchair accessible shower and toilet for people using the pool and an upgrade of the existing showers and toilets.

Not so sweet

Royal Prince Alfred Hospital stopped selling sugary drinks in November and the move has been embraced by visitors.

The World Health Organisation recommends a maximum of six teaspoons of sugar per day, but one 600ml bottle of Coke contains 16 teaspoons of sugar, a 600ml bottle of Solo has 17, and a 1.25 litre bottle has 33.

“As a health service, we treat the sick, but we also work very hard at ensuring people in our community don’t need to be admitted to our hospitals,” says RPA’s acting general manager, Nobby Alcala.

“Consuming excessive amounts of sugar increases your risk of obesity, type 2 diabetes, high blood pressure, stroke, inflammation, kidney disease, fatty liver disease, heart disease and tooth decay. So, it’s an easy one - choose water.”

Staff, patients and visitors can still be able to buy juices with no added sugar, diet soft drinks, tea, coffee and milk from RPA retailers and soft drinks purchased externally can be consumed at RPA.
CAROLS AT YARRALLA ESTATE

SYDNEY DENTAL STAFF BBQ
VOLUNTEERS CHRISTMAS PARTY

Merry Christmas

EMEDS 10TH ANNIVERSARY
CONCORD HOSPITAL

VOLUNTEERS APPRECIATION
Staff member of the year

Clinical nurse consultant Annie Hepworth took out this year’s staff member of the year award for her work with patients who arrive in our emergency departments with delirium or dementia.

“I’m really there to make sure the patient has a good experience, as well as they can in this environment, because it can be quite chaotic,” she says.

Annie, pictured with Chief Executive Dr Teresa Anderson, is passionate about educating her patients’ families on the long term impacts of dementia.

“There’s a lot of grief involved because dementia is a terminal illness and it’s the second leading cause of death in this country. We’re treating the whole family, not just the patient.”

After roles in transplant and management, Annie took on the dementia role four years ago because it allowed her to work in her area of passion - aged care.

Not only are the staff in aged care “kind and committed”, but the patients have often led “the most incredible, diverse lives”.

“Elderly people have always got this other life that they’ve lived outside their hospital admission and I think sometimes we can lose sight of that. Part of my role is to make sure whenever we’re caring for someone – whether they have cognitive impairment or not – that we recognise who they are outside of hospital.”

Humbled and honoured by her award, Annie hopes it will lead to better recognition of patients with dementia and delirium.

“They’re in a group that are incredibly vulnerable because of their cognitive impairment and I feel this award allows them to be seen.”

View the full list of 2017 Quality Award winners at www.slhd.nsw.gov.au/agm

EVENTS CALENDAR

Opening of Eurella mental health
20 December, 12-1pm
11 Eurella Street, Burwood
Sydney Local Health District in partnership with New Horizons will officially open Eurella, a mental health community based hospital alternative.
For more information, contact 9515 9002.

Get Healthy initiatives
12-16 February
We’re making healthy choices easier in hospital cafes and retail outlets, along with a range of initiatives to improve healthy and active living. Look out for information at each hospital during Smart Eating Week.

The Pitch
16 March 2018, 4-6pm
Concord Medical Education Centre
Have you got a brilliant idea to change the way we deliver health care? Get planning and submit your idea for the first Pitch of 2018, entries close 19 February.

Save the date – Innovation Week 2018
Sydney Innovation and Research Symposium – Friday 22 June
The Big Idea – Thursday 21 June
Sydney Robotics Summit – Saturday 23 June
More information and events will be announced in 2018.

Merry Christmas

HealthMatters is all about you. We would love to hear your stories.
Simply email sydneymedia@ss wahs.nsw.gov.au