



Children's Tumour Foundation of Australia

Annual Report

2017

Table of Contents

- 04 What is NF?
- 06 About CTF
- 08 CEO and Chair Update
- 10 Patron and Ambassador Profiles
- 12 Highlights
- 14 Financial Report
- 16 Bella's Story
- 18 Kylie's Story
- 20 What We Do
- 22 Meet the Team
- 24 Update on the NF Clinics
- 26 Cupid's Undie Run
- 28 Mega Hero March
- 30 Stories from the Community
- 32 2017 Supporters List



What is Neurofibromatosis?

Neurofibromatosis (NF) is a genetic disorder that covers three conditions: NF1, NF2 and Schwannomatosis. NF1 was first described by a German doctor, Frederick von Recklinghausen, in 1882. It is sometimes referred to as von Recklinghausen's disease or syndrome.

NF is one of the most common genetic conditions, affecting up to 1 in 2,500 individuals. It is at least as common as Cystic Fibrosis, Muscular Dystrophy and Huntington's disease.

NF causes neurofibromas (tumours) to grow on nerves throughout the body. Essentially, every nerve cell in the body has the potential to become a tumour. NF has a wide clinical spectrum and complications are variable, unpredictable and widespread. This can lead to a range of significant health issues across a lifetime, including: blindness, bone abnormalities, cancer, deafness, disfigurement,

learning disabilities and chronic disabling pain.

No two cases are the same. People with NF can develop multiple features at the same time; which ones, when and how severe cannot be predicted.

It is estimated that around 10,000 Australians are currently living with NF. It is most commonly diagnosed in children and young adults. It can be harder for adults to identify potential symptoms of NF as they can mistakenly attribute chronic pain, for example, to other causes for many years. NF can vary from mild, allowing patients to live active and productive lives, along a spectrum to debilitating and life-threatening.

“Despite the discovery of the genes for NF1, NF2 and Schwannomatosis, currently there is no known cure and few treatment options are available.”

As a genetic disorder, **NF is inherited from a parent around 50% of the time.** The other 50% is caused by new mutations in NF genes around the time of conception. We do not know why these spontaneous changes occur. There is much that we still have to learn about NF.

People with **NF can be susceptible to discrimination and poor treatment in the community, which can lead to feelings of isolation and loneliness.** An NF diagnosis can leave an individual or family feeling afraid and uncertain for years, especially not knowing how and when it will manifest itself next.

The fight against NF is an international one. We have developed strong links with NF organisations and researchers in: the US, Great Britain, Ireland, Canada and Europe. In Australia, we are fortunate to have some of the world's leading NF clinicians and researchers. They collaborate with their international peers and act as advisors to our organisation.

Through these concerted efforts, we aim to make significant progress in our collective aims of improving treatments for NF and ultimately finding a cure.



About CTF

Our enduring aims

CTF exists to deliver on three major objectives:

- 1 Improving medical services to ensure that people living with NF receive adequate, multidisciplinary care throughout their lives.
- 2 Funding critical research to find effective treatments as well as a potential cure for NF.
- 3 Providing support to children and adults living with NF, their families and carers.

TIMELINE

1985-2005

Founded by George Armstrong and a handful of NF families in NSW

First NF Family Camps and social get-togethers organised

First part-time employee managing memberships and information

Closing of Melbourne NF Clinic upon death of Professor David Danks

2010

Reorganisation as company limited by guarantee with nationwide focus

Change of name to NF Australia and trading name to CTF

Bequest of \$900,000 from the late Lisa Palmer for NF research

Commencement of relationship with Thorn Group and Radio Rentals

2011

CTF selected as main charity for Thorn Group and Radio Rentals

Board appoints first CEO of CTF

CTF moves from Ku-ring-gai Senior Citizens Centre to office facility in Drummoyne

2012

Founder George Armstrong passes away

Expansion focus on Victoria and the Murdoch Children's Research Institute

First Victorian board director appointed

2013

Cupid's Undie Run launched in Sydney on Sunday 10 February

Inaugural Gala Dinners in Sydney and Melbourne

2014

Launch of NF Support Network

Commenced funding for NF Clinic at the Royal North Shore Hospital in Sydney

Annual fundraising exceeds \$1 million

2015

Reopening of NF Clinic at the Royal Children's Hospital in Melbourne

Expansion of NF Support Network into Victoria

2016

Continued funding to NF Clinic at the Royal North Shore Hospital in Sydney

Launch of Mega Heroes walk in Sydney and Melbourne

Annual fundraising reached \$1.36 million

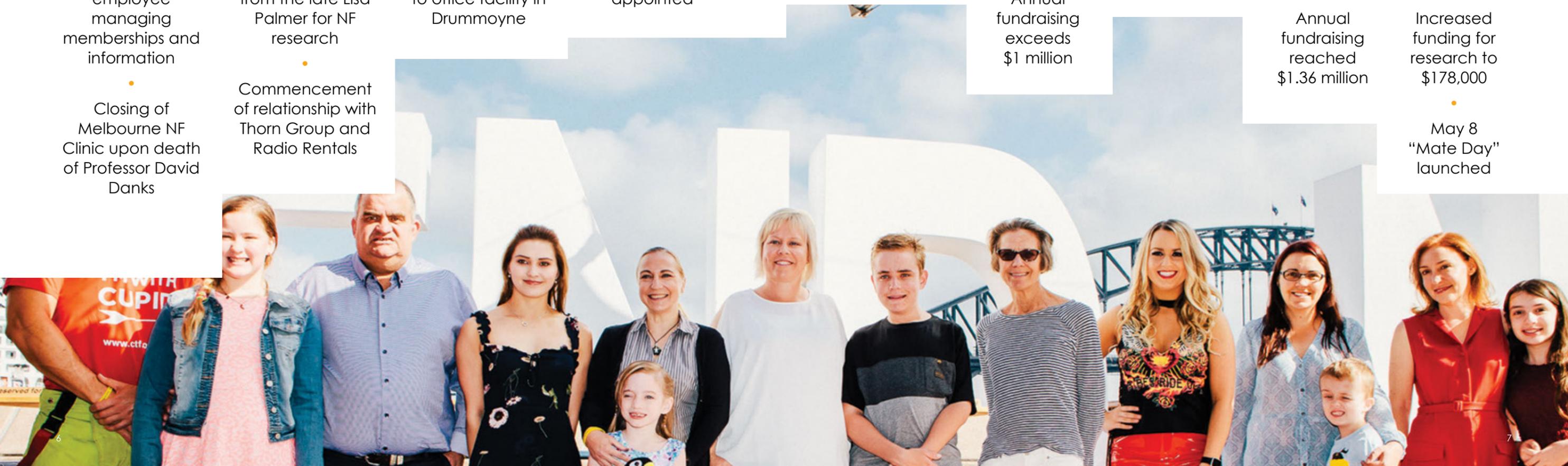
2017

Groundwork laid for support network expansion into QLD

NF community events increase from 6 to 13

Increased funding for research to \$178,000

May 8 "Mate Day" launched



CEO and Chair Update

This past year has brought change, investment and progression within CTF.

During the year, we strengthened our team and expanded our services and research funding.

NF Awareness Month

This is a relatively new initiative which gained momentum in attempting to focus attention on NF in general and medical communities. A breakfast was held with many stakeholders, with a focus on how we can improve the wider community's understanding of the condition to help conquer NF.

May 8, "Mate Day" launched as part of NF Awareness Month.

Community Support

Community support through Camps, Family Days and other activities expanded throughout 2017 from 6 to 13 and the number of Support Groups grew from 11 to 13. In addition to this, an official CTF Facebook Group was formed, attracting many followers. There we provide important and newsworthy information.

Cupid's Undie Run

From a community engagement perspective, the 2017 Cupid's Undie Run remained our most successful fundraising event, assisting in increasing national awareness. Bonds were again our Major Undie Sponsor, and with our amazing runners, we raised nearly \$400,000! 900 people over 12 locations enjoyed the party atmosphere whilst the media ran several stories, providing us with national media coverage with a reach of 12 million.

Silent Auction

This was held as an alternate to the Gala dinner and raised \$80,000. Special thanks go to the Doves Nest Foundation as well as Eddie and Melanie Listorti.

Corporate Partners

The funding of our clinics, CTF team, community activities and research grants would not be possible without the support of our loyal sponsors.

We offer special thanks to our Corporate Partners for their continuing support:

- Thorn Group and Radio Rentals, our Founding Partner
- Acer now into Year 2 of their partnership

- Bonds our long-term Cupid's Undie Run sponsor
- Nine Cares

The Year Ahead

We are excited about 2018, with big plans to benefit our community such as:

- 17 cities planned for the Cupid's Undie Run
- 2 new clinics
- Commencement of funding of the Barney Fellowship
- Inaugural NF Symposium for the medical community
- Online NF seminars to increase participation

Research Funding

CTF's funding of research reached new heights last year, with grants to Murdoch Institute for a study on Autism and links to NF as well as agreeing shared funding for the Barney Fellowship with thanks also to the Dell family and friends.

This support has allowed us to plan increased funding in 2018 and expand the cities where we can offer assistance over and above previous years by holding seminars in SA, Tasmania and WA in addition to the two new clinics.

Our support for people living with NF is expanding, with funding agreed for new clinics, and planning is underway for an inaugural NF Symposium.

Our aims and objective do not change. We will continue to serve you, our community, by: funding the best research, purchasing state of the art equipment and supporting the NF community in as many ways as possible.

“ 2017 saw major growth in the Cupid's Undie Run and also detailed planning to extend our national reach whilst increasing research funding to record levels

”



John Hughes
Chairman



Derrick Hubble
CEO

Patron and Ambassador Profiles



The Hon Nick Greiner AC
Patron

The Children's Tumour Foundation of Australia would like to publicly thank and recognise the continued commitment of its Patron, The Hon Nick Greiner AC.

The Hon Nick Greiner AC

Nick Greiner was Premier and Treasurer of New South Wales from 1988-1992 and, since retiring from politics, has been heavily involved in the corporate world as well as many charitable causes.

In 2014, Mr Greiner was appointed as Patron of CTF. Since then, his willingness to be involved, his availability to our community, staff and Directors as well as his passion for CTF to succeed have been extraordinary.

“
CTF is a very special organisation caring as it does for children and adults with Neurofibromatosis, posing particular challenges for all concerned. Both its research assistance and its support networks are invaluable.
”

-The Hon Nick Greiner AC

Mr Greiner is an ideal person with whom to discuss advocacy. He has personally provided CTF with assistance to spread awareness about NF and openly talk about the challenges that our community face with this condition. CTF continues to work closely with Mr Greiner to ensure we can deliver outcomes and look for ways to engage with local and federal government.



Melissa Wu
Ambassador

Australian diver and silver medal winner at the Beijing 2008 Olympics

Melissa is an exceptional ambassador representing CTF and the Cupid's Undie Run. We are so thankful for her ongoing support.

In her own words...

I've been diving for 14 years now and, despite having my fair share of challenges and obstacles to overcome, I've been lucky enough to compete for Australia at 3 Olympic Games.

I feel extremely privileged to be an elite athlete and I've dedicated most of my life to my sport and to achieving at the highest possible level. Most of the setbacks I've encountered have been related to my sport, and it was never easy to overcome them, but I always kept fighting and pushing forward no matter what. However, I didn't know what it was really like to struggle and face the impossible task of moving forward each day until I lost my younger sister 2 years ago.

Living without my sister feels unbearable and it's the hardest thing my family and I have ever had to go through. I felt numb for so long and couldn't see any way that I would be able to continue living without her. My family is extremely close, so losing Kirsten had a huge impact on us. Whenever I think about Kirsten it makes me happy, but it's always followed by the

agonising thought of knowing she's not here anymore. It hurts and it will never go away, but I knew 2 years ago that I had to be strong for my family and find a way to not only keep going in life, but to make it count and live my life to the fullest for Kirsten.

After taking time away from everything to be with my family, I decided to return to diving. I knew I needed something in my life to distract me from my grief and something to work towards that I could put everything into. Going back to diving gave me time with people that love and support me as well as the chance to not only get back to my peak, but to also improve and qualify for my 3rd Olympic Games. Despite this, the past 2 years have been the most difficult of my life and I've had to work really hard with my psychologist to stay positive and keep going in life. I've also learnt to appreciate life more and, although there will always be obstacles to overcome, there are also plenty of positive things to be grateful for too.

When I met the CEO of the Children's Tumour Foundation, I learnt about Neurofibromatosis for the first time. Although I'd never heard about this condition and didn't know anyone who has it, I wanted to help because it affects so many people and I can only imagine how difficult it must be for people living with NF and their families. Even though I will never be able to completely understand NF because I've never been affected by it, I want to do whatever I can to help. Although my experience is not the same, I've dealt with adversity, experienced loss and hardship and wouldn't want anyone else to have to go through that. I've also experienced the suffering that my family has gone through for the past 2 years, so I can relate to the impact that NF would have on parents and families.

I would love to help raise awareness for this condition so that more people, including myself, can better understand what NF is, how it affects people and what we can do to build a brighter future for those affected.

Highlights

Key Highlights

Financial

Major fundraising contribution from Cupid's Undie Run increased

by **77%**
to **\$315k**

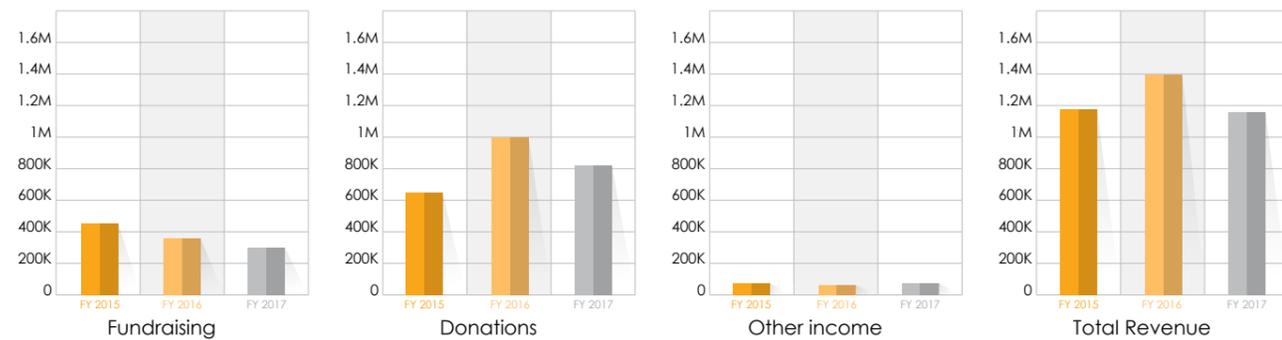


Cupid's Undie Run now undertaken through **12** locations

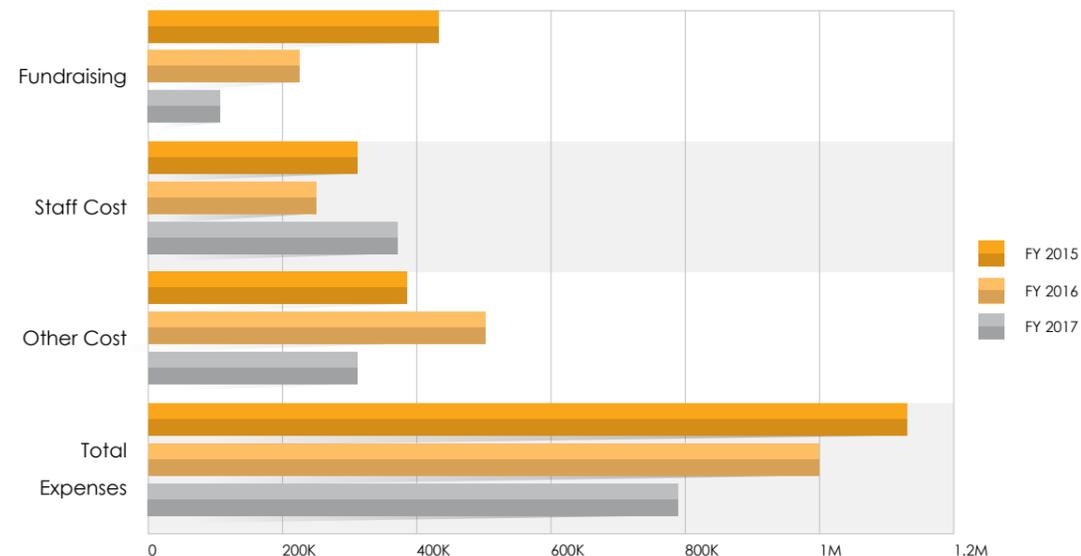


Total revenue declined by **\$235k** owing to deferral of gala dinner event to October 2017 to align with the NF Symposium event

Revenue



Expenses



Support Services



Over **700** patients attended NF Clinics



Groundwork laid for a **new clinic to open** in Brisbane in 2018



Information seminars were held in Melbourne, Adelaide and Hobart



Contributed cumulatively **\$493k** towards support services, mainly in the past 3 years

NF Research

Increased research funding to **\$178k** in FY 2017

Contributed over 7 years cumulatively **\$708k** towards NF research

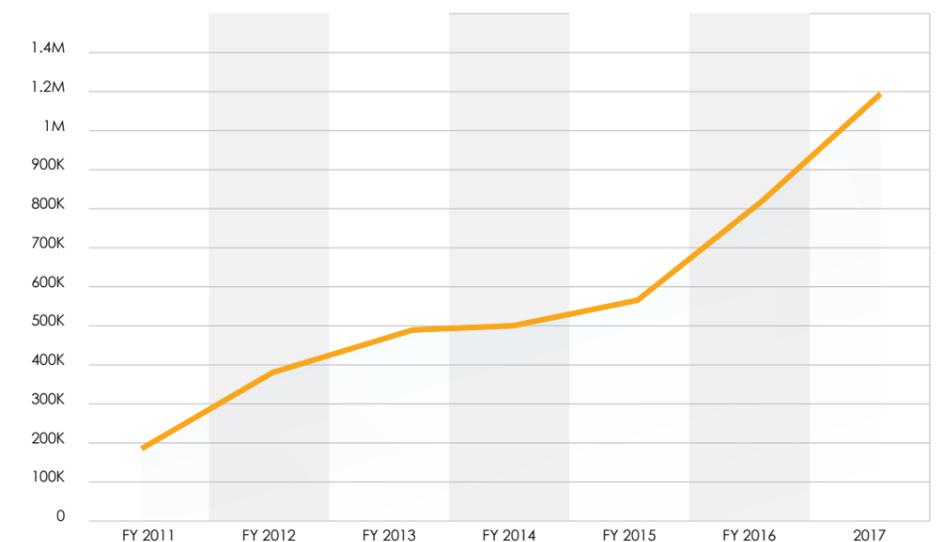
\$493k

Support

\$708k

Research

Cumulative Grants



Financial Report

The statutory accounts for the year ending 30 June 2017 have been audited and the full copy of the accounts can be found on our website www.cff.org.au.

The following information is an abbreviated version of the Audited Annual Accounts for Children's Tumour Foundation of Australia for the past 5 years.

CONSOLIDATED FINANCIALS SUMMARY

5 YEAR HISTORY

	FY 13 \$ 000s	FY 14 \$ 000s	FY 15 \$ 000s	FY 16 \$ 000s	FY 17 \$ 000s
Revenue	501	1,105	1,172	1,398	1,163
Expenses	394	712	1,123	1,003	777
Operating Surplus	107	393	49	395	386
Grants - Research	102	26	88	48	178
Support Services	11	12	91	165	137
Grants & S/Services	113	38	179	213	315
Net Surplus (Deficit)	(6)	355	(130)	182	71
Cash	759	1,113	974	1,182	1,297
Other Assets	55	88	92	63	62
Total Current Assets	814	1,201	1,066	1,245	1,359
Fixed Assets	-	5	5	6	4
Total Assets	814	1,206	1,071	1,251	1,363
Current Liabilities	18	54	49	47	88
Net Assets	796	1,152	1,022	1,204	1,275





Bella's "Birth Marks"

BELLA'S STORY

Prior to my daughter Bella being born, I had never heard of Neurofibromatosis. This is now a word that is synonymous with fear, dread and pain. It is a word that Bella, at three, cannot pronounce and yet a word that is used to define a genetic disorder. Neurofibromatosis is one of the most common genetic disorders; it is progressive, unpredictable and has caused my baby to develop tumours in her spine.

On the day my daughter was born, I thought she was perfect. Little did I know that this perfect existence, this bubble of happiness we lived in, would only last for six weeks. I had six weeks of sheer joy and bliss before our perfect world

was turned upside down and our happy bubble well and truly burst. At four weeks old, I noticed Bella's "birth marks" were multiplying. I fought desperately for answers; I saw countless doctors and paediatricians who discounted my fears and assured me I was being "a typical first time mother." At five weeks old, I found a paediatrician who casually threw the word "Neurofibromatosis" at me and informed me that Bella's spots were café au lait marks. Any more than six would be a marker for a genetic disorder. Bella had over 40, spread out across her tiny 5-week old torso. I went home and googled Neurofibromatosis. The marks on Bella's skin were now the least of my worries...

Bella was given a formal diagnosis of NF1, caused by a spontaneous mutation, at two months old by a geneticist at the Neurogenetics Clinic at the Westmead Children's Hospital.

At one of her check-ups, the neurologist noticed Bella had brisk reflexes and instinctively ordered her an MRI. At just over one year old, we learnt that Bella had multiple spinal tumours. One was found to be compressing her spine and causing symptoms. The fear and pain I felt hearing the words "spinal neurofibromas" is indescribable. My baby had a tumour slowly crushing her spine, in her neck! Whilst this news was devastating, the realisation that these were just the first of many tumours that Bella could develop, shocked me to my core. Not knowing how this will impact Bella's quality of life in years to come is one of the most overwhelming aspects of NF.

Despite the enormity of Bella's diagnosis and my profound hatred of Neurofibromatosis, I have so much to be grateful for. Bella is unaware of her tumours. She knows she has spots and she knows she has "NF." However, she is a normal, happy and funny kid in every sense of the word. Bella is a typical three year old, she loves playing in mud, dancing, eating ice-cream and asserting her authority. She is cheeky, hilarious and obsessed with "knock, knock" jokes. She is strong, brave and we treat every day as a precious gift together. I feel so fortunate to know that she is mine.

It is impossible to not worry about Bella's future and it is hard to accept that there is literally nothing I can do to protect her from the progression of this disorder. I have no choice but to be strong for my daughter and tackle life, one day at a time. I am extremely grateful to the Children's Tumour Foundation. It is through them that I have found a support network of lifelong friends.

They frequently update us on their mission to conquer NF and it fills my heart with appreciation to know that there is an organisation out there fighting for my daughter's future.



Living with Sneaky Tumours

KYLIE'S STORY

Kylie was diagnosed with NF2 in November 2014 at the age of 32. Until then, Kylie had no knowledge of anyone else living with the same condition. It took her diagnosis to discover that, for years, several distant family members had also been living with NF2. In March 2015, Kylie and her family received the devastating news that her brother also had the condition.

"I was really scared when I found out about the condition," says Kylie. "The thought 'why me?' ran through my head. I was scared of the unknown and was doing far too much reading on the Internet...You can't always believe 'Dr Google'!"

Since being diagnosed, Kylie has undergone her first of potentially many surgeries to have an NF tumour removed from her spine.

"Although successful, it's been a long haul to get to where I am today, and I know that I still have a long way to go," says Kylie. "I am left with a constant pain in my leg, which gets me down, but I keep reminding myself that I am lucky I am able to walk."

As a result of her condition, and a hallmark symptom of NF2, Kylie's biggest challenge has been her loss of hearing. Doctors discovered bilateral acoustic neuromas; benign tumours on the nerves that lead to the ear, which are responsible for balance and hearing. The presence of the tumours has left Kylie with only 20% hearing in her left ear and a constant ringing in her ears known as tinnitus.

"I struggle in most social situations," says Kylie. "I am unable to be in an environment that is too noisy due to my sensitive ears, and I found that I had to be honest and make people aware of my disability."

Further surgery is required to remove the tumours, but doing so will mean Kylie will no longer be able to hear. Transitioning from a life of hearing to living completely deaf is an outcome that Kylie fears, but it's a decision she will have to make.

"A silent world scares me, but I will most likely go deaf at some stage," says Kylie.

Much of her ability to come to terms with her diagnosis, and readjust to life with the symptoms of her condition, is thanks to her supportive family network, especially her partner Brad, friends and colleagues.

Kylie is also grateful for reconnecting with a cousin who also suffers from NF2.

"We talk to each other frequently, share thoughts and ideas, and inspire each other. I am truly thankful to her for getting me through the last 6 weeks since my first surgery," says Kylie.

Though her struggle has been hard and her future remains uncertain, Kylie has emerged stronger, with a more positive outlook on life, and has become committed to raising awareness about neurofibromatosis.

"My diagnosis has made me appreciate life so much more; I am more aware of the little things and try not to take things for granted," says Kylie.

In May, Kylie spoke about her condition with her local newspaper, Cranbourne Leader, and has since launched a personal blog entitled 'Living with Sneaky Tumours' (at www.kyliewebb.com) to document her journey with NF.

"I get so much out of sharing my experiences and ideas, and hope others can too."

"I am very lucky that I have such wonderful teammates and a great boss," says Kylie. "I have been able to adapt the way I work to accommodate my needs."

What We Do

NATIONAL SUPPORT FOR FAMILIES LIVING WITH NEUROFIBROMATOSIS

CTF provides information and support to people around the country who have NF, their family and friends, teachers and schools, doctors and health professionals. CTF has worked hard this year expanding its national reach and providing much sought after support and information with a focus on Tasmania, South Australia, Queensland and Western Australia.

Seminars

Information seminars were held in Melbourne, Adelaide and Hobart and were well attended. Most of these seminars emphasised features and complications of NF in children. With 2018 fast approaching, planning has commenced to develop a seminar series with an adult focus.

Family Events

Family weekends were held at Port Stephens and Ballarat in March as well as Gold Coast and Kiama in May, with many individuals and families meeting for the first time. Participants reported enjoying meeting other people on the same NF journey as them and felt they were in a safe environment to exchange information and make connections. Everyone also loved the opportunity to attend a camp in their own state.

Meet-up days were held in Hobart, Townsville, Shepparton and Launceston this year. These were

mostly NF1 individuals and families, with NF2 meet-ups held in Adelaide and Melbourne. These days achieve good turnouts and are held in place of a weekend activity where distance and location are difficult.

Clinics

As well as facilitating these events, CTF has worked closely with clinicians at the Royal Children's Hospital NF Clinic in Melbourne, the Children's Hospital Westmead and the Royal North Shore Hospital in Sydney. The CTF team's role has expanded, taking on the role of Clinic Coordinator and Case Manager to some families, and continues to act as a support person to families attending clinic appointments, following up patients at the clinician's request and acting as a liaison between the clinics and families.

CTF Resources

We have developed CTF-branded brochures and aim to develop our resources further. Currently available on our website and in print in some clinics are: (NF) – Neurofibromatosis – a general awareness brochure, the Neurofibromatosis Type 1 brochure and the Optic Pathway Gliomas (OPG) in NF1 brochure. There are a further 3 brochures under development.

Our moderated, closed Facebook group continues to grow with 707 members, an increase of 17% from last year. Members continue to use this group to network, ask questions and find information; they see it as a valuable resource that helps prevent

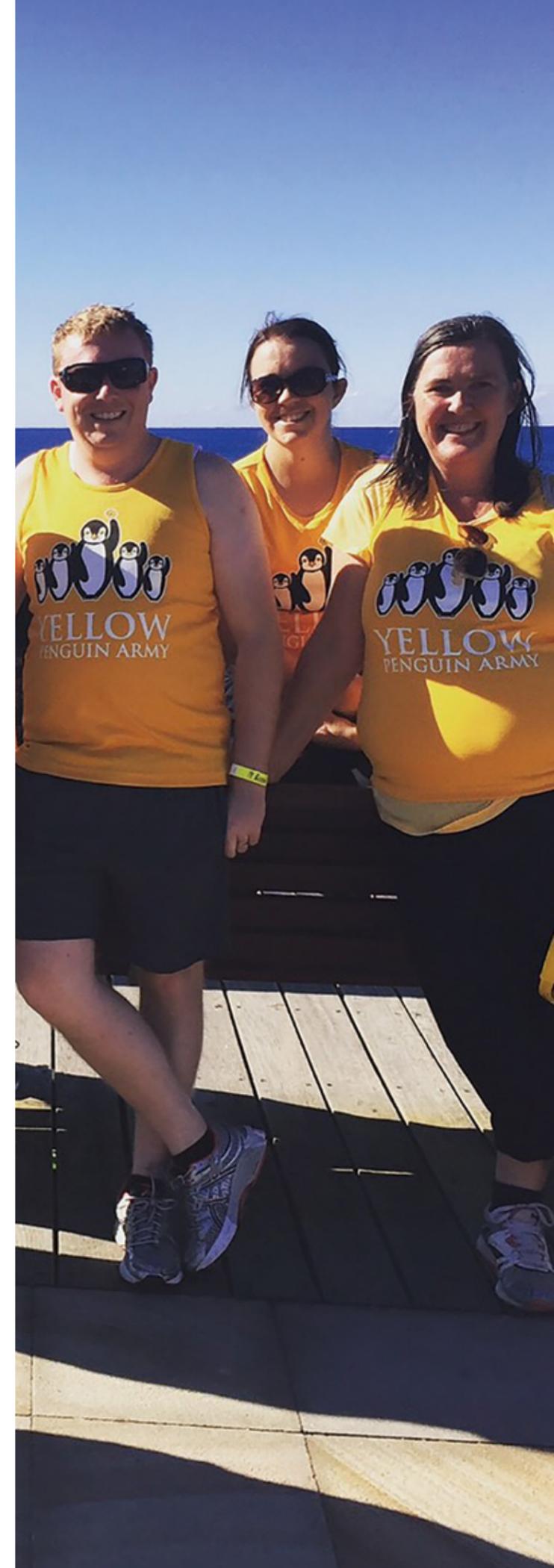
feelings of isolation that many people with NF experience.

We distribute our monthly e-Bulletin to 7,470 readers. During this financial year, we have made changes to increase readership and clicks through to our website, but still provide relevant information and opportunities to the NF community. It is used to promote our events and we have achieved great results, evidenced by positive feedback and strong RSVPs.

Support Groups

We have worked hard to continue expanding our national network of Community Support Groups (CSGs), now with 13 in total, along with 4 independent NF support groups around Australia. The groups act as a local contact for people and host informal get-togethers in the local area. CTF visited a number of these CSGs throughout the year and their involvement has been welcomed by members.

Work has also begun on a number of projects focused on broadening our scope and targeting the needs of the community in new ways. This includes: providing our CSG Peer Leaders with training, webinars to expand who we can reach with information, a youth program and several other initiatives that will continue to be developed over the coming financial year.



Meet the Team

This year we wanted to provide an insight into some of our team members, all working towards our shared goals of: building a supportive NF community nationwide, improving clinical treatments and access to them as well as raising awareness about NF. Meet three members of our dedicated team below:



Jodie Cooper

Social Media and Marketing Coordinator

What is your main role at CTF and what is the most rewarding part for you?

My role at CTF is to communicate information relating to CTF, NF and Cupid's Undie Run to our NF community and the wider public through social media, email, our website and various other means. I am also the point of contact for all of our celebrity ambassadors. I feel incredibly grateful to work in a position that allows me to assist in raising awareness of NF, which is such a vital step to finding a cure. Engaging with so many amazing individuals, whether they are parents

of a child affected by NF or ambassadors wanting to support a disorder they had previously never heard of, is an incredibly humbling and inspiring experience.

What was a highlight for you in 2017 and what are you looking forward to most in 2018?

My personal highlight was attending the Kiama Family Camp, which we were able to provide for free to families affected by NF. This was the first time that I had the opportunity to meet and engage with the NF community and I was absolutely blown away by their strength and hope in the face of adversity. I was particularly humbled by the many beautiful children who were able to keep smiling and enjoying life, despite having endured more hardships than some adults ever will.

I am really looking forward to Cupid's Undie Run in 2018. I believe this event has the potential to be bigger and better than ever, and I can't wait to see it grow. Cupid's Undie

Run is the perfect event to bring awareness of NF to a wider audience and it is something I love being involved with.



Georgia Willesee

Event Manager

What is your main role at CTF and what is the most rewarding part for you?

My role at CTF is to oversee and manage our portfolio of events, including the: Mega Hero March, Donor Dinner and the inaugural NF Clinical Symposium. The most rewarding part of my role is being able to work on a range of amazing events that bring diverse communities of people together, all united around such a worthwhile

cause. It's especially great when we help to raise much-needed funds and awareness of NF!

What was the highlight for you in 2017 and what are you looking forward to most in 2018?

Joining the CTF team has been by far the biggest highlight for me. The team at CTF are incredibly hard-working and passionate about our cause. I have also had the pleasure of meeting some incredible families in my short time here, and they never cease to astound me with their courage and strength. In 2018 I am looking forward the Cupid's Undie Run - the event has grown again and is shaping up to be the best yet!



Rachel Skelton

Campaign Manager

What is your main role at CTF and what is the most rewarding part for you?

I am the campaign manager of the Cupid's Undie Run, our largest community fundraising event. The most rewarding part of my role is working closely with our community at a national level to increase awareness about NF. I am inspired daily by those I meet through my role, whether it be an NF family or a local business wanting to support CTF. My role gives me hope for the future of NF and it is rewarding to feel as though I am making a difference in generating funding for a disorder from which my daughter suffers.

What was a highlight for you in 2017 and what are you looking forward to most in 2018?

This year I joined CTF in an official capacity after years of volunteer work and fundraising.

My highlight was getting to know the team and seeing firsthand their dedication in our mission to conquer NF. I have developed some of the closest friendships through my role at CTF and feel so fortunate every day to be working alongside a team of the most incredible humans I have ever had the pleasure of knowing. Another highlight that stands out for me has been communicating with the Cupid's ambassadors. It means so much to see people using their social influence to affect positive

change for NF (and I also get a little star struck)!

What is your message to the people you serve?

I want the NF community to know that the entire CTF team dedicate their heart and soul every day to creating awareness and increasing funding for NF. I want them to know that Cupid's is personal to me because my daughter Bella was diagnosed with NF1 from a spontaneous mutation at 6 weeks old. My three-year-old Bella has three tumours in her spine and we are currently playing the watch and wait game. I understand how NF impacts a family and know the horrible unpredictability of this condition. I want nothing more than to find a cure or, at the very least, an effective treatment for NF. They can be assured that I will be on a personal mission to improve awareness about the three types of NF and do my very best to ensure Cupid's continues to grow so that we have the means to fund world-class research and continue supporting our NF community.

Update on the NF Clinics

CTF PROVIDES FUNDS AND OTHER ASSISTANCE TO HELP SUPPORT THE NF CLINICS AT:

The Royal North Shore Hospital (RNSH) in Sydney, the Children's Hospital Westmead (CHW) in Sydney and the Royal Children's Hospital (RCH) in Melbourne.

Royal North Shore Hospital

Ongoing CTF support has enabled the RNSH NF Clinic to further develop its NF services, with: additional genetic counsellor time assisting with care coordination for patients with NF, increased clinical geneticist specialist hours, engagement of a specialist neurologist and continuation of the NF1 Skin Clinic. **Over 120 patients have been seen in the clinic.**

The Skin Clinic now uses a laser for some patients who report it as the favoured treatment option. A study being conducted into patient experiences of NF1 and their treatment is showing an overwhelmingly positive response from patients involved in the NF1 Skin Clinic.

Children's Hospital Westmead

Many of the children living with NF in NSW and ACT are managed by the experienced, multidisciplinary team at CHW, with a small number coming from interstate to receive specialist

care. **Seventy new NF patients are seen in the weekly Neurogenetic Clinic each year, with a total of 300 NF patients being seen each year.** Additionally, the CHW NF1 Learning and Development Clinic has **conducted 105 assessments each year.** CTF team members attend the weekly clinic, providing support to families as well as clinicians, providing follow-up calls checking on referrals, ongoing appointments, investigations, etc. They also use that time to promote CTF to the families and explain how they might benefit from subscribing to the e-bulletin, linking with their local support group or simply joining the closed Facebook group. Once that contact is made, the families know there is someone with whom they can keep in touch and ask any questions.

Royal Children's Hospital Melbourne

The CTF team works with the NF Clinic team at RCH. During this year, our role has developed and

we now coordinate the clinic. This includes: managing multi-disciplinary appointments for children with complex needs, ensuring appropriate follow-ups, liaising with clinicians and other hospital departments as well as many other tasks needed to keep the NF Clinic running smoothly. This year, the NF Clinic at RCH saw 113 new referrals and had a total of 280 children requiring ongoing management.

The CTF team also works closely with the Murdoch Children's Research Institute (MCRI) neuropsychology research team and is building links with the Royal Melbourne Hospital and the local Primary Health Network.

The development of our role in this way has ensured that the NF community in Victoria truly has a single point of contact that meets their clinical and support needs.

Natalie has assisted the team in creating a research registry to contain medical records of NF patients with the aim of conducting and aiding further research into these conditions.



Cupid's Undie Run Went National in 2017

OUR LARGEST COMMUNITY FUNDRAISING EVENT

For the first time, Cupid's Undie Run went NATIONAL in 2017. The event surpassed all expectations and saw over 900 people, in 12 locations, strip down to their BONDS undies and run to conquer NF!

The total amount raised reached \$390,000, which will be used in part to fund a much-needed Support Officer based in Queensland for families and adults affected by NF. In the coming years, we hope to see the event continue to grow, reaching more participants and raising more money to help fund NF support in every major city in Australia.

Each Cupid's event was unique, with locations ranging from the city streets of Sydney to the beaches of the sunny Gold Coast. In Sydney, we saw the local police run alongside our participants in their undies and even had a world record attempt for the most people in one pair of underwear. Thanks to the support of our Ambassador Beau Ryan and our media partnership with 9 Cares, we were able to secure a live cross to the Today Show on Channel 9 - what an incredible way to increase awareness about Neurofibromatosis! Andrew "Reidy" Reid, one of our longest-standing and most dedicated ambassadors, was there to MC and ensured the

event was filled with laughs and camaraderie. Our ever-increasing contingent of passionate ambassadors were hugely successful in raising awareness of the event through social media, bringing in more participants and fundraising dollars.

Our appreciation and a huge 'thank you' must of course go to the supporters and participants, who blew us away with their passion, and worked tirelessly to reach some massive fundraising goals. Without their support, Cupid's Undie Run would simply not be possible! Once again, the Barney Army was our highest fundraising team, raising an amazing \$85,496! Alice Dell, of the Barney Army, was the top fundraiser for Melbourne and raised \$26,443. Team Libby Lionheart raised \$36,870 and Cameron Elliott, Libby's dad, raised \$25,750 of the team total! Best Undressed was our third highest fundraising team, raising \$27,368, followed by Lenny's Entourage who raised \$20,977, and Emme's Cupid's who raised \$13,700. Special mentions go to our Chairman, John Hughes, who was the highest fundraiser for Sydney, raising \$15,634 and Felicity Egginton, who was our highest fundraiser and ambassador on the Gold Coast. Thank you to all our fundraisers on your incredible efforts!

The funds raised by Cupid's Undie Run will go a long way, towards: supporting the world-class research that we help fund at Australia's leading NF clinics, increasing national support services and purchasing state of the art equipment that improves quality of life for those in our community living with NF.

Thank you so much to our key partners and sponsors for supporting Cupid's Undie Run in 2017, including: Bonds, Radio Rentals, Thorn, Acer, and our media partner, 9 Cares. Thank you to our ambassadors: Allana Ferguson, Andrew Reid, Beau Ryan, Belinda Hocking, Breanna Blick, Brooke Bevan, Byra, Carleen and Michael, Caro and Kingi, Chris and Jenna, Ebony and Luke, Emma McKeon, Emma Tonegato, Felicity Egginton, Hollie Azzopardi, Jade Hatcher, John Bric, Jono Pitman, Justyna Kalka, Katrina Webb, Libby Trickett, Lisa Darmanin, Lisa Shearon, Mariafe Artacho del Solar, Max and Karstan, Melissa Wu, Poppy and Adam, Tahan Lew, Taryn Williams, Tresne and Carly. Each played a pivotal part in helping us increase awareness about NF.

Thank you also to our amazing volunteers across all 12 cities, without whom this event would not be possible.

Finally, and most importantly, thank you to the participants and supporters for your dedication and fundraising, and for ensuring Cupid's was a memorable event. We can't wait to see you all again in 2018!



A new heroic initiative: Mega Hero March

**LOCATIONS: ADELAIDE, BRISBANE,
CANBERRA, MELBOURNE, PORT MACQUARIE
AND SYDNEY**

This year saw the introduction of the Mega Hero March, a brand new annual event that took place in 6 cities across Australia!

As part of this special event, everyone that registered received their very own Mega Hero cape, which demonstrated the Mega Hero powers of those affected by NF. These include: strength, courage and determination to conquer NF.

Held on the morning of Sunday 23 July 2017, the event consisted of a 6-10km walk finishing with a light meal for participants who were sure to have built up an appetite after activating their Mega Hero powers and taking on the march. Plus, we had some fun activities for the kids to enjoy including jumping castles and face painting!

This new family-friendly event was specifically designed for the NF community, constructed from their ideas and suggestions, with the key objective of bringing people together to raise funds for research and awareness into NF.

One participant said, "I like the fact that the feedback was taken into account to make sure it was a great event and accessible to

everyone." Another added that it was a "great opportunity to meet other NF families and raise the profile of NF."

Over 450 people took part across the country and helped raise an incredible \$53,000, with the money raised going towards research projects, support programs and the funding of specialised equipment. Cameron Elliott was the highest fundraiser overall, raising a huge \$6,880!

We would like to thank our incredible race directors for making this event possible: Rachel Skelton, Emily Cardus, Kylie Webb, Sarah Hayes, Carey Russell, Peter Kirkpatrick and Beth Connor. We couldn't have done it without you.

We look forward to next year's event, which we expect to be even bigger and better!



Stories from the Community:

OUR COMMUNITY HEROES

Some events raise a lot, some events raise a little; every community event brings much-needed public awareness of our collective fight against NF! A huge Thank You to all the organisers and participants in this year's various community events.

May 8 Day

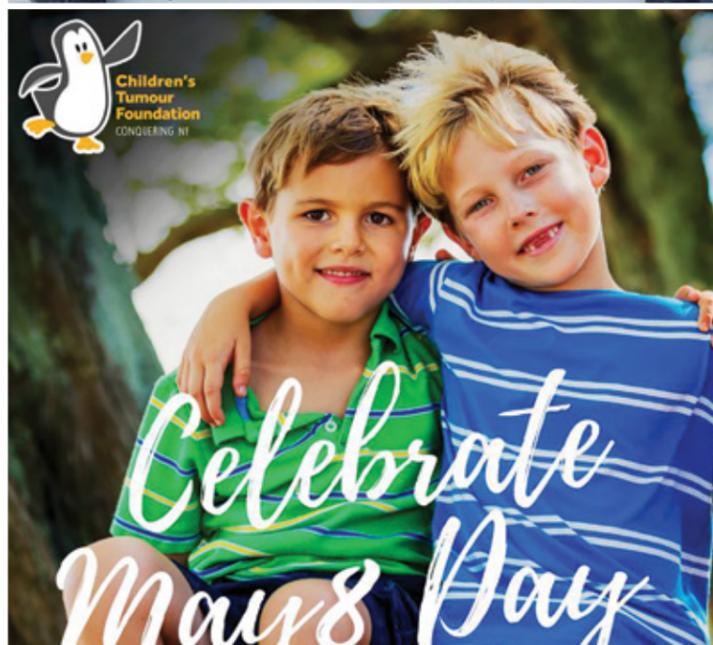
This was a new initiative in 2017 and an idea from one of our parents who had become concerned about the lack of understanding amongst children with differences.

Whether we have lumps or bumps; whether we are the best readers in our classes or need a little extra help; whether we speak with our mouths or sign with our hands – we ALL need a mate!

Peter and his daughter Emily encouraged the children at her school to dress in yellow and make a gold coin donation. James and Melanie's son Casey, with NF1, held a "Mate Day" at his primary school to show that, no matter our differences, we all fit together.

We hope to see this event grow in the future.

May 8 = Mate!



Beach Day, 24 February 2017

The Dodges Ferry Primary School generously supported us with a Beach Day fundraiser. Styled as a colour run, the kids ran along Blue Lagoon Beach, near Hobart, and asked each student to contribute a gold coin in support of our community member Emily and CTF.

Parkes Colour Run, 19 March 2017

On the 19th of March, more than 300 people took part in the Parkes NF Colour for a Cure Fun Run raising money for CTF. Libby, Hamish's wonderful mum, was the main organiser. She gathered friends and family to help make this amazing event happen.

Participants ran the 5 km course, sometimes dodging buckets of paint, but - more often - lining up to have the colourful paint thrown at them!

Judging by the photos, everyone had a fabulous time while raising community awareness about NF. With all that paint and the amazing colours, the whole town was talking. Also, professional photographer Jay-Lee Zagrovic kindly donated all proceeds from the photo sales to CTF!

This event was highly successful in generating community buzz and raising a phenomenal \$19,980! What an amazing result by our friends in Parkes!

2017 Supporters List

Patron

The Hon Nick Greiner AC

Ambassadors

Andrew "Reidy" Reid
Allana Ferguson
Beau Ryan
Belinda Hocking
Breanna Blick
Brooke Bevan
Byra
Carleen & Michael
Caro & Kingi
Chris & Jenna
Ebony & Luke
Emma McKeon
Emma Tonegato
Felicity Egginton
Hollie Azzopardi
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Top 50 Fundraising Teams

The Barney Army
Libby Lionheart
Best Undressed
Lenny's Entourage
Emme's Cupids
Libby Lionheart
The NF Unicorns
Dexter's Warriors
Team Yellow Penguin Army
Bella's Army Gold Coast
Team Ethan and Nate
Johnson & Friends
Team Pash and Dash
TheShaws
Mega hero ride Silverton
STORMED OUT HRVHERO
MEGA HERO
Hannah's Angels
Running Undies
Giorgioni' Fitness fundraiser
boot camp
Funtastic
Jane's Squad
Team Lightspeed
Team Duds
Chasing Booty
Olivia's fairies
Super Ben
Dancin Divas
Team Marozzi
Harps 4 Cupid

In memory of Nick Carfora

Darcy Boy
Hollie's Cupids
Charlie's Crew
Seren's Shooting Stars
IWCFM
St Clare's OSHC Super
Underpants Team
TheShaws
Don't want none unless
you got funds hun
Ness for NF
Joel Ronayne
Hawker Boys
Maddy's Marchers
Bendigo Heroes
Sarah Hayes
D4E Angels
Tyler's Tooshie Team
Cupid's Cutest
Bella's Army Brisbane
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