LET'S BRING NF OUT OF THE SHADOWS

Annual Review 20/21

Children's Tumour Foundation
CONQUERING NF

FROM THE CHAIR

I am pleased to introduce the annual review for the Children's Tumour Foundation (CTF) for financial year FY21; another challenging period given the continuing impact of the COVID-19 pandemic.

A general decline in donations and hence cash levels also meant the Board and Management needed to carefully manage overall operating costs. This has meant that the CTF continued to operate without a CEO, administrative support and an office for the whole financial year.

Importantly, we continued to provide funding to four in-hospital NF clinics, maintained our funding commitments to clinical trials, and expanded our support services, information, and educational resources. We also invested in awareness-raising campaigns. Although a large majority of NF Camps and Community Days were again cancelled due to COVID-19, we were able to provide valuable phone and digital support services.

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 end to the financial year. We secured new grant income with the most significant development being a $1M grant over a three year period from the Federal Government. The first grant payment of $500,000 was received in June 2021, providing a positive financial outcome for FY21.

The CTF also received grant funding from the NSW Government of $150,000, which included $50,000 for infrastructure and IT. This significantly boosted our cash reserves and gave the CTF the ability to secure a new office and appoint a new CEO, Leanne Dib, for FY22. We all look forward to working with Leanne as we continue with our vision to conquer NF.

In the area of NF research, the CTF worked with the NF community and successfully lobbied the Federal Government for an allocation of $7M for NF clinical trials and research, of which $4.6M was successfully granted to four research projects.

Finally, I would like to reiterate my thanks to the CTF team who have operated in a challenging environment, highlighting their commitment to support the NF community. I would also like to thank my fellow directors for their ongoing commitment during this period.

Best wishes,

PETER DOWDING
Chair

FROM THE CEO

The Children's Tumour Foundation (CTF) was not spared from the impact and effects of the global pandemic, yet with the ongoing support of the community, our supporters and stakeholders, including the Federal and NSW Governments, we are able to focus our energy on improving the health outcomes for everyone impacted by neurofibromatosis in Australia.

I joined the CTF team in August 2021, so the team are to be complemented for their commitment and efforts to the foundation across FY21; adjusting and navigating through such a difficult and uncertain climate. Adjusting operationally to work and provide services remotely has created opportunities for greater access and support; something we hope to build on in the future, along with the welcomed return of physical events and programs.

Thank you to our Chair, Peter Dowding, and the Board who continue to show their commitment, guidance and support to the CTF team and the Foundation, this is greatly appreciated.

Many of the Foundation's fundraising events were cancelled or modified last year due to COVID-19, impacting the CTF's revenue from fundraising in FY21. Advocating for change is at the heart of what we do, not just at an individual level, but also with government. It was through the efforts of the team and key community that millions have been invested into research and support by the Federal Government in FY21. Something we are incredibly proud to have achieved.

As we move forward, I am looking forward to building relationships and partnerships in support of our NF community and delivering on our mission to be the leading voice for change, advancing research and empowering people impacted by NF with the support needed at every stage of their journey.

Thank you,

LEANNE DIB
Chief Executive Officer

Proudly supported by:

Australian Government
Department of Health

NSW GOVERNMENT

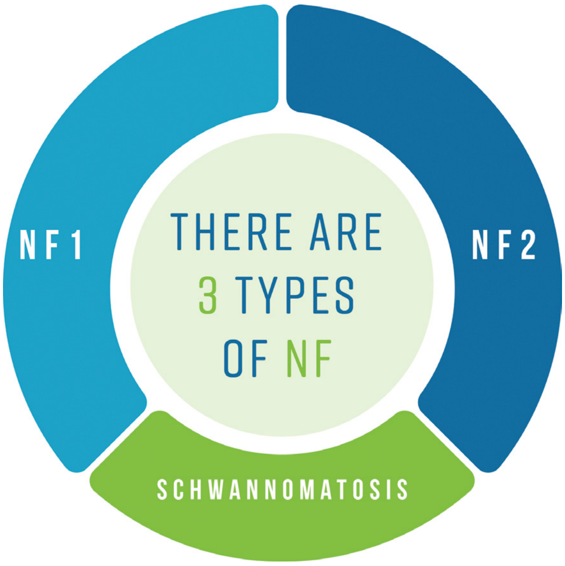
Health
NSW GOVERNMENT
Northern Sydney Local Health District

WHAT IS NF

Neurofibromatosis (NF) is a set of three complex genetic conditions that cause tumours to form on nerve cells throughout the body and affects more than 10,000 people in Australia.

The signs, symptoms, and management of each condition are different, as is the treatment for every individual.

NF AFFECTS ALL POPULATIONS, GENDERS & ETHNICITIES EQUALLY



THERE ARE 3 TYPES OF NF

NF1

NF2

SCHWANNOMATOSIS

EVERY 3 DAYS A CHILD IS BORN WITH NF IN AUSTRALIA

ABOUT US

VISION

A life without limitations for everyone living with neurofibromatosis.

