

ISSUE 6 • MARCH 2020

CHARLIES' NEWS

How you're
helping a mother
fighting for
her life ➔



www.charliesfoundation.org.au



From Vicki's desk

We've just come back from the Fundraising Institute of Australia's national conference. Each year the FIA offers incredible professional development for fundraisers around the country and even internationally.

This annual event brings together fundraisers to focus our thoughts on people like you: The incredible and generous people who bring hope to our world – our donors.

I am always inspired when I come back from the conference to do more than I have before. This year is no exception, and it's because of you that together we can make amazing things happen.

That's why, in May I will be taking part of the Cape to Cape for Charlies, showing my commitment by fundraising and walking alongside all our wonderful Charlies Champions.

Not only am I looking forward to the cheese, wine and gourmet food (and the walking too, of course!) I am most looking forward to hearing why the other people doing the walk have done so for Charlies. It's these stories that are so inspirational and give you an idea of exactly why it's so important to be funding medical research.

We are still looking for a few more special people to join our team, so if you'd like to jump on board and hike, wine and dine with us, enquire now. Time is running out!

I hope you enjoy reading this newsletter about how you're actively changing people's lives. And I hope you will join us in Margaret River in May!

Thanks and take care.

Vicki

Vicki Rasmussen
Executive Director

Cape to Cape Competition Winner!



A very generous donor offered to pay the full registration costs for one very lucky person to attend the Cape to Cape. Entrants were asked to write a short paragraph describing why they believe they should win...

Diane Smiles is a retired 64-year-old. In her retirement Diane is studying bio-medical science at university after suffering many medical issues herself.

"Having always had an interest in the human body and disease, it's causes and treatments and after the cancers I decided I may be able to contribute to research or diagnostics with this qualification as a volunteer in a

laboratory, assisting those who are already diagnosing (eg pathologists), or assist a research team," says Diane.

Diane is quite extraordinary. She has beat not one but two types of cancer, breast cancer in 2017 and bladder cancer in 2019.

Diane was living in Lancelin at the time of her treatment and said the constant travel was very draining.

After radiation therapy, multiple operations and a few hiccups along the way Diane is now cleared of Cancer and is jumping into life whole heartedly.

She is now working on raising money for Charlies Foundation for Research for her upcoming Cape to Cape trip in Margaret River!

How you're helping a mother fighting for her life...

Rebecca Logan, when you look at her, is the picture of health, she's young, motivated and a mother of two young children. The last thing you'd suspect is that she was unwell and currently on the transplant list for a new kidney.

Diagnosed with kidney disease when she was just 23 years old, Rebecca didn't suffer many symptoms, so continued to live a normal life under the supervision of her GP and doctors. It wasn't until she was about 32 years old that she became severely unwell and her kidneys began to fail due to Focal segmental glomerulosclerosis (FSGS), causing the scarring of her kidneys.

Rebecca was and still is very career driven and focused on

making a good life for herself, her husband and her two children. At this stage of her life, she was given the opportunity by her employer to move to Karratha for 3-4 years for a work operation. The logistics of having found out she was very unwell and that her kidneys were failing and moving to Karratha were something she didn't expect.

Rebecca began dialysis for her kidney disease quickly after becoming symptomatic, and with the help of doctors from Sir Charles Gairdner Hospital was able to partake in peritoneal dialysis from Karratha.

"I was living in Karratha but had to travel back to Perth a lot. There are so many things you don't expect, like picking up medications, you can't just pick them up from the chemist you have to come to the hospital," Rebecca says.

"On top of the travel I also had to consider accommodation and transport while I was here. Renting a car and an apartment for a couple of weeks at a time can get expensive," she says.

"I can't imagine if I was struggling what that would have been like."

Rebecca has since had a kidney transplant thanks to her very generous sister, but unfortunately the donated kidney is now failing too.

Rebecca is now fighting to save her life, in the hopes that someone will be a match and donate a kidney.

To hear the rest of Rebecca's amazing story of survival and the latest research that has recently had a share in a 2.5-million-dollar grant, keep an eye out for our tax appeal!

How you are helping this mum while she waits for a kidney transplant to save her life...



Charlies Art Curator

Walking around the hospital, whether it be in the wards or the outpatient clinics one might observe a myriad of expressions be it anxiety, stress or sadness on the faces of patients while busy doctors, nurses and other clinical staff go about doing their utmost to treat and care for patients in their quest to provide relief and healing.

There is no doubt that the environment of a hospital can be stressful for staff, patients and loved ones alike. But although you might not notice it, there are forces at work attempting to provide some quiet relief to this overwhelming stress - in particular one amazing lady, Maria Yakimov.

Maria is Sir Charles Gairdner's art curator. Typically, you might not think a hospital would have an art curator, but a very generous donor has made it their mission to support the efforts of the part-time art curator by covering the cost of the preservation and display of the art collection as well as gifting new works to add to the Hospital's collection.

