Annual Report

Children's
Tumour
Foundation
CONQUERING NF

TABLE OF CONTENTS

WHAT IS NEUROFIBROMATOSIS?

Neurofibromatosis (NF) is a genetic disorder that covers three conditions: NF1, NF2 and Schwannomatosis.

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.

NF is like a snowflake: 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 being mild (allowing patients to live active and productive lives) along a spectrum to being debilitating in numerous ways and life-threatening.

Psychological issues, especially depression, can also be significant due to physical abnormalities, learning difficulties and other issues that can lead to discrimination, bullying and isolation.

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

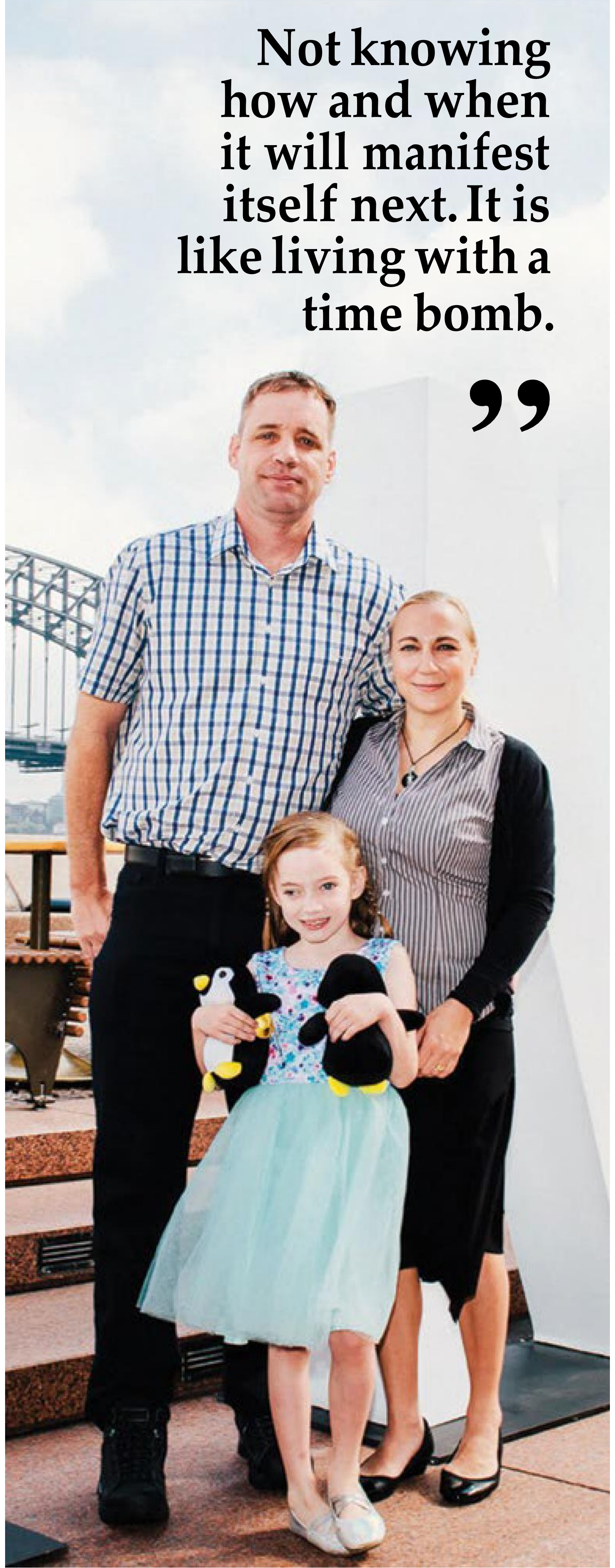
As a genetic disorder, **NF is inherited from a parent around 50% of the time.** The other 50% is caused by new mutations in NF genes around the time of conception. We do not know why these spontaneous changes occur. There is much that we still have to learn about NF.

Because NF is so variable, a diagnosis can leave an individual or family feeling afraid and uncertain for years, especially not knowing how and when it will manifest itself next. It is like living with a time bomb.

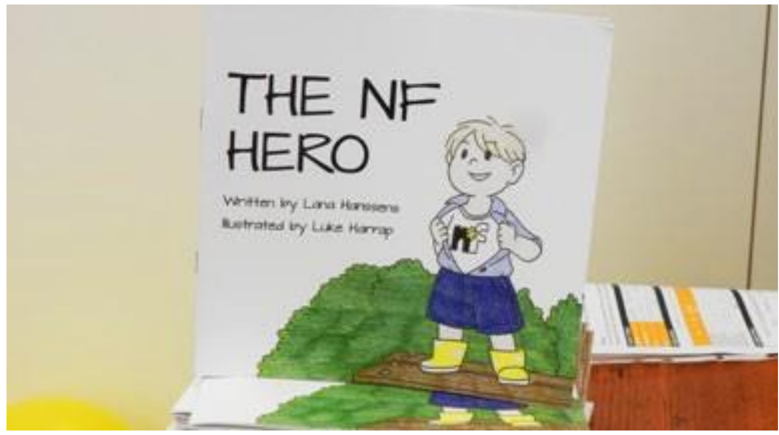
The fight against NF is an international one. We have developed strong links with NF organisations and researchers in the US, Great Britain, Ireland, Canada and Europe.

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.

> “Not knowing how and when it will manifest itself next. It is like living with a time bomb.”



BOOK LAUNCH



We were excited to announce the publication of a wonderful NF Hero book by community member, Lana Hanssens. This beautifully written and illustrated book tells the story of Alex, who has NF, as well as several superpowers!

The inspiration came from when the family found out that their son Fraser had NF, with the diagnosis taking a couple of years as he developed more of the signs. During that time, Fraser's older sister, Jayla, was curious to know why he was seeing so many doctors.

Lana began looking for a children's book to help Jayla understand what was happening and, when she couldn't, decided to write one herself. The book is beautifully illustrated by a local young artist who used Fraser as his inspiration for the main character, Alex.

For Lana it was quite emotional seeing it in print: “Knowing the book can now be shared with other young people and families is truly wonderful. I am also excited that the sale of the book will help CTF to continue doing the work it does for the NF community. I hope that others will share the book with their children and speak about NF openly. I do not want Fraser's NF to be a taboo subject and hope this book will help make all the NF Heroes out there more willing to share their story.”

***The NF Hero* book is available for purchase via our website: ctf.org.au**

OUR MISSION: TO CONQUER NF

We do this by:

- Providing practical support to people and their families impacted by NF through:
    - Specialist NF clinics in major hospitals
    - Support services
    - Information and related resources
    - Peer support groups
    - Family camps and other community activities
- Funding world-leading research into effective treatments for NF and ultimately finding a cure
- Delivering advocacy and awareness campaigns to build greater understanding of NF within the medical profession, government and community at large

Funding research is critical if we are to understand NF and better treat sufferers. Fortunately, Australia is home to some of the best NF researchers in the world and, **as the leading non-government funder of NF research in Australia,** we are proud of what we have achieved to date with our research partners.

Our many achievements have been enabled by community spirit and the generosity of our many donors and supporters.

ABOUT CTF

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

2010

- Changed organisation status to a company limited by guarantee with nationwide focus
- Changed name to NF Australia and trading name to Children's Tumour Foundation (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
- Provided first NF research grant of $163,000
- CTF moves from Ku- ring-gai Senior

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
- Annual fundraising exceeds $500,000

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 $1.38 million

2017

- Groundwork laid for NF Support Network expansion into QLD
- NF community events increase from 6 to 13
- Approved grant of $277,000 over 2 years for NF Research
- May 8 "Mate Day" launched

2018

- Agreement with Royal Brisbane and Women's Hospital for appointment of CTF Support Officer
- NF Sippers Club launched and starts national take-up
- Cupid's Undie Run raises nearly $500,000
- Inaugural Australasian NF Medical Conference held
- Conducted first National NF Community Seminar
- Approved grant of $116,000 over 2 years for Barney Research Fellowship

CHAIR UPDATE

I'm pleased to report that throughout the year we were able to further consolidate and expand our activities to support our NF community, improve medical services and fund research.