MISSION

To provide hope for everyone impacted by neurofibromatosis in Australia by advocating for change, advancing research and empowering this community with the knowledge, connections and support needed at every stage of their journey.

WHO WE ARE

- We advocate and work collaboratively to make neurofibromatosis a national priority.
- We provide personalised, accessible support and resources free of charge to every person impacted by neurofibromatosis in Australia.
- We collaborate to progress promising Australian NF research by investing in new technologies, studies and clinical trials.

This report provides the key outcomes for services and projects completed during the period 1 July 2020 – 30 June 2021. Although the COVID-19 pandemic impacted the way we deliver support, we made a commitment to being flexible and adapting our services as required to minimise disruption for everyone. We implemented new digital services to connect remotely and increased our capacity for phone support.

SUPPORT SERVICES

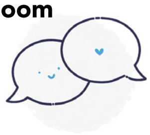
$335,000 spent on support services FY21

1,444 support related interactions by phone and email

803 total hours of phone support

400 people with NF and their families engaged in supportive interactions

NF Connect support groups via Zoom



50+ Hours facilitated

- 200+ people across Australia connected

Training & Development for NF Community

19+ Hours

- Tuning into Kids Workshop
- Peer Leader training
- Educational Webinars

The CTF proudly contributes to NF Clinics across Australia to fund a range of vital projects and support roles

Royal North Shore Hospital – St Leonards, NSW:

- Centre for Transitional Excellence NF Skin Clinic

The Children's Hospital at Westmead – Westmead, NSW:

- NF Clinical Nurse Specialist

The Royal Children's Hospital (Murdoch Children's Research Institute) – Flemington, VIC:

- Support Coordinator

The Royal Melbourne Hospital – Parkville, VIC:

- Clinical Care Project Support

NF Health Management Kits

A tailored NF kit to empower clients

- 100+ kits distributed
- 300% increase on FY20

Community Events

- 1 event held in Adelaide

(In person events impacted by COVID-19)

RESEARCH CONTRIBUTIONS

The CTF committed more than $200,000 to Australian research projects in FY21

Below is a snapshot of the ongoing projects the CTF has contributed funding to:

Australian & New Zealand Children's Haematology/Oncology Group
Study the efficacy of Trametinib (MEK inhibitor) in shrinking plexiform neurofibromas and optic pathway gliomas in young people aged 3 months – 25 years.

Murdoch Children's Research Institute
Establish the nature and frequency of autism in children with NF1.

Royal North Shore Hospital
Evaluate the quality of life of patients with neurofibromatosis before and after treatment of the cutaneous manifestations using validated scores and targeted questions.

Royal North Shore Hospital
To determine the number of false positives and false negative breast screens in women with NF1 over 30, including the frequency of further biopsies/ investigations/ adverse events.

The Royal Children's Hospital / The Royal Melbourne Hospital
To create a biobank of plasma from NF1 patients for future analysis and the development of a "liquid biopsy" (blood test) to detect MPNST.

The Royal Children's Hospital
Create a tool that seeks to quantify overall symptom severity. A tool beneficial for research purposes.

Murdoch Children's Research Institute
Create a database that seeks to compile all relevant clinical, imaging and genetic information from patients attending the RCH NF clinic and associated state-wide genetics services.

RESEARCH COLLABORATIONS

$4.6m

invested into NF Research through MRFF grant

Throughout the FY21 reporting period the CTF was instrumental in securing the first ever federally funded neurofibromatosis grant round.

Funding was made available through the Federal Government's Medical Research Future Fund (MRFF). It was the culmination of numerous discussions between the CTF, the NF community and the Minister for Health and Aged Care, The Hon. Greg Hunt MP.

Four projects were successful:

INSTITUTION	PROJECT
Murdoch Children's Research Institute – $1.6 million	Malignant Peripheral Nerve Sheath Tumour Genomics in neurofibromatosis 1 (MaGeN)
The University of Newcastle – $1.6 million	The neurofibromatosis type 1 (NF1) Cutaneous Neurofibroma Consortium: Identifying Genetic modifiers of disease burden to inform treatment pathways
Monash University – $818,000	Defining NF1 clinical variation at the microscale to discover new therapeutic targets
Murdoch Children's Research Institute – $599,000	A randomised control trial of remote microphone listening devices in children with neurofibromatosis type 1 and central auditory deficits

The CTF has been communicating with all four research teams and will be contributing or collaborating on each project as they progress. The CTF would like to acknowledge the role Shelly Lynde, Kirsty Whitehead and the CTF community played in highlighting the need for funding to The Hon. Greg Hunt MP, Minister for Health and Aged Care.

ADVOCACY AND AWARENESS

"Through responding to government papers, listening to individual advocacy needs and engaging both State and Federal Governments we have advocated for ALL Australians living with NF."

Our Marketing Team are driven to increase awareness of NF to support greater community understanding and encourage fundraising.

The Support Services Team provides tailored, individualised support and discusses a wide-range of issues with each person they interact with. This includes reaching out to schools, health services and workplaces, providing NDIS support and creating information sheets that respond to the needs of the community.

We also engage with General Practitioners and other medical and health professionals by providing information and resources to assist with the management and referral of patients to clinics and NF specialists.

THANK YOU
TO ALL NF HEROES

The CTF would also like to recognise all NF Families, individuals, schools, suppliers, health specialists and media for the role they played throughout 20/21 in raising awareness of NF.

FACEBOOK NF SUPPORT GROUP
1025 MEMBERS

4 Resources for teachers developed

- NF1 Teacher Toolkit
- NF2 teacher toolkit (primary)
- NF2 teacher toolkit (secondary)
- Addressing attention in NF1

99% success rate for NDIS letters sent on behalf of families

NF AWARENESS MONTH

In May 2021, we started a national conversation about NF to ensure every Australian impacted is supported and every Australian not impacted is made NF aware.

We teamed up with renowned international photographer Scott Ehler to "bring NF out of the shadows" with striking imagery and a new video splashed across owned, earned and paid media channels. Many of these images are included in this annual review.

80,943,330 total reach across print, digital and broadcast media

Over $90,000 raised in conjunction with tax appeal

More than 60 locations across Australia joined together to 'Make NF Shine' by turning blue and green in May

HIGHLIGHTS

> NF HERO CHALLENGE

$83,325 raised

More than 100 NF Heroes signed up for our first NF Hero Challenge, which was held over the month of September 2020. Our NF Heroes shaved their heads, challenged themselves in three-minute ice baths, flipped tyres and even rock climbed. **Our highest fundraiser, Cameron Elliott (pictured), did nearly all these challenges and raised more than $16,000 in honour of his daughter Libby who has NF2.** Donations were matched by our corporate partners, Gresham, to the value of $8,000.

> CHRISTMAS APPEAL

$50,000 raised

The Marketing and Fundraising team launched a new online gifting tool for the 2020 Christmas Appeal. Supporters could gift a virtual Christmas bauble to a loved one and place it on our online Christmas tree for all to see. **Thanks to our generous donors, and our partners at J Farren-Price who matched every dollar up to $20,000, nearly $50,000 was raised for the MEK Inhibitor TiNT trial for children with inoperable plexiform neurofibromas that started enrolling patients in January 2021.**

> TAX APPEAL

$90,116 raised in conjunction with NF Awareness Month

Following on from a very successful NF Awareness Month, we shared father and son Jo and Joshua's (pictured) journey of diagnosis for our end of financial year appeal. Jo took Joshua to 16 doctors before he received an unexpected diagnosis of NF1 on a chance meeting with a surgeon when Josh was nine. The delay in Joshua's diagnosis meant critical early intervention was delayed and Joshua struggled with social issues and learning difficulties in his early school years. Combined with the NF Awareness Month, over $90,000 was raised from generous donors and matched by our patrons Eddie and Melanie Listorti up to $50,000 in May and June.

> CUPID'S UNDIES RUN

$94,024 raised

More than 150 supporters signed up to "Take the Cupid's Undie Run Challenge" over a fortnight in February 2021, many able to take part for the first time in the event due to its virtual format. Thanks to our corporate partners Morgans Foundation and Whiteley Corporation for matching donations, $94,024 was raised by our enthusiastic Cupids. We finished the fortnight with a celebratory virtual Sunday Session and we wish to thank TV personality Richard Reid and singer Casey Burgess for joining us and awarding our highest fundraisers with prizes donated by Harvey Norman.

FROM OUR PATRON

ALICIA LOXLEY

Journalist & Presenter
Nine News

In 2021 I proudly became Patron of the Children's Tumour Foundation.

Over the last few months I've had the pleasure of talking to people and families impacted by NF. I've learned that the condition is unique to every person that is diagnosed.

I have been a journalist for many years, and I understand that a strong public awareness is key for all charities seeking to encourage positive change, advocate and raise funds. I'm committed to playing my part in this process.

I've been able to participate in events on behalf of the CTF and have been able to formally interview people impacted by NF for Nine News.

I have come to realise that people living with NF truly are heroes and I look forward to my continued involvement alongside the dedicated CTF team.

ACKNOWLEDGEMENT OF COUNTRY

In the spirit of reconciliation, the Children's Tumour Foundation acknowledges the Traditional Custodians of country throughout Australia and their connections to land, sea and community. We pay our respect to their elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples today.

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 and each other. This includes, but is not limited to:

- National phone and online support
- Supporting specialised NF Clinics in major hospitals
- Family camps, community days and other social events
- Parenting and peer support groups, information seminars and webinars
- Virtual meet ups, monthly NF Connect Zoom sessions.

RESEARCH

With over $1.3 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 with the hope of finding a cure.

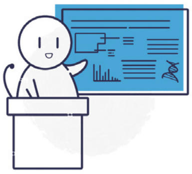
ADVOCACY AND AWARENESS

NF is more common than Cystic Fibrosis, