



CHILDREN'S TUMOUR FOUNDATION OF AUSTRALIA ANNUAL REVIEW

JULY 2019 - JUNE 2020



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MESSAGE FROM OUR CHAIR

I am pleased to introduce the annual report for the Children’s Tumour Foundation (CTF) for financial year 2020; a period that was incredibly challenging for our country given the drought, bushfires and then COVID-19.



After a strong start to the financial year with campaigns like the NF Hero Challenge, the cancellation of our biggest fundraising event in March (Cupid’s Undie Run) due to COVID-19, the impact of donor fatigue from the drought and bushfires, followed by further uncertainty around the economy, meant some critical changes were needed to ensure our support of the NF community was not compromised.

Although the CTF team did an extraordinary job shifting the Cupid’s Undie Run “from the streets to the screen” at short notice, the financial impact of cancelling the physical event was significant – with a shortfall of 52% on prior year’s fundraising and below our 2020 plan.

A general decline in donations over the period meant the Board and Management needed to review its commitments to all research studies and clinical trials, ongoing support services, as well as our overall operating costs.

Given our cash position, the Board made the difficult decision to find ways to reduce its operating cost structure. As a result, sadly the services of both the CEO and Office Manager were terminated, and an Executive Committee of the Board formed to oversee some of the operational duties.

We continue to fund our hospitals including clinical trials, invest in support services, and ensure that information, educational resources and awareness raising initiatives are maintained. Although NF Camps and Community Days were cancelled due to COVID-19, we have continued to provide valuable phone and digital support services.

Given our earlier investment in IT and telecommunications, (including website update), our staff were able to seamlessly transition from the office to their homes without disruption to service.

Our staff have shown immense resilience and commitment to supporting the CTF and NF community and the Board is thankful for their hard work and dedication.

Despite various challenges, we had a successful year with following key highlights:

- A successful NF Symposium with over 100 medical specialists and three overseas guest speakers;
- In conjunction with NF Awareness Month, we launched our new website and brand colours;
- Launched a new Peer Leader Program as part of our local community support group initiative;
- Launched NF Connect – a virtual platform for information sharing amongst targeted groups, and
- The Federal Government announced a grant of \$760k for the TiNT MEK Inhibitor Clinical Trial, which the CTF co-funds in partnership with Flicker of Hope.

We would like to thank all our donors and supporters for their belief in us and our mission to #conquerNF.

With your continued support, we can deliver on our promise to the NF community.

During the year Kerry Kelly was appointed Chair of the Board. Unfortunately, after eight months she had to resign for family reasons, and we thank Kerry for her role.

I would also like to thank the directors who retired during the year for their contributions, and my fellow directors for their ongoing commitment in helping the NF community through the CTF.

Best Wishes,

Nirmal Hansra
Acting Chair, Children’s Tumour Foundation

ABOUT US

OUR PURPOSE

The Children's Tumour Foundation (CTF) is the only support service for families living with Neurofibromatosis (NF) in Australia.

The NF journey from diagnosis through to treatment is challenging and most of what people will experience is unknown.

The CTF exists to provide a pathway from fear to hope by investing in promising research, advocating for better resources and empowering individuals and their families with the knowledge, connections and support needed at every stage of their journey.

Conquering NF is about more than just finding a cure.



WHO WE ARE

We are the link that connects people with NF to services and each other. We are dedicated to raising money to fund vital research, awareness and practical support services for people with all types of NF.

We are focused. We work in pursuit of improving the lives of people impacted by NF and understand that many people are counting on us.

We are a small and collaborative team. Teamwork comes naturally to us because of our passion and dedication to do the absolute best we can to fight the one common enemy.

We are not afraid to work hard and know that trust must be earned. We accept responsibility for our actions and hold ourselves accountable.

We are continually evolving. We encourage feedback and are always striving to do things better. We are confident enough to know that just because we do things a certain way now, doesn't mean we can't find a better way.

WHAT WE DO

We empower individuals and their families impacted by NF with the knowledge, connections and support needed at every stage of their journey, working to improve life outcomes in three ways:



SUPPORT SERVICES

Beyond the need to treat the physical symptoms of NF, living with this condition can also take an emotional toll on patients and their families, so addressing a person's mental health is one of our key priorities.

To combat the feelings of isolation and anxiety, the Children's Tumour Foundation creates opportunities for people to come together in safe, supportive spaces, connecting them with balanced information, treatment options and each other. This includes, but is not limited to:

- National phone and online support
- Specialised NF Clinics in major hospitals
- Family camps, community and other social events
- Parenting & peer support groups, information seminars and webinars
- Introduction of new virtual meet ("NF Connect")



RESEARCH

With over \$1.1 million invested to date, the CTF is focused on supporting established research initiatives that directly impact those living with NF in Australia and contribute to a global body of work to better understand and treat NF symptoms.

Recently we have funded phase 2/3 clinical trials, treatments for skin disfigurement and studies on the social, learning and behavioural aspects of children with NF.



ADVOCACY & AWARENESS

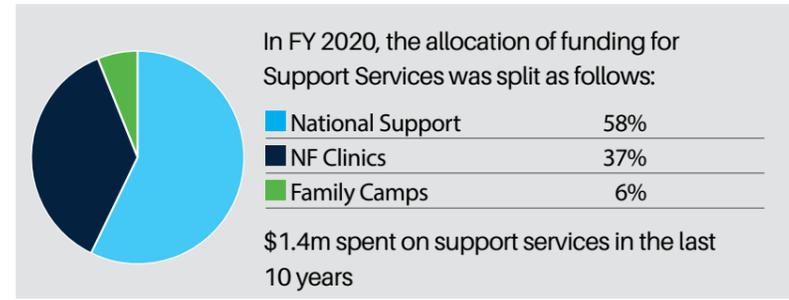
NF is as common as Cystic Fibrosis, Muscular Dystrophy and Huntington's Disease, but awareness is lacking — even among healthcare professionals. In addition to raising awareness through our own campaigns, we also collaborate with hospitals to help our community navigate health systems, as well as their government entitlements.

We are also a referral source that connects our community to medical and allied health professionals who have experience treating NF patients. We work with State and Federal Governments, advocating for improvements in availability and cost of diagnostic scans, medications and improved treatment options.

SOCIAL IMPACT

This report provides the key outcomes for services and projects completed during the period 1 Jul 2019 – 30 June 2020.

SUPPORT SERVICES



830+ CHILDREN ASSESSED AT NF CLINIC

The Children's Hospital Westmead

- 335 patients seen at the clinic
- 155 patients assessed via telehealth services leading to a 31% increase in appointments YOY
- 54 new referrals

Royal Children's Hospital, Melbourne

- 229 patients seen at the clinic
- 113 patients assessed via telehealth services
- 18 new referrals

260+ ADULTS ASSESSED AT NF CLINIC

Royal North Shore Hospital

- 196 patients seen at the adult clinic (15% increase YOY)
- 56% of those who attended were new patients seeking treatment

Royal Melbourne Hospital

- 67 patients seen at the clinic

.....

During this time, best practice templates for an adult clinic were initiated and development started.

1. A triage plan for waiting referrals
2. A first attendance assessment template

The remaining three parts of the project are to be completed next year.

3,400+ support-related interactions by phone, online or in-person

28 hours of facilitated online chats across three different sub-groups

28 hours of online training and development facilitated for NF community

ONE webinar hosted with A/P Aaron Schindeler

SIX COMMUNITY EVENT DAYS

hosted with more than 550 people attending as part of the NF Hero Day in September 2019.

ONE COMMUNITY INFORMATION DAY

hosted at Parramatta Leagues Club in Sydney (March 2020) and attended by more than 40 people, with local and international speakers.

- Professor Michael Fisher (CHOP)
- Assoc. Professor Mimi Berman (RNSH)
- Dr Geoff McCowage (SCHW)
- Dr Nigel Biggs (St Vincents)
- Dr Belinda Barton (SCHW)

34 HEALTH KITS

created and distributed to parents of children, teens and adults living with NF across Australia.

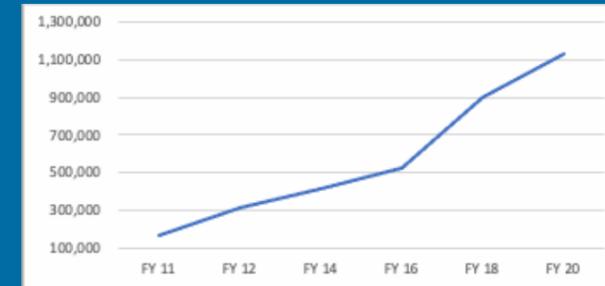
TWO NF FAMILY CAMPS

hosted in two states and attended by more than 80 people and 23 families prior to COVID-19.

It was the first time we ran a camp in Far North Queensland.

RESEARCH

More than \$1.1m spent on NF research over the last 10 years.



Below is a snapshot of the projects funded by the CTF on an ongoing basis:

CENTRE FOR TRANSLATIONAL EXCELLENCE AT RNSH

NF1 Breast Screening Study

This study aims to establish a successful breast screening program in women with NF1.

Virtual MDT for NF2 and Schwannomatosis

This program seeks to improve the clinical management of patients and educate healthcare workers across local health districts through monthly NF Multi-Disciplinary Teams (MDTs).

Treating Disfigurement & Itch

120 patients treated as part of a study at the multi-disciplinary skin clinic using laser equipment.

MURDOCH CHILDREN'S RESEARCH INSTITUTE (MCRI)

Cell-Free DNA BioBank

Development of a large cohort biobank of plasma samples ready for future analysis and identification of tumour transformation of MPNST in NF1 patients.

The Predictors of Autism in Neurofibromatosis Type 1: Development to Adolescence (PANDA)

Establish whether children with NF1 demonstrate abnormal function within the social brain network, and the relationship between structural and functional brain abnormalities and ASD/social dysfunction.

ADVOCACY & AWARENESS

Part of the role of the Support Services Team is to discuss any issues you may have with schools, employers or health services and assist with information and advocacy where appropriate.

We also reach out to General Practitioners and other medical and health organisations to provide information and resources to assist with the management and referral of patients to clinics and NF specialists.

36 TEACHER TOOLKITS

distributed via health kits to parents of children across 4 states and territories.

100% SUCCESS RATE

to date on NDIS letters submitted on behalf of families seeking funding.

ADVOCATED FOR 50+ INDIVIDUALS

with specific and/or life-limiting issues that required dedicated development of resources or letters of support.

ONE NF SYMPOSIUM

attended by more than 100 NF specialists and clinicians from Australia and the US. There were 14 speakers invited to share their knowledge and results.

NEW WEBSITE LAUNCHED

Information rich, user-friendly website launched in May 2020, showcasing new branding.

REACHED OVER 2M PEOPLE

via our owned and earned channels, through the sharing of stories, facts and information about Neurofibromatosis.

80+ STORIES DEVELOPED

and shared on our social channels and eDMs, with up to 35 new stories provided by individuals and families with NF.

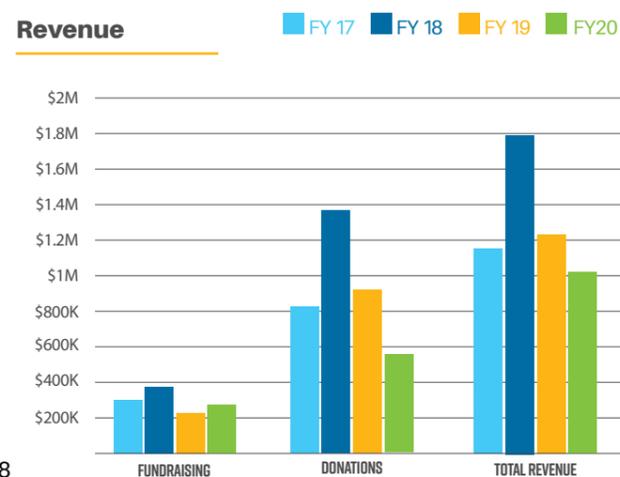
FINANCIAL STATEMENTS

The statutory accounts for the year ending 30 June 2020 have been audited and the full copy of the accounts can be found on our website: www.ctf.org.au

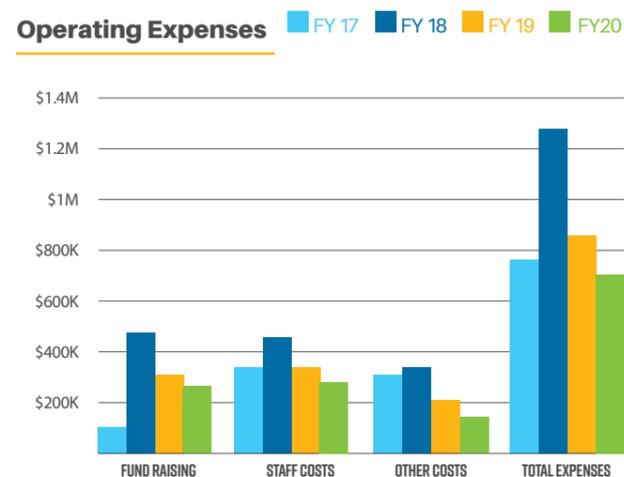
The following information is an abbreviated version of the Audited Annual Accounts for the Children's Tumour Foundation of Australia for the past five years.

	FY 16	FY 17	FY 18	FY 19	FY20
	\$ 000s				
Revenue	1,398	1,163	1,813	1,185	1,043
Expenses	1,003	777	1,288	862	689
<i>Operating Surplus</i>	395	386	525	323	354
Grants - Research	48	178	191	133	94
Support Services	165	137	201	412	320
<i>Grants & S/Services</i>	213	315	392	545	414
<i>Net Surplus/(Deficit)</i>	182	71	133	(222)	(60)
Cash	1,182	1,297	1,296	1,234	1,093
Other Assets	63	62	244	129	129
<i>Total Current Assets</i>	1,245	1,359	1,540	1,363	1,222
Fixed Assets	6	4	5	15	44
Other Assets	-	-	35	7	-
<i>Total Assets</i>	1,251	1,363	1,580	1,385	1,266
Current Liabilities	47	88	172	200	141
<i>Net Assets</i>	1,204	1,275	1,408	1,185	1,126

Revenue



Operating Expenses



HIGHLIGHTS

NF FAMILY CAMPS IN FAR NORTH QLD AND VICTORIA

Mission Beach, October 2019

When you are from a regional area access to specialist health services can be limited, which is tough when you are living with a complex life-long condition such as NF. Added to this are the feelings of isolation that can come from not having access to a network of people who are going through a similar experience.

Thanks to the generosity of QBE Foundation, the CTF was able to run an NF Family Camp in far North Queensland (Mission Beach) for the first time. It was an incredible opportunity for families to come together to learn, connect, share and enjoy some fun in the sun.



Roses Gap Recreation Centre, November 2019

The Victorian camp was held at Roses Gap Recreation Centre, and was a huge success. With beautiful weather and many new families joining in the fun.

Heading to the Grampians is quite a drive for most in the state, but everyone who attended commented that it was "well worth the trip". There was no shortage of activities for both kids and adults to get involved with, including crate stacking, canoeing and bushwalking. Our movie night always goes down a treat too, but most importantly we witnessed some incredible friendships being formed.



2020 NF CLINICAL SYMPOSIUM

In March 2020, we were very proud to have once again worked with our founding sponsor Whiteley Corporation, to bring the third NF Clinical Symposium to Sydney.

Attended by over 100 of Australia's best Neurofibromatosis researchers and clinicians, as well as three invited international presenters, the 2020 NF Clinical Symposium covered a wide range of topics, including stem cell research, gene therapy and genome gene editing, as well as MEK Inhibitors and Auditory Processing studies.

Additionally, clinicians shared NF best practice with information on supplements to improve muscle strength, social, learning and behavioural development, treating skin disfigurement, options for treating NF2 (especially hearing loss) and the need for NF1 women over the age of 30 (not 50) to have regular breast screens.

Congratulations for the successful and well organised events last week. The symposium was certainly the largest gathering of NF researchers and health professionals in Australia that I have attended, providing an excellent platform to share knowledge, expertise and network. It was a pleasure to be involved.

The conference achieved its main goal, which was to foster sharing at a local and international level so that NF knowledge and best practice treatments continue to expand and be applied.



Prof. Fisher, along with five other Australian NF specialists presented at our Community Information Day.

More than 40 community members were able to hear first hand about the latest research and ask questions directly to leading professionals who are working on more effective treatment options.



Professor Fisher during his talk

The International Keynote Speaker was Professor Michael Fisher, Chief of the NeuroOncology Section (Division of Oncology) at The Children's Hospital of Philadelphia (CHOP), and the Director of the NF Program at CHOP.

His research focusses on identifying new treatments and novel biomarkers (particularly using new imaging modalities) and exploring functional outcomes for children with tumours associated with NF1.