There were a number of key elements and highlights for the year.

Inaugural Australasian NF Medical Conference

Royal North Shore Hospital worked with CTF to deliver this ground-breaking initiative. Over 70 NF specialists attended, from across Australia and New Zealand, which assisted in raising awareness of existing research and clinical advances in NF amongst clinicians along with encouraging collaboration. This also assisted CTF to raise its profile within the medical community.

National NF Community Seminar

The Children's Hospital Westmead hosted this event, which was streamed online via Facebook and the CTF website. Hundreds of people participated and it even attracted members of the NF community across the world.

Given the very positive response, other events such as this will be a continuing part of our programme for providing the latest information on research and advancements in care to the NF community.

Community Support

Agreement has been reached for an NF Support Coordinator to be based at Genetic Health Queensland, Royal Brisbane and Women's Hospital in Brisbane. This will enable CTF to provide face to face, telephone, and clinical support to the NF community across Queensland and the Northern Territory. It will also assist us in our endeavours to develop an NF Clinic in Brisbane and expands our support network to cover the whole east coast.

Centre for Translational Research and Complex Care

In addition to the continued support of clinics at Children's Hospital Westmead, Royal North Shore and Royal Melbourne, we are delighted to be able to fund this new initiative at Royal North Shore under the stewardship of Dr Mimi Berman. The funding will enable increased multidisciplinary and specialist involvement in the NF clinic and facilitate use of new treatments in the care of NF1 and NF2.

Cupid's Undie Run

This continued as our major fundraising event, raising nearly $500,000 and helping to increase national awareness about NF and the work that we do. The event surpassed all expectations and saw over 1,200 people Dare to Bare and run to help us Conquer NF!

The campaign message, Celebrate Difference, was used to highlight that "stripped down, we are all different in our own special way". This resonated strongly with everyone in the community and was effective in gaining media attention for our cause across the country!

Corporate Partners, Sponsors and Supporters

The funding of our clinics, CTF team, community activities and research grants would not be possible without the loyal support of so many organisations and people in our community.

Along with numerous other sponsors and supporters, who work tirelessly to assist our efforts, we offer special thanks to our Corporate Partners for their continuing support:

- Thorn Group and Radio Rentals, our Founding Partner
- Acer now into Year 3 of their partnership
- Bonds, our long-term Cupid's Undie Run sponsor
- Nine Cares

The Year Ahead

Our focus for the 2018/19 year will be to further develop and enhance activities in our ongoing efforts to deliver positive outcomes for the NF community. Some key elements will be:

- Further expansion of Cupid's Undie Run
- Continuation and growth of the Australasian NF Medical Conference and National Community Seminar
- Change of NF Hero March to NF Hero Challenge with a broadening of activities to attract a wider audience and develop it as a fundraising event to rival Cupid's
- Developing a Peer Leadership Support Network
- Empowering community members to fundraise through a selection of planned activities
- Increasing awareness amongst the medical community by providing additional information resources about NF

> "Our aims and objectives do not change. We will continue to serve our NF community by funding critical research, striving to increase the number of clinics and providing day-to-day support in as many ways as possible, with the ultimate goal of Conquering NF."

John Hughes
Chairman

PATRON AND AMBASSADOR PROFILES

The Hon Nick Greiner AC
Our Invaluable Patron

> “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”

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.

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…

Despite having my fair share of challenges, I’ve been fortunate enough to compete for Australia at 3 Olympic Games.

I feel extremely privileged to be an elite athlete and have dedicated my life to my sport and achieving at the highest level.

Whilst I’ve encountered setbacks related to my sport, I didn’t know what it was like to really struggle and face the almost impossible task of staying positive and moving forward until I lost my younger sister 3 years ago.

It was through this experience and my desire to help others that I’ve become involved with CTF to assist in fundraising and lift awareness about NF, so that people living with NF and their families can be supported and know that others care about them.

Although my experiences are not the same as those impacted by NF, I’ve dealt with adversity, experienced loss and hardship and can relate to the impact NF can have on sufferers and their families.

So, I want to do whatever I can to assist CTF and help build a brighter future for those affected.

Ben Fordham
Ambassador

Ben Fordham is often asked what his preferred media medium is – radio or television?

The truth is he finds both equally challenging and enjoyable.

At Sydney's No. 1 rating radio station, 2GB, Ben, since 2011, has hosted Sydney Live in the 3pm-6pm shift, a program that consistently tops the ratings.

His talents have been recognised at the Australian Commercial Radio Awards, being voted best metropolitan talk presenter (2014-2015-2016) and best metropolitan current affairs presenter (2017).

After launching his media career at Sydney's Radio 2UE and Sky News Australia, Ben joined the Nine Network in 1999 and, after lengthy stints with A Current Affair and the Today Show, his television talents these days spread across a number of Nine's news, current affairs and entertainment programs, including co-host of the 2017 ratings blockbuster Ninja Warrior.

Ben's coming-of-age in journalism arrived before he celebrated his 21st birthday. Then a 2UE political correspondent in the Parliament House Press Gallery in Canberra, Ben won a Walkley Award – Australia's top award in journalism – for his coverage of the Thredbo landslide tragedy and a Raward – the top accolade in the Australian radio industry – for excellence in journalism. He became the youngest reporter in history to win a Walkley-Raward double and was honoured on Australia Day with a Young Citizen of the Year award.

Thanks to his job, Ben has built close contacts with some inspiring people who've dedicated their lives to helping others.

Ben is married to Seven Network journalist Jodie Speers and they have a son Freddy and daughter Pearl.

> **"Away from his media engagements, Ben volunteers for several charities in the areas of fundraising, lobbying, strategy and as a Master of Ceremonies."**

Melanie And Eddie Listorti
Ambassadors

Melanie and Eddie Listorti have been long-time supporters and benefactors of CTF on behalf of their daughter Anna.

Most recently, the Listortis, along with CTF Chairman John Hughes and his wife Robyn, made a commitment of $50,000 each for 3 years - a total of $300,000 - to establish and develop the NF Centre for Translational Research and Complex Care at Royal North Shore Hospital on behalf of CTF.

This clinic will specialise in the treatment of complex medical problems related to NF and serve as a hub for NSW Health to advance patient care. It will assist in ensuring better diagnosis and care for NF sufferers across NSW. Hence it is a critically important initiative.

Melanie and Eddie said they hoped their support would make it easier to help NF patients.

In their own words…

It has been our great honour and privilege to be recognised as Ambassadors of CTF and we hope that from our contributions and the many, many others that have done the same, that there will be some benefits, relief and hope to sufferers of NF. Every day we witness firsthand what it is like living with NF. The anxiety, fear of the unknown, constant monitoring, untold doctors' appointments and scans. Then there are the daily emotional impacts on our daughter of not feeling normal, because she lacks the skill sets most kids take for granted, and just wanting to feel accepted at school. Then it's topped off with all the related physical issues that make her life so tough.

We have the utmost sympathy and respect for all families living with NF and we are reminded frequently how fortunate we have been to have met and become friends with many of them. So many times we have heard and seen the stories of bravery, selflessness, acceptance and innocence from the sufferers and their carers. This has only encouraged us to accept, love and help as much as we can.

> **"We are delighted to have this opportunity to support the Children's Tumour Foundation and the work being carried at out Royal North Shore Hospital.**
>
> **- Melanie and Eddie Listorti"**

GOVERNANCE

Highlights

Financial

24% ↑

Fundraising from Cupid's Undie Run reached **$508k** with net contribution up 24% on last year

Increased fundraising from Sydney Gala and Mega Hero March

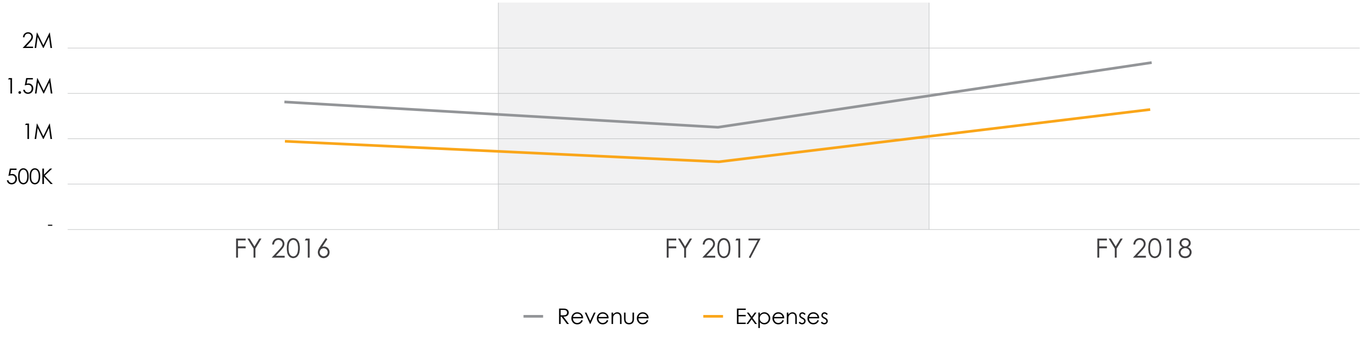
Decision not to outsource any fundraising activities

36% ↑

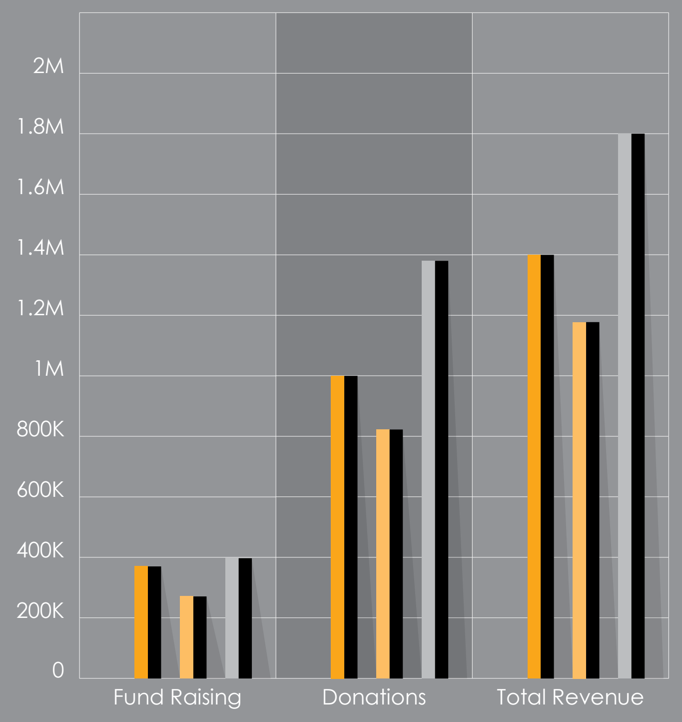
Total revenue increased by **$649k** owing to successful fundraising generating operating surplus of $525k – up 36% on last year

Continued support from corporate sponsors Radio Rentals and Acer

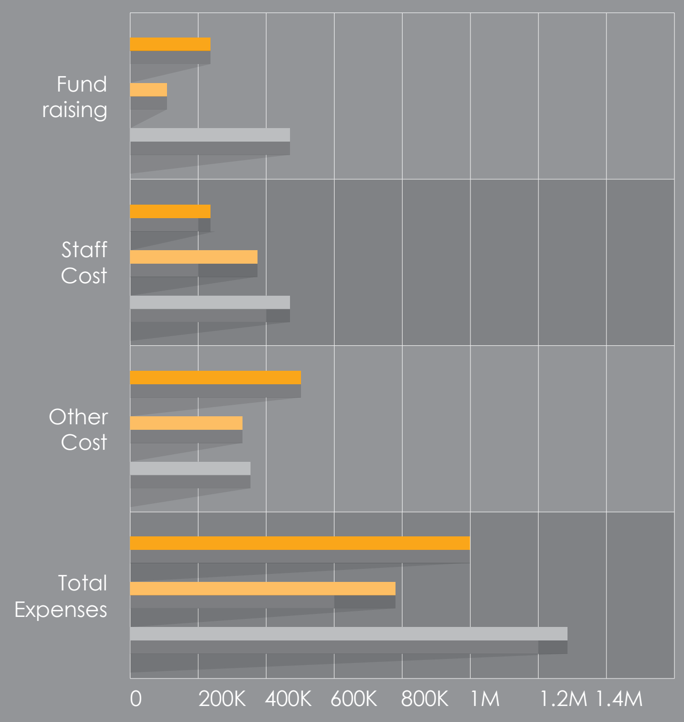
Revenue & Expenses



Revenue



Operating Expenses



$693k

Support

$899k

Research

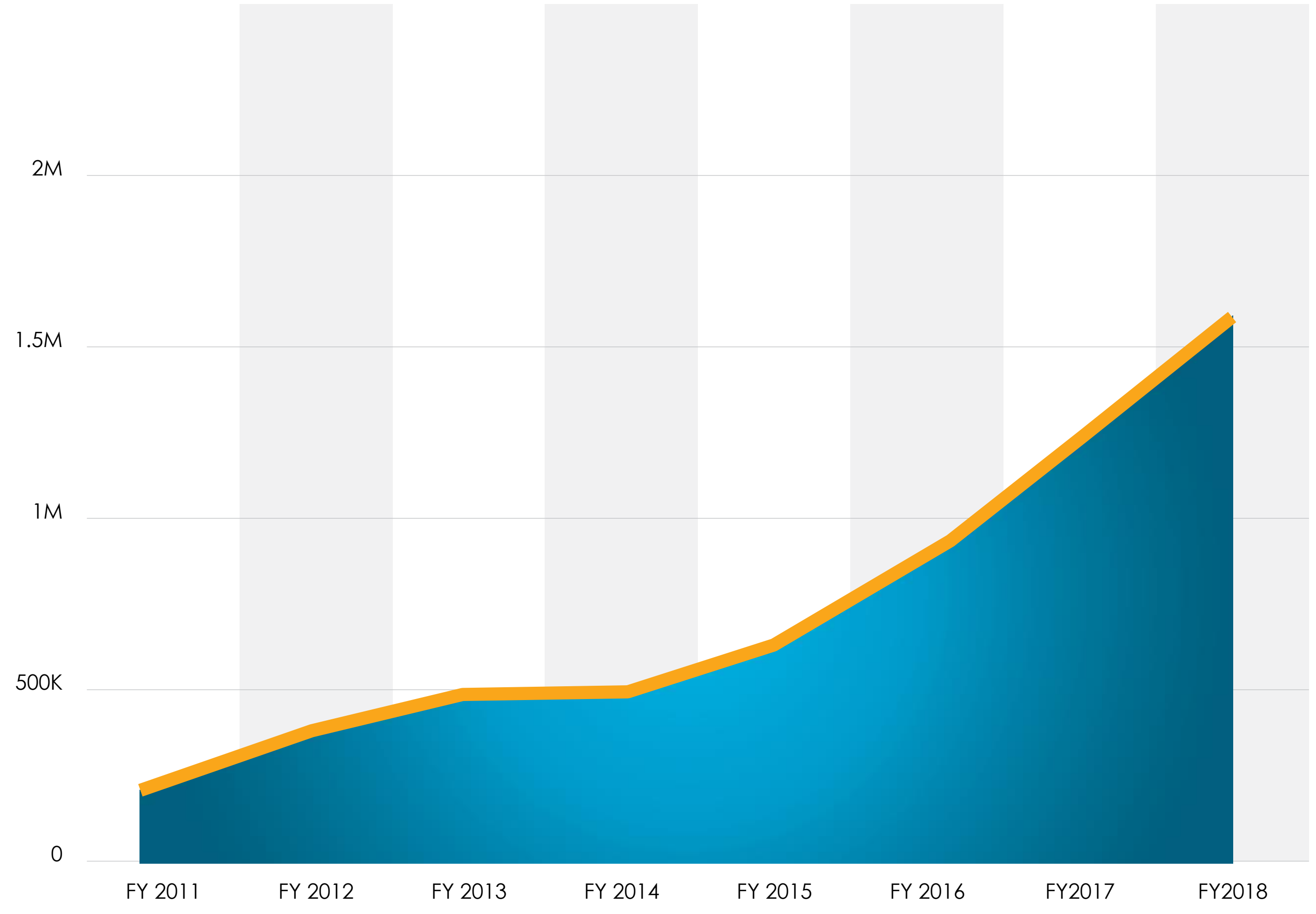
Support Services

- Contributed **$200k** towards support services – highest on record with cumulative spend of $693k mainly in the last 4 years
- **26 community** support events
- NF Sippers Club gaining national momentum
- NF Community Information Seminar
- Information webinar series launched
- Continuation of family camps