Maria has an incredible international resume behind her having held coveted roles in New York, Switzerland and Italy. Maria's role is to manage all aspects of the art collection including its disposition, display, preservation, movement, administration and record management.

With the generous donation provided by our donor, Maria has been able to systematically prioritise works in dire need of conservation treatment ensuring the works are returned to their original quality, preserving them for future

generations. On top of this Maria gets the opportunity on occasion to acquire more art for the hospital.

"The desire to acquire and display art that is meaningful for patients and staff is always there," Maria says.

"But the nature of this donation has made me consider it even more deeply."

In acquiring new artworks Maria says the art must first pass a number of requirements, including being of a high artistic integrity, as well as being conducive to wellbeing, meaning the art cannot be dark or gloomy.

Maria says she thinks the art subconsciously, or in some cases consciously, plays a role in providing relief. She says the art allows people to think of something other than their own pain and suffering or that of a loved one, which is her intent entirely throughout the hospital.

"I look for works that are colourful, that offer the viewer a different outlook, a different perspective; whether they conjure up feelings of happiness or wellness or even curiosity," says Maria.

"I like abstract works, they take each individual to different places, they generally hold a different meaning for every individual."

Maria says she believes the art plays a therapeutic role in healing.

"Art absolutely has a therapeutic role to play, I think."

"It is a well-founded fact now that it does generally calm people down, it makes people feel hopeful and provides them with an alternative viewpoint as well."

"I think all those things are very conducive to reducing the anxiety they may feel from being at the hospital, whether they are a patient, visitor or staff."

"There's a lot written about art in medical settings and it having the effect of shortening the period of recovery."

"Art therapy isn't my background, but as a curator of a hospital collection, there is definitely overlap with art therapy," she says.

When asked what her favourite artwork in the hospital is, Maria recalls one that is cherished among the nurses in the Short Stay Unit.

It is Florence Nightingale and the Crimean War, a drawing by Miriam Stannage which is located at the nurse's station.

The drawing depicts a letter written by Florence Nightingale - a very moving letter written from the front line of the Crimean War.

"I like this one," she says.

"Stannage herself trained as a nurse early on in her life and, apart from its artistic qualities, the work encapsulates the essence of nursing as well as the human condition"

Maria couldn't express enough how thankful she is to the anonymous donor for allowing her the opportunity to restore priority works in the collection and to acquire some new artworks.

"The main business of a hospital is not the curation of an art collection it is not even second or third in order of priority, so to have a donor who has made it their mission to support this in the hospital has been really special to me."

So the next time you're in the hospital, stop and look at what's on the walls, you never know what you might find, not to mention the healing and restoration it might bring you in time of need.

Charles Day Tissue Bank

Sir Charles Gairdner Hospital is lucky enough to have a leukemia and lymphoma tissue bank here within the hospital. The tissue bank was started by an incredibly generous donation from Mrs Day, whose husband had been a patient at SCGH.

Mr Charles Day had suffered a rare haematological disorder, which relapsed many times.

“His case was unusual in that his disease, although relapsing many, many times, remained sensitive to treatment each time.

“This meant he was seen in the department over many years and came to be well known to many of us,” says Prof. David Joske, clinical professor.

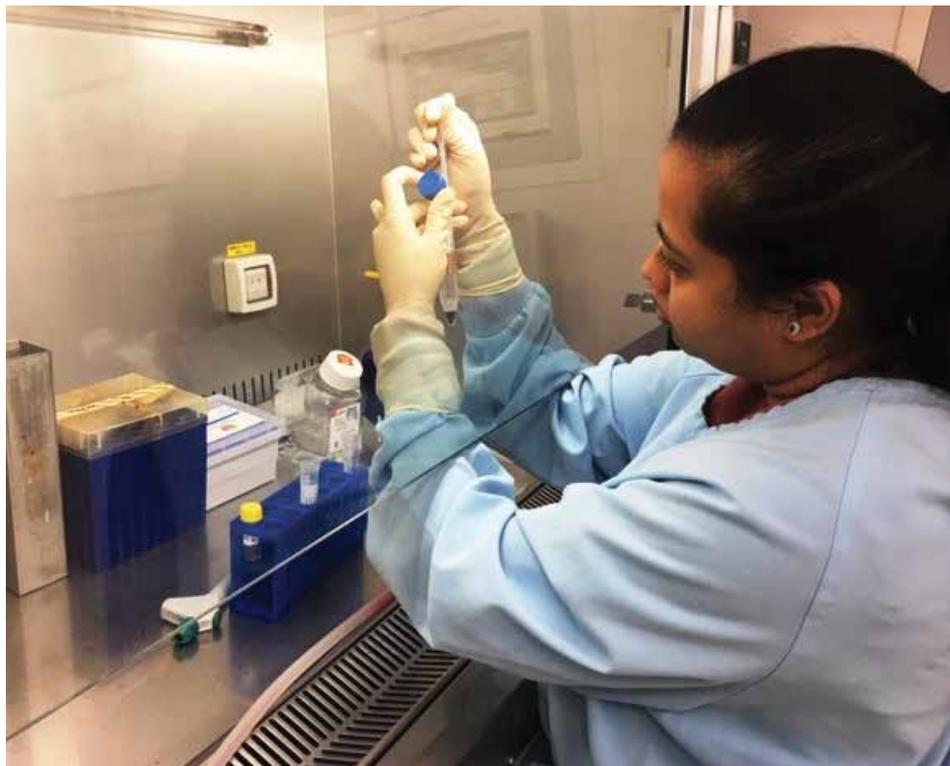
David Joske mentioned the idea to Mrs Day back in 2012, and she was delighted to be the sole benefactor to the official Charles Day Tissue Bank.