Hilda Maroun and Family:
Highest National Fundraiser for the 2019 NF Hero Challenge
and Mum to NF Hero, Bianca

NF HERO CHALLENGE AND COMMUNITY DAY

August 2019 was NF Hero month and what a month it was for people kicking goals, tackling fears and generally have a great time as we worked as a big, extended family to raise the profile of NF and show the world what courage looks like.

Thanks to you, we raised over \$121,000, more than double the amount raised the year before. We witnessed members of our community overcoming real fears, while others put their bodies on the line in the name of loved ones, as well as people they have never met.

We saw them proving to themselves and to others that they could do it. It was glorious to watch and share those stories of triumph.

It all culminated in celebrations in five locations around the country, where everyone came together in their capes, participated in an awareness walk and had a fun day out in the sun.

As a family, we decided to jump into Brighton Bay in the dead of winter to raise money and support our daughter. I describe the experience of jumping into the freezing water in much the same way I remember feeling when Bianca got diagnosed with NF.

My toes were the first thing to hit that freezing water and my brain was trying to comprehend what was about to happen, then all of a sudden, I just felt numb. I was struggling to come back up out of the water. Kicking so hard, but it felt like I wasn't moving. I felt trapped, not knowing which way was up.

When I finally popped up and gasped for air, the sound of everyone cheering made me realise I wasn't alone in this struggle and neither was Bianca. It was an awakening. No matter what NF would have in store for her, I now knew she would be loved and supported on her journey.

Thank you to Dooleys Lidcombe Catholic Club for sponsoring the NF Hero Day in Sydney

FROM THE STREETS TO THE SCREEN, CUPID'S 2.0 WAS BORN IN LOCKDOWN

Cupid's Undie Run is the highlight of our fundraising calendar. Whether you take the opportunity to dress up or down, or maybe just donate, at the heart of the campaign is ensuring the future health and wellbeing of the families we support.

This year we made the decision to move the event to March 22 (except for Kiama and Hobart), who went ahead as planned on Valentine's weekend with great success.

All of our careful planning put us in good spirits as we headed into the new year, but no one was prepared for what was to come. Despite years of drought, the horror of the bushfires and then threats of flooding, we were still looking pretty solid and fully expected to reach our goal of \$500,000.

Ten days before Cupid's was scheduled to run in the remaining 13 locations, we made a decision that would guarantee we fell well short of our goal but ensure the safety of everyone in our care. We cancelled Cupids.

We were devastated and broken, but we were not down and out.

To ensure the only thing we spread on Sunday 22 March was awareness of NF, we launched Cupid's 2.0, a virtual campaign that moved our runners off the streets and onto their screens.

We asked everyone who registered to still strip down or dress up in their Cupid's gear or costumes and to share photos and videos for the chance to win some awesome prizes!

We were rewarded with hundreds of entries that showed off the creativity and commitment of our community to their annual undie run experience.

Thank you to everyone for your understanding and support.

#celebratedifference



WE REFRESHED OUR BRAND AND WEBSITE DURING NF AWARENESS MONTH 2020

May is NF Awareness Month, a time to raise our collective voices in support of all who live with Neurofibromatosis (NF). We form one part of a global community working to improve awareness and deepen understanding of the condition, while raising much needed funds to support better treatment options and enable access to critical support services.

To celebrate, we not only launched our new website, but completely refreshed our brand to reflect the international colours of NF — blue and green. As a result, there were a number of changes to our branding that has been reflected on the new website, including an updated logo and introduction of the NF Ribbon.



Love it. The breadth of information is great — so informative and helpful. Not only great for the newly diagnosed, but also for those looking for accurate information about a change in their condition, or the condition of someone they care about.

I also love the new colours and design. Well done!