NF Research

- Hosted Australasian NF Conference in Sydney sponsored by **Whiteley Corporation**
- Committed up to **$140k** over 2 years to support NF Research Fellowship at Murdoch Children's Research Institute
- Contributed over 7 years cumulatively $900k towards NF Research

Cumulative Grants



FINANCIAL REPORT

The statutory accounts for the year ending 30 June 2018 have been audited and the full copy of the accounts can be found on our website: **www.ctf.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 14	FY 15	FY 16	FY 17	FY 18
	$ 000s	$ 000s	$ 000s	$ 000s	$ 000s
Revenue	1,105	1,172	1,398	1,163	1,813
Expenses	712	1,123	1,003	777	1,288
Operating Surplus	**393**	**49**	**395**	**386**	**525**
Grants - Research	26	88	48	178	191
Support Services	12	91	165	137	201
Grants & S/ Services	38	179	213	315	392
Net Surplus/ (Deficit)	355	(130)	182	71	133
Cash	1,113	974	1,182	1,297	1,296
Other Assets	88	92	63	62	244
Total Current Assets	1,201	1,066	1,245	1,359	1,540
Fixed Assets	5	5	6	4	5
Other Assets					35
Total Assets	1,206	1,071	1,251	1,363	1,580
Current Liabilities	54	49	47	88	172
Net Assets	**1,152**	**1,022**	**1,204**	**1,275**	**1,408**

CLINICAL SUPPORT AND MEDICAL RESEARCH

Royal North Shore Hospital (RNSH)

Neurofibromatosis Clinic

RNSH has a role in coordinating the care of adults and children with NF, particularly those with complex disease and ongoing health needs. Coordination of care is done within the NF clinic and outside clinic times. The RNSH Clinical Genetics Department is often the first point of contact for Adult and Paediatric patients with NF1 across the state, who have new or worrying symptoms. They then assist patients in accessing local specialists wherever possible or provide an appointment at RNSH where needed.

Waiting Times continue to be reduced from 12 months (prior to funding) to 1-3 months with an average of 8 weeks.

CTF funding enables RNSH to spend dedicated time focused on improving and innovating care in NF. The development of a 'specialist central hub' for NF care and innovation allows for the development and introduction of new protocols and treatments that will benefit patients throughout Australia.

Increasingly patients are being seen from across the state, with most coming from outside the RNSH catchment of Northern Sydney Local Health District (NSLHD).

NF Skin Clinic

This was established in response to evidence that cosmetic impacts of NF are of high importance amongst affected adults.

The purchase of a laser machine has been funded by CTF and it has been in constant use since acquisition with most patients having two treatments.

A recent study by RNSH demonstrated a uniformly positive response to treatment with LASER and this was considered the favoured treatment option in all patients interviewed. Patients strongly valued an NF1 specialist skin service being available, with requests for more appointments and further treatment. The ability to treat more patients, however, is restricted until additional funding is available.

The clinic is now a member of the Response Evaluation in Neurofibromatosis and Schwannomatosis (REiNS) International Collaboration cutaneous neurofibroma working group.

There are also a number of innovative interventions being introduced that are world-firsts:

- Development of a protocol to test the efficacy of botox in treatment and prevention of neurofibromas.
- Expanding the scope of the procedure clinic to include nursing support and treatment under sedation. This will facilitate the treatment of whole body fields (e.g. forehead, shoulder, etc.) with LASER to reduce disfigurement.
- A trial has recently commenced trialling FRAXEL resurfacing in patients with skin lesions not amenable to excision.
- It has been demonstrated in the clinic that itch is a significant concern for some patients with NF1 and is amenable to effective pharmacological treatment. Recruitment of patients with itch is expanding, with the aim of publishing a case series to inform the broader medical community of better management of NF patients with itch as well as demonstrate the immense impact of treatment in improvement of quality of life.

Centre for Translational Research and Complex Care

The key objectives of this project are to:

- Increase multidisciplinary and specialist involvement in the NF clinic
- Facilitate use of new treatments in the care of NF1 and NF2

CTF funding has enabled a number of actions to be taken including:

- Appointment of a neurologist to offer specialist consultations for patients with complex neurological issues
- A sessional Dermatologist provides additional skin clinic consultations and treatments
- A genetic counsellor has begun developing research protocols and ethics applications have been made. From January 2019 a research officer will be recruited to continue these research projects and explore additional research funding sources.
- Employment of a part-time nurse to assist in the clinic
- Purchase of consumables and equipment to improve clinical care and support research projects

CTF Survey

A questionnaire is being developed to gather the experiences and concerns of people with NF1 about their NF care. This survey will allow the targeting of future service delivery to patient concerns. Results will be published widely to improve care of patients across Australia and internationally.

Associate Professor Kristi Jones

Dr Mimi Berman

> **The staff and patients of the RNSH NF clinic are extremely grateful for the generous support of CTF and its donors. That support is vital in our continued work together to conquer NF.**
>
> **- Dr Mimi Berman**

Children's Hospital Westmead (CHW)

NF Clinic

Many children living with NF from across NSW, the ACT and some from interstate are under the care of the experienced multidisciplinary team at CHW. This service is now being enhanced by CTF funding through a Neurofibromatosis Clinical Nurse Specialist position with Sally Maspero joining the team. Sally is a familiar face to many members of our NF community given her previous support services role with CTF. She brings a very sound knowledge of NF as well as previous clinical experience gained while working in the Neurofibromatosis Service based at Guy's and St Thomas' Hospitals in London.

This important position is providing a valuable role in the clinic, ensuring continued ongoing quality care to children and their families attending the NF Clinic. Sally assists with the coordination of investigations and appointments at the NF clinic and with other sub-specialist and allied health teams. She is providing a vital role in liaising with families, external medical and other health providers involved in the care of patients with NF and provides a valuable service to those families needing extra support managing their child's complex care needs.

> **"Children with NF are extremely vulnerable and together with their families face many challenges and an uncertain future. So it is such a blessing to have the continued support of CTF in our endeavours to assist those impacted by NF.**
>
> **- Associate Professor Kristi Jones"**

Royal Children's Hospital/MCRI Neurofibromatosis Clinic

This clinic provides care for children and adolescents affected by complex and non-complex neurofibromatosis type 1 (NF1), neurofibromatosis type 2 (NF2) and schwannomatosis. It is Victoria's leading centre for the diagnosis and management of neurofibromatosis and is recognised nationally and internationally for excellence in clinical care and research to guide improved treatment.

The NF Clinic is a multi-disciplinary team focussed on providing excellent clinical care and ensuring that the interaction with the healthcare system is as seamless as possible by coordinating same-day appointments with the relevant specialists. This is underpinned by research that ensures the care provided to individuals remains at the forefront and is based on the best research evidence.

The clinic cares for over 350 children and adolescents, and the number of individuals cared for by the NF Clinic continues to grow – with over 10 new referrals each month.

The partnership between CTF, doctors, allied health professionals, researchers, and the NF community is key to rapidly translating the best research evidence into the best clinical care.

Professor Rosalie Ferner

NF Complex Care State-wide Service

Dr Berman from RNSH and Associate Professor Jones at CHW have collaborated to complete a proposal for a state-wide approach for NF in NSW, using a hub and spoke model. The proposal has been well received and it has been requested that the state-wide NF service plan become a demonstrator project for future rare disease services. A detailed proposal is being developed for submission in late 2018.

Inaugural Australasian Neurofibromatosis NF Conference

RNSH worked with CTF to deliver an incredibly successful clinical symposium in October 2017. With over 70 NF specialists in attendance from across Australia and New Zealand, the symposium raised awareness of existing research and clinical advances in NF amongst clinicians and raised the profile of CTF amongst the Australian NF medical community.

Professor Rosalie Ferner was the keynote speaker and her knowledge of NF is respected worldwide. Professor Ferner is a consultant neurologist at Guy's and St Thomas' Hospitals and is chair of the medical advisory board of the Neuro Foundation as well as being the national lead for NF services in the UK.

It was especially good to hear speakers from a wide range of medical disciplines that are required in the care of patients with a disease as complex and challenging as NF. The conference also acted as a base for future collaboration amongst clinicians, surgeons and researchers across various fields.

Our special thanks go to Whiteley Corporation for their funding of the event and continued support of CTF including a pledge to fund the 2018 event in Melbourne.

NF Community Seminar

We were pleased to have hundreds of people watch our NF Community Seminar hosted by the Children's Hospital Westmead, which was also streamed online via Facebook and our website. It even attracted members of the international NF community.

This seminar was particularly focused on teenagers and the issues in transitioning to adult services.

Professor Ferner was again the keynote speaker along with a range of other practitioners from various disciplines.

Feedback was extremely positive and this has laid the groundwork for further seminars aimed at providing the latest information on research and advancements in care.

We were fortunate to have the kind support of the Australian Chinese Charity Foundation who funded the event and who committed support for another event in 2018, for which we are very grateful.

CTF SUPPORT SERVICES

What a year for Support Services. With Mona Saleh joining as Support Services Manager, covering national and NSW issues, very ably assisted by Natalie McCloughan as Support Coordinator covering Vic/Tas and Daniel Hinson who recently joined as Support Coordinator for Qld/NT, the organisation has established a solid base for providing community support across the country.

CTF has a key objective to also have Support Coordinators based in Adelaide and Perth; however, this depends solely on our ability to obtain sustainable long-term funding and the assistance of hospitals in those areas.

The team hosted events in NSW, Vic, Tas, Qld and SA during the year including two webinars, one on skin treatments for those with NF1 and another on NF2 regarding the options for treating acoustic neuroma and other tumours. They also encouraged community members to get involved and make a difference in their local area through activities such as the NF Sippers.

Our support team works hard to connect not only face to face with the community but also by phone, email and through our Facebook pages.

Mona Saleh

Mona is the Support Services Manager and, whilst initially training as a scientist, she became interested in genetic counselling and completed her Human Genetics Society of Australasia Fellowship in 2000. As a genetic counsellor, Mona has worked with individuals and families in a variety of settings including prenatal, adult onset conditions and pediatric genetics. Her experience includes working at NSW Ministry of Health in Genetics Education, University of Sydney Masters training of genetic counsellors and more recently being CTF's Support Services Manager.

Mona's goal is to create a knowledgeable and supportive community for everyone involved with or affected by NF in Australia. CTF has a solid support strategy in place and Mona wants to deliver initiatives that make a real difference for the community.

Whilst she is based in Sydney, Mona enjoys the opportunity to link up with NF community members near and far.

Natalie McCloughan

Natalie is the Support Coordinator for Victoria and Tasmania, based in Melbourne at the Royal Children's Hospital (RCH). She coordinates the multidisciplinary NF Clinic, provides case management to families attending the RCH, assists families and adults impacted by NF to access community services, organises family camps, information days and other community events and works behind the scenes driving a number of CTF's support services strategies.

Natalie also facilitates our CTF Youth Facebook page and hosts sessions where young people with NF can gather and chat online in a safe and professionally moderated environment.

She loves seeing the community members grow strong and resilient and reach a place in their journey with NF where they can be themselves despite the challenges that NF creates. She also enjoys working on projects with the aim of supporting the day-to-day needs of the community like the Peers Supporting Peers online learning tool and the Youth Support Group and strategy that which she has developed.

Daniel Hinson

Daniel is the NF Support Coordinator for Queensland and the Northern Territory based at Genetic Health Queensland, Royal Brisbane and Women's Hospital in Brisbane. He will provide face to face, telephone, and clinical support.
Daniel is new to CTF and wants to get to know as many people as possible across Qld and NT. He hopes to keep making positive and meaningful connections with the NF community and is keen to get to work supporting children, adults and families impacted by NF.

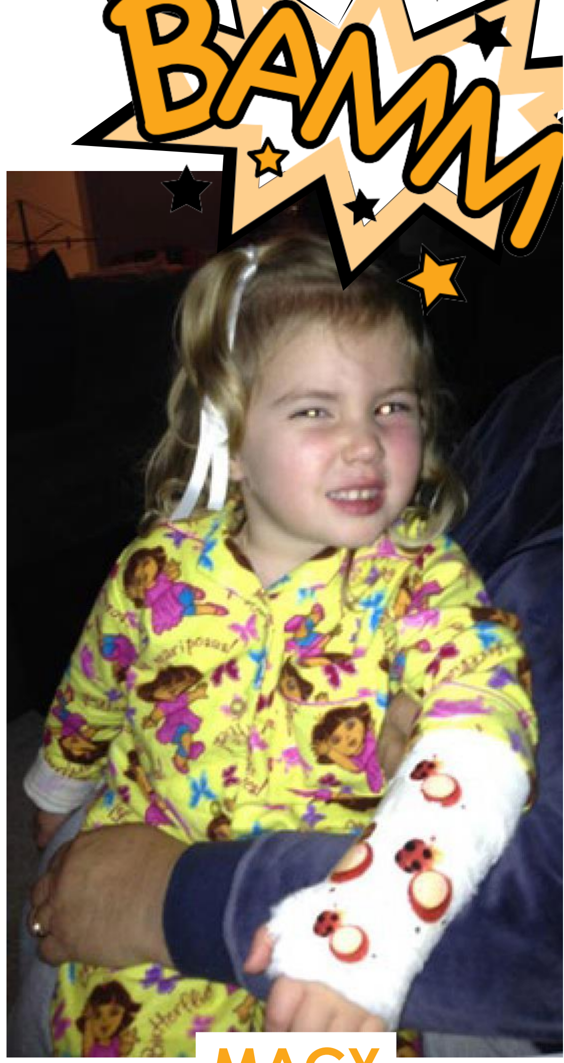
Daniel graduated from Queensland University of Technology (QUT) with a Masters of Social Work and has also studied Art History at the University of Queensland (UQ), and Applied Theatre at Griffith University. Since graduating, Daniel has worked in various social work roles across Queensland Health and the community sector, working therapeutically and supportively with patients and families in general medical, oncology, palliative care and intensive care settings.

NF HEROES

ZANE

Zane is a lively, bright and fun-loving 10-year-old, who also happens to have NF. Zane was diagnosed at 3 months due to a clinical diagnosis of the hallmark café au lait spots and pseudoarthrosis of his right tibia and fibula. *"To say that his diagnosis was shocking would be an understatement,"* said his mum Arianne. *"In fact, I barely remember the first year and a half of his life due to being thrown head first into the world of multiple doctors' appointments, terrifying Google imagery and now having to navigate the perils of not only being a first-time mum, but also a first-time mother to a child with a disability."*

> **"Zane has had to endure so much in his 10 tender years on this Earth, from multiple surgeries, MRIs and missing out on being a 'normal kid'. NF has taken so much from us as a family, but Zane has confronted every setback with gusto, grace and true grit. He is always smiling and gives his all, every time. Zane inspires us to be better people and to never give up and never give in, thank you for being such a terrific son."**



MACY

Macy was diagnosed with NF at 18 months; she had twelve birthmarks and wasn't walking due to low muscle tone. Her mum, Suzannah, was told not to Google NF, because it can be confronting and 99% of the possible symptoms would not happen to Macy… Sadly, this was not the case, and her family could never have predicted how NF would tear their lives apart.

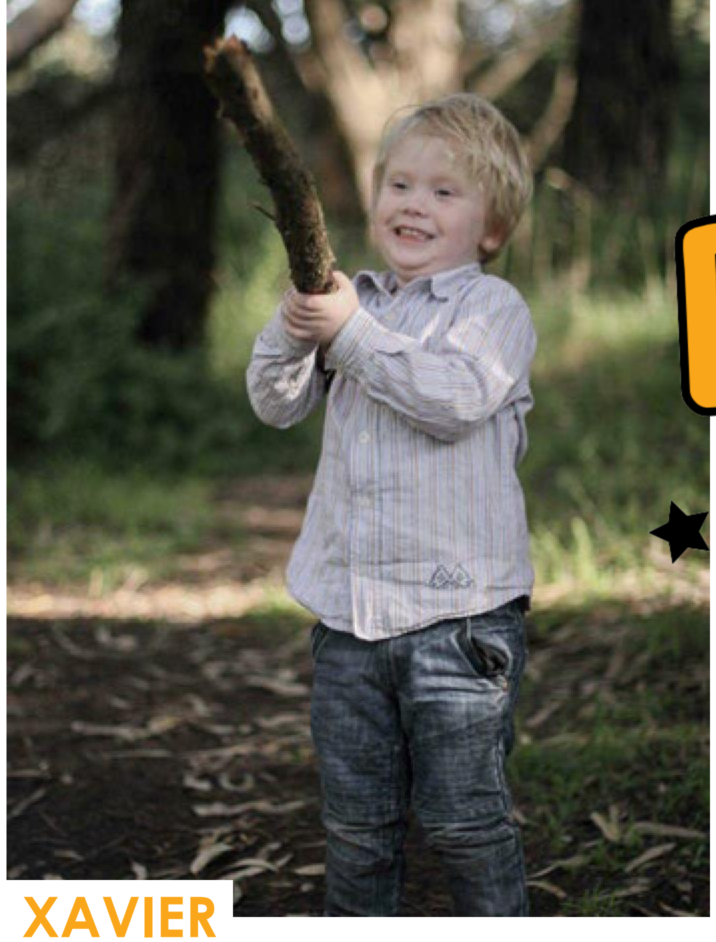
Macy broke her arm on her 3rd birthday and, when the cast came off, her mum noticed that she hadn't started to use it again. Macy was referred to an orthopaedic surgeon who suggested that her gross motor development could be signs of Cerebral Palsy. Suzannah was shocked: how does a healthy three-year-old go from a broken arm to having Cerebral Palsy? Something didn't feel right. Things became progressively worse. Macy began to fall asleep in random places throughout their home and Suzannah's motherly instincts suggested that something was "not right".

Suzannah rushed her to the pediatrician and demanded someone examine her daughter. The next thing she knew, an "urgent MRI for a suspected tumour" was organized for the next morning. Suddenly the frightening seriousness and reality of NF became all too real. It took one week for Macy to be diagnosed with multiple pilocytic astrocytomas (brain tumours). At just three, little Macy had lost partial mobility down the left side of her body and was scheduled for brain surgery. Unfortunately, the surgery did not go as well as hoped: one tumour in particular could not be completely removed due to the risk of blindness and paralysis. And so, Macy's chemotherapy journey began.

Macy's family was terrified. For two years, she received chemotherapy and had MRIs every 6 weeks. During a break from chemo, she had her annual ophthalmology checkup and, devastatingly, it was discovered that her vision had rapidly declined. In 2014, she was diagnosed legally blind. This decline in vision meant that Macy's tumours were no longer stable and, after four years of chemotherapy, they were refusing to respond to treatment. Fortunately, Macy was included in a clinical trial at the Royal Children's Hospital in Melbourne which was completed on 5 March 2018.

Today Macy's tumours are finally stable, after a long and torturous treatment cycle lasting 6 years. The clinical trial was Macy's last treatment option. She is due back for follow up and her mother fears that, "if her tumours are no longer stable, where do we go from here?" Effective treatment options for NF-related tumours are limited and there is no cure. According to Macy's family, "superheroes don't always wear capes, but this one truly deserves one." So much of Macy's childhood has been taken from her because of NF but her family are still hopeful and fighting!

Suzannah is a volunteer Race Director for Cupid's Undie Run in Hobart in 2019 as she wants to ensure she can improve awareness for this horrific genetic condition and make a difference for her beautiful daughter.

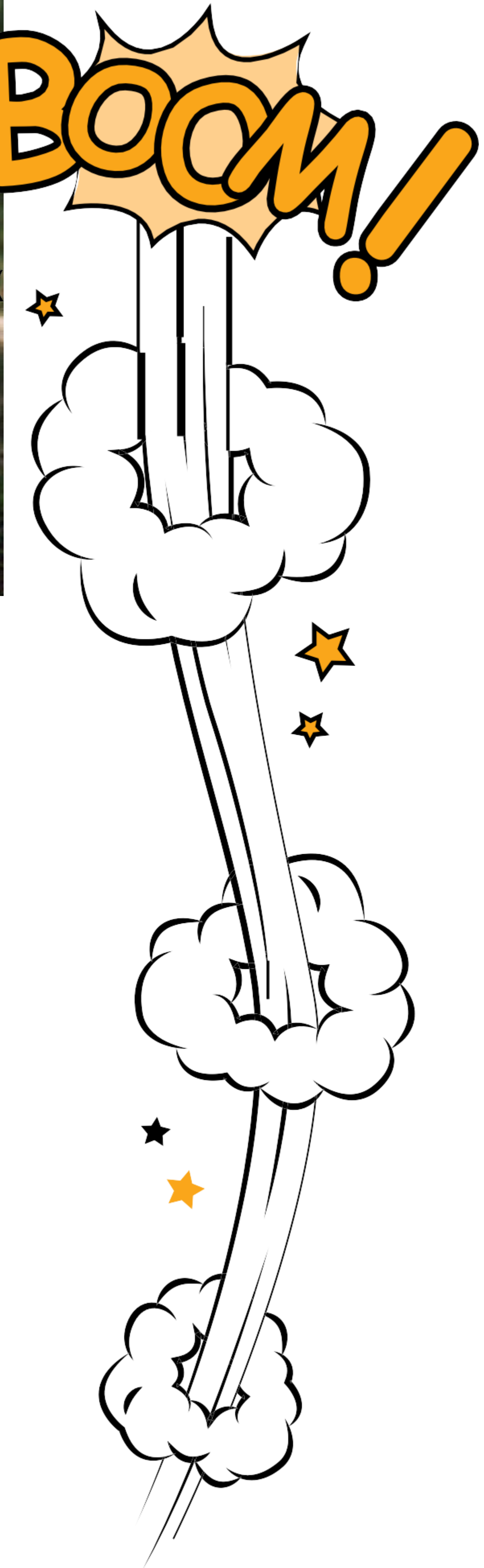


XAVIER

Xavier was born in 2013, and what a battle he has faced. Xavier, like his mum Karla and sister Chantelle, has NF. Xavier is a strong Richmond supporter and states his favourite player is Jack Reidwoldt. He loves AFL and loves kicking the footy. He also, like most kids, loves Paw Patrol and Peppa Pig.

Xavier was slow to reach his milestones and spent most of his first year crying. He started walking just before turning 2 and within 6 months his family noticed things were very wrong. He lost confidence in his abilities and stopped doing tasks he previously did well. That is when Karla contacted the NF Clinic. They were seen there within a couple of weeks and had an MRI very soon after. The MRI found a very large plexiform neurofibroma in his spinal/hip region going down his left leg impacting his strength and control of his left leg. He can't run and falls often. He has a higher than average pain threshold, meaning, if he injured, it is hard to know what happened and when. He also has a small growth on the hypothalamus region of his brain. Xavier has limited speech, and many developmental delays believed to be part of his NF. He also requires regular MRIs to ensure his tumours are stable and not causing any further issues.

Mum Karla knows all too well about life with NF and is thankful that she has such a brave little boy who is such an NF Hero.



In her mother's words from Zoe:

Our beautiful girl should be at the park today. She should be squealing as she goes down the slide or yelling for me to push her higher on the swing. She should be going to Kindy. She should be making friends. She should be healthy. She shouldn't be asking me every day if she has to have 'Captain Chemo' today, or whether she'll be getting the little feeding tube in her nose again. She shouldn't know that she has a lump in her head that's making her sick, and that making her sicker is the only chance we have at winning. She shouldn't have a scar on her chest where her port, 'Mr Bump', sits with its little tube delivering poison straight into the vein near her heart. She shouldn't have NF and she shouldn't have a brain tumour. But this is her reality, and it's a tough one right now.

Emme has an extensive diffuse low-grade brain stem glioma, reaching from C5 in her spinal cord right up through the middle of the brain. It's inoperable because of its location - the brainstem being the center for all our subconscious bodily functions - heartbeat, breathing, swallowing, blood pressure, and sleep, and our only chance of controlling its growth is through chemotherapy. And to be honest it's not a very successful treatment option.

In March this year, we watched Emme go into surgery to have the port placed into her beautiful little chest, and the following day the first horrific round of chemo began. The effects were instantaneous and so very cruel. The weight fell off her tiny frame, food became intolerable, and sickness and pain hit her hard every day. I have never cried as many tears as I did in those early weeks. The day her hair started to fall out in chunks was devastating, and watching it dangling from her little hands was shocking. It was a relief to get rid of it completely and move forward with a brave face. She's so beautiful exactly as she is. She's brave and fierce and happy, and she teaches us to be all of those things in the face of adversity every single day.

Emme has had chemo 10 times in the past 4 months, and she has another 8 months to go. Our hope is that the treatment stabilises her tumour and that we'll get a bit more time to find another, better, option for her. There are days when I'm furious and filled with grief that this is happening. Watching her terrified and in pain nearly breaks me. But most days I think 'we've got this'. Because, despite everything, our brave girl laughs often and hard, is clever, and curious, and strong, and she lives life large. She is the silver lining in this journey, and I know with all my heart that we'll never give up trying to find a better treatment option for her, and for all children fighting their own NF battle.

EMME

FUNDRAISING AND COMMUNITY EVENTS

Cupid's Undie Run - our largest fundraising event

2018 saw our most successful Cupid's Undie Run yet, expanding from 12 to 17 locations across Australia and raising just over $500,000! The event surpassed all expectations and saw over 1,200 people Dare to Bare and run to Conquer NF.

After the success of Cupid's in 2017, it was decided to expand the event to reach a larger national audience. The decision was also made to rebrand our marketing, with the slogan 'Dare to Bare' and new campaign message, 'Celebrate Difference'. We wanted people to understand why we run in our undies and give the event a strong meaning that resonates with the community...

To Celebrate Difference highlights that stripped down, we are all different in our own special way. It was effective in gaining media attention for CTF and generating headlines through various media outlets across the country!

A huge congratulations and thank you to Cairns, Albury, Geelong, Kiama, Hobart and Darwin who held their first ever Cupid's Undie Run and did a brilliant job in improving awareness about NF in their communities.

Melbourne topped the country in fundraising, thanks to the Barney Army, who achieved a staggering $127,200! Such an incredible team effort that shows what is possible when you create a team and come together to fundraise for our NF heroes.

We welcomed new ambassadors, including Terry Campese, who got a shot of the boys from the Italy World Cup squad in their Cupid's Undies, and many others including Christie Lamb, Apollo, Josh Schache and Alex Silvagni, who all went above and beyond to help promote Cupid's and meet our NF community.

Our ever-increasing contingent of ambassadors were hugely successful in raising awareness of our event through social media, bringing in more participants and fundraising dollars! A special shout out to some of our veteran ambassadors, including Andrew "Reidy" Reid, who expertly and hilariously emceed our Sydney event again, and to Mel Wu, who volunteered her weekend to fly from Sydney to Melbourne, to attend a very special Cupid's Christmas Party and meet some of our NF families.

Venue sponsors helped make the event a great success by generously providing their venue and catering for all participants. Places like West Beach Bathers in Melbourne, Watt in Brisbane, The Opera Bar in Sydney, Ball and Chain in Fremantle and the River Deck Café in Albury all enthusiastically promoted Cupid's Undie Run with emails and social posts and were instrumental in the success on the day. We can't thank them enough for their partnership with the CTF and their commitment to make Cupid's an event to remember.

We also welcomed Jungle Body on board as a Cupid's partner, who created a fundraising team and provided amazing conga style warm ups across the country. We discovered our Cupid's participants love to dance and it was hilarious to see the photos and videos of our undie and tutu wearing participants, busting out their dance moves on the day. We definitely have the bravest and most joyful participants of any fun run!

Thanks to our partnership with 9 Cares, we were able to see a Cupid's television ad play around the country and we also welcomed 2GB to our list of Cupid's partners, who very generously promoted our event across Sydney. Media across the country embraced Cupid's, with front page articles highlighting the event and our cause. Mostly notably, we received a full-page feature in numerous issues of the Women's and Men's Health magazines free of charge.

Cupid's would not be possible without our volunteer race directors. The 2018 Cupid's team was phenomenal and their passion and motivation to create an incredible event, to fundraise and raise awareness about NF was, as always, awe-inspiring.

A huge thank you must of course go to the supporters and participants, who blew us away with their passion and tireless efforts to achieve some massive fundraising goals. As always Cam Elliott was outstanding for Libby's Lionhearts, who livestreamed himself being waxed and tattooed, and then there was Ell shaving her head in Canberra along with other teams creating their own special challenges.

We are constantly inspired and humbled by our NF community and their tremendous efforts.

The funds raised by Cupid's Undie Run go towards increasing national support services and funding critically important medical research. Thank you so much to our key partners and sponsors, including: Bonds, Acer, Thorn and our media partner 9 Cares. Our ambassadors, each played a pivotal role in helping us increase awareness about NF and we are so grateful.

NF Hero March

The NF Hero March is a chance for the community to get involved and help raise vital funds for The Children's Tumour Foundation along with increasing awareness about neurofibromatosis and the work that is done to support those impacted by NF.

This is now an annual, family-focused event with everyone taking on the challenge of a 5km walk and obtaining sponsorship from family and friends.

Each participant received a superhero cape – a symbol of the power that comes when we join together to #conquernf – and was encouraged to wear yellow on the day, representing CTF and our aim of promoting friendship and togetherness.

It was a great day out in 6 cities across the nation, which saw nearly 500 people take part. After the walk, everyone enjoyed a light meal and there were plenty of activities to keep little people busy, including face painting and jumping castles.

Feedback was very positive and, as one said: "It was a great opportunity to meet other NF families and raise the profile of NF."

Thank you to everyone for participating and helping to achieve an amazing $53,000 raised, which has enabled CTF to continue a number of community support programs.

Cam Elliott (pictured above) was the highest fundraiser overall, raising a huge $6,880, and is an absolute NF Hero in all the tremendous work he does to help raise funds for CTF and build awareness of NF.

We would also like to thank our incredible race directors for making this event possible and look forward to an even bigger and better event next year!

Donor Thank You Dinner

Sunday 22nd October was a very special night where we had the opportunity to thank those people and organisations who had significantly assisted us to fund our medical and community programs.

The event was held at the fabulous Rockpool Bar & Grill with Neil Perry doing a special welcome. In addition, Neil and his Head Chef Corey designed an exclusive menu especially for the occasion.

Whilst donors had supported CTF throughout the year they also contributed $250,000 on the night, which is enormously appreciated.

Three of our little NF Heroes, Fiona Bottom, Mitch Fenton and Libby Elliott, captured the hearts of everyone and did a magnificent job assisting our MC Davina Smith from Channel 9 in announcing the lucky winners of the Luxury Lotto and Silent Auction.

A Luxury Affair

To launch NF Awareness Month, A Luxury Affair evening was held on May 1st. Hosted by Ben Fordham, the event showcased products from leading Australian and international brands, including: Tesla, Fairfax & Roberts, Wentworth Galleries, Rolex and the Sofitel Wentworth.

We had the pleasure of welcoming Dr Charlie Teo as a special guest. Dr Teo has a number of NF sufferers as patients and so has a deep understanding of the challenges faced by members of our NF community.

Our sincere thanks to the Sofitel Wentworth who provided a wonderful cocktail party experience.

The evening generated some $50,000 through donations and a live auction of a select number of luxury goods including paintings from some of Australia's leading artists including Palla Jeroff and John Maitland who generously donated some superb examples of their works.

Sippers Club

This is a wonderful opportunity for members of our NF communities to catch up over a tea or coffee, share their experiences and provide mutual support.

It started in Wollongong thanks to the initiative of Julia Szulerowski and has now expanded to over 25 locations across the country including Central and Western Sydney, Hunter Valley, Brisbane and Melbourne.

NF Community Fun Day – Melbourne

Over 60 people attended our Fun Day at Phoenix Park Community Centre on the 3rd June for some CIRCUS themed fun!

We received numerous positive comments, but one mum summed it all up:

“Thank you for organising this. I attended with my two boys - one has NF2. For me it was so great to see him being himself, meeting and playing with other kids without feeling self-conscious of his brace or how he walks. In his words: I don’t have to worry today mum.”

> **“And the face painting was awesome – there were compliments and jealous looks from other kids at the shops on the way home.”**

QLD Family Weekend

The South East QLD NF Family Weekend at the NRMA Treasure Island Holiday Resort from May 25th to 27th was a wonderful experience for all who attended. Around 30 people, many of them camp regulars and some new faces, had a great time relaxing, chatting and enjoying the fantastic facilities and activities.

Special thanks to Mary Walker, grandma of Zane with NF1, who organised most of the weekend and ensured it ran so smoothly.

Feedback from families was very positive, especially the opportunity to connect with others impacted by NF who understand each other’s experiences and providing advice and support to those new to the challenging world of NF.

May 8 = Mate Day!

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!

This wonderful initiative was the idea of Peter Kirkpatrick, whose daughter Emily has NF, due to his concern about the lack of understanding amongst children with differences.

Children are encouraged to dress in yellow and make a gold coin donation to CTF but most importantly to show that, no matter what our differences, we should all help and support each other.

We hope to see this event grow in the future. May 8 = Mate!

2018 SUPPORTERS LIST

Patron

The Hon Nick Greiner AC

CTF Ambassadors

Ben Fordham

Eddie & Melanie Listorti

Alex Silvagni

Alicia Loxley

Amoss McKinley

Andrew ‘Reidy’ Reid

Apollo Jackson

Belinda Hocking

Christie Lamb

Davina Smith

Felicity Egginton

January Diaries

Josh Schache

Justyna Kalka

Lisa Darmanin

Luke and Cody

Maddi and Lloyd

Mariafe Artacho Del Solar

Melissa Wu

Sabrina Smeaton

Terry Campese

The Australian Firefighters Calendar

Australian Stockbrokers Foundation	Andrew Tracey
	Danny Dreyfus
	Wentworth Galleries
	Ray Aitken
	Maria Aitken
	Peter Aitken
	John Maitland
	Machiavelli Restaurant
	Nicolae Bicher
	Fairfax & Roberts
	Sarah Orfanosvant

Corporate Partners

Australian Chinese Charity Foundation

Acer

Australian Stockbrokers Foundation

Bendigo Bank

Bonds

Calvin Klein Channel 9

Commonwealth Bank Gregory Jewellers Gresham Partners

J Farren Price Morgans Nine Cares

The Beluga Foundation

Thorn Group

Whiteley Corporation Yieldbroker Pty Limited

Major Supporters Alec Redpath Andrew Toovey Andrew Tracy Anthony Toovey

Australian Chinese Charity Foundation

Bernardi Group Pty Ltd

Brian Gallery

Business Essential Pty Ltd Charles Teo

Dominique Robinson Doves Nest Foundation Eddie & Melanie Listorti Glen Toovey

INSITU GROUP

John & Robyn Hughes Larry & Alice Dell Maree Anderson Meaghan Heckenberg Nicole & Peter Bernardi Oliver Smith

Ollie & Brooke Smith

Opera Bar

PBK Management

Peter Kettley

Rosemary Grant

Rotary Club of Kings Cross

Sydney Women's International Club Inc

Tertini Charitable Foundation

Visual Identity

Watches of Switzerland

Pro Bono Support

Brand Haven

Consultus

Crowe Horwath

Elevencom

Google

Herbert Smith Freehills

Retail Oasis

Simcosec

V.I

Top 100 Fundraising Teams

The Barney Army

Libby's Lionhearts

Best Undressed

Eddie Brothers Village

Emme's Cupids

The Barney Army - Tasmanian Regiment

Team Britty

Darcy Boy

WALKWITHWILLIAM

Super Ben

Bottom Army

Hannah's Angels

Mega Hero Ride Silverton

STORMED OUT HRVHERO MEGA HERO

Richos for Rehbeins

The Shaws 2018

Giorgioni' Fitness fundraiser Boot Camp

Jane's Squad

Team Mayli

Running Undies

Morgans Sydney Smugglers

Felicitys Angels

Lennys Entourage

Olivia's Fairies

TEAM BELLA

Team NoÃ©mie

Royal North Shore Hospital

Team Bum-bury

TEAM THORN

Danni's Devils

Christie Lamb Team

Seren's Shooting Stars

Harps4Cupid

Charlie's Crew

The A Team

Funtastic

Dexter's Warriors

Swartsenickers

Team Fanservice

Ness for NF

Joel Ronayne

Team Buchanan

Hawker Boys

Bendigo Heroes

Cupid's Little Helpers

Wills Warriors

Velvet

Under where?

Team Pacelli

Squat squad

Real life X-Men

Kellygang

Team Duds

AUSTRALIAN FIREFIGHTERS CALENDAR

Team Blakey

Captain Underpants

Scrambled legs

Emily's NF Squad - Port Macquarie

Team Weir

Wu's Warriors

The Underdogs

KATIE'S CUPIDS

Team CFOA-KPMG

Beth's team

Team Tilley

Nudie Cutie

Smiles 4 Miles

MARIANO'S TEAM

Dancin Divas

Bourned Again

DNA Undies

Jessica and the Pussy Cats

Kaydee Kates Crusaders

Queanbeyan Blues

Chasing Booty

Silvagni's NF Heroes

Sparkle Pants

Team Giddins

TEAM DONCS

Team Lightspeed

ANGEL'S KISSES

TEAM ACER

Team Teghan!

Maddi & Lloyd

Happy Feet

Team Larsen sans undies

Bathurst City Life Cupids

Team Kc

For Jessica

Amy gleeson

Kylie's Crusaders

Power Walkers

NFAWA

Andrew's Allies

Doing it for Evie

lakeside lovelies

Sole Sisters

Tassie's Devils

#DoitforBella

mini and her monsters

Children's Tumour Foundation
CONQUERING NF

ctf.org.au

We're here to help!

Office: 2/451 Lyons Road West Five Dock NSW 2046
Post: PO Box 454 Five Dock NSW 2046
Phone: +61 2 9713 6111
Fax: +61 2 9712 8524
Email: info@ctf.org.au

f Like us on Facebook
www.facebook.com/CTFAus