The tissue bank is where samples of tissue taken from patients with haematological disorders, including cancer can be stored long term and used for research purposes.

Eight years on, we recently caught up with Carolyn Grove, a clinical haematologist and day-to-day manager of the Tissue Bank, to discuss the progress and use of the tissue bank since its beginning.

Carolyn says the tissue bank is an essential resource to facilitate haematological research.

“If someone has a great idea and funding to do research, they need to have access to samples, not then spend years gathering the disease samples they need to do the study,” says Carolyn.



Since the beginning of the tissue bank, Carolyn and other haematology doctors, as well as scientists within PathWest, have worked hard to store and catalogue samples so they are available for researchers when they need them. As you can imagine, building up enough samples to be used for research takes many, many years.

Since 2014 Carolyn says they've put processes in place to ensure all patients having biopsies through the Sir Charles Gairdner Hospital Haematology Department are asked whether they will consent to tissue bank.

The number of samples banked has increased from just 4 per month in 2013 to over 80 a month in 2020.

The aim is to collect multiple samples from each patient through their disease course, to facilitate diverse research, such as investigating markers of response to therapy or how blood disease changes over time.

The tissue bank has recently expanded to also collect samples

from Fiona Stanley Hospital and Carolyn is working on expanding further and bringing Royal Perth Hospital on board.

“The aim is to make this a state-wide repository for samples for use in haematological research, the samples released so far have been given to various research projects, locally and interstate,” says Carolyn.

“Contributing samples to other peoples' projects is a great way for local researchers to establish collaborations and build publications, which will improve the recognition of WA research and help with competitiveness in future grant applications.

“However, we really want to foster local researchers and locally initiated studies wherever possible.”

“We want these samples to be used in as many high quality research projects as possible, to honour the donation made by the patients who have contributed them with the hope of improving outcomes for those in future.”

WHAT'S ON

Cape to Cape ▾

The Cape to Cape for Charlies is fast approaching! We have 12 excited people taking part in a bucket list experience that will see them walk along the beautiful coast of WA, stopping at Margaret River's finest wineries and restaurants. There are still a few places left if you want to raise some money for medical research while taking part in a luxurious escape!

Taking part is easy, after paying the registration fee you just need to fundraise \$1000 to go directly to medical research here at SCGH and OPH. Take a look at these amazing pictures to see why you should sign up today!



- **When:** 21st-23rd May
- **Where:** Margaret River, WA
- **Cost:** \$1750 registration, \$1000+ fundraising target

HBF Run for a Reason ▾

Registrations for HBF Run for a Reason are now open! Sign up to walk the 4km, 12km or half marathon. Run, walk or stroll your way through and raise money for Charlies Foundation for Research.



By participating, you're giving hope to those suffering the most. So, what will be your reason for running this year? Perhaps your mum, dad, sister or brother. A family friend, a loved one. Whatever your reason is by running for Charlies you're saving and changing people's lives.

- **When:** 24th May 2020
- **Where:** Corner of Hay Street and William street – Gloucester Park
- **Cost:** \$20-\$92 dependant on age and distances

Easter Craft Fair ▾



The Easter craft fair is just around the corner. Come down and see the lovely and incredibly dedicated craft fair ladies display an amazing array of goodies just in time for Easter. Proceeds from the craft fair are donated to Charlies Foundation for Research to support life-saving, life-changing medical research.

Come and pick up beautiful clothing, handmade candles, wooden toys and so much more.

- **When:** 30th March - 9th April, Weekdays
- **Where:** Out-patients, Ground Floor, E Block

City to Surf ▾

The City to Surf is coming up in August! Keep an eye out on our socials and website to sign up for Charlies!

- **When:** 30th August

Entertainment Books ▾

Entertainment books are back! This time better than ever! Entertainment has gone all digital, so you can now purchase them online and use them on your phone. Say goodbye to the physical book and say hello to more savings! You can purchase your entertainment book through our website, or by using this link: <https://www.entertainment.com.au/orderbooks/83s028>

- **Cost:** \$69.99

Get updates on what's going on at Charlies Foundation by leaving your email address on the donation slip! It will allow us to more effectively and sustainably communicate with you!

For more details, please contact Emma Huijs on 6457 3362 or email emma@charliesfoundation.org.au