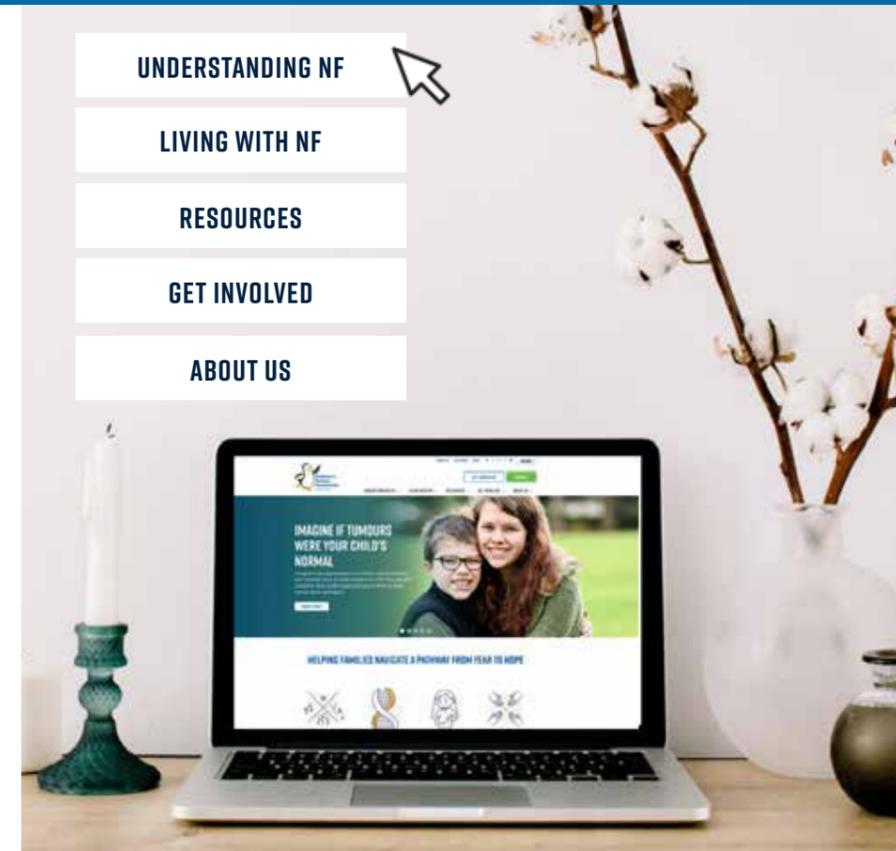
UNDERSTANDING NF

LIVING WITH NF

RESOURCES

GET INVOLVED

ABOUT US

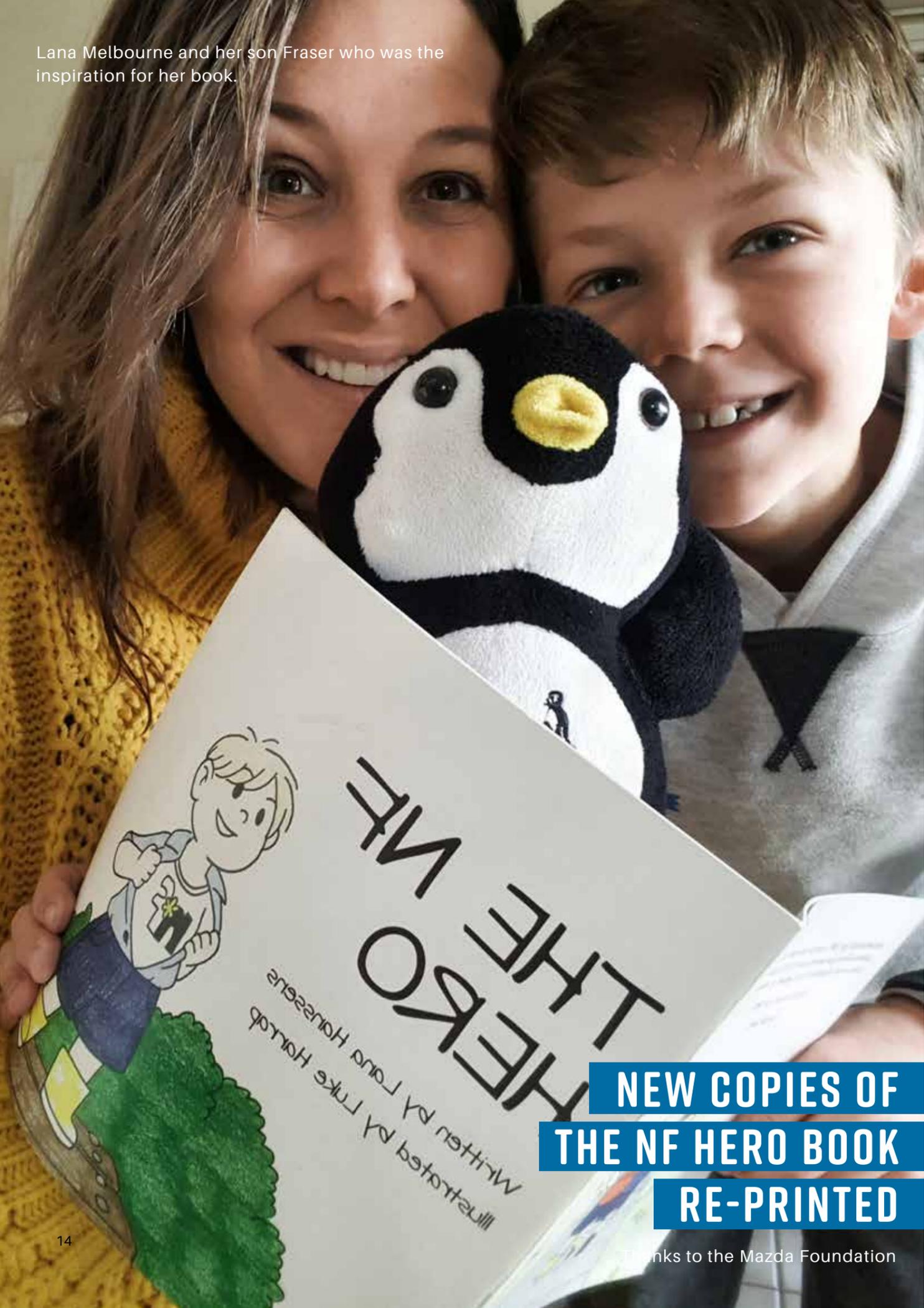


The new website was launched in stages throughout May, and we are thrilled with the result. It is a resource that will serve the NF community at any stage of life.

We hope it becomes a useful companion and safe space to access balanced and up-to-date information throughout a person's NF journey, while also serving as a tool to bring greater understanding of NF to everyday Australians, media and educators.

CHECK IT OUT
WWW.CTF.ORG.AU

Lana Melbourne and her son Fraser who was the inspiration for her book.



**NEW COPIES OF
THE NF HERO BOOK
RE-PRINTED**

Thanks to the Mazda Foundation

ACKNOWLEDGEMENTS

The CTF collaborates with such a wonderful range of people and organisations across all spectrums of business and community who seek to share our commitment in assisting and supporting families impacted by Neurofibromatosis (NF).

We are grateful for their support and being a valued part of the NF community, particularly during such difficult times.

Due to the space available, we are only going to list significant partners here (in alphabetical order). However, please know that we appreciate all donations of time, talents and treasures both big and small.

CORPORATE

AFL Players Association
Essential Energy
Gresham Partners
Insitu Group
J Farren-Price
Nepean Business Network
Orion Print Management
PBK Management
Petit Barcelona
Scentre Group (Westfield)
Whiteley Corporation

FOUNDATIONS

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Elevocom
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Nova Entertainment
Yoghurt Digital
vBe Creative

MAJOR DONORS

Eddie and Melanie Listorti
John and Robyn Hughes
Greg and Michelle Whiteley
Peter Ketley
Sergio Colosimo

GOVERNMENT

Federal Government
NSW Government/Health
Resourcing Parents

EVENT SPONSORS

Deni Truck Show
Greater Shepparton City Council
Harvey Norman
Jufan Investments
Plus Fitness
Whiteley Corporation

COMMUNITY CLUBS

Bankstown Sports Club
Canada Bay Club
Dooleys Lidcombe
Five Dock Rotary
Guildford Leagues Club
Mission Beach Rotary

COMMUNITY FUNDRAISERS*

Alex McHugh-Douglas (NFHC)
Amanda Black (Cupid's)
Amy O'Rourke (Cupid's)
Ashley Pienaar (Cupid's)
Cam Elliott (NFHC/Cupid's)
Caroline Rogers (Cupid's)
Craig March
Dena Farley (NFHC)
Geoff Bottom (Cupid's)
Hilda & Roger Maroun (NFHC)

Johnny Kasprzak
Julianne Phelan (NFHC)
Kate Chambers (NFHC)
Kelly Burgess
Lee & Mel Schrimpton (NFHC)
Meg Marshall (Cupid's)
Nine Mile Station Ride

* Raised more than \$4000

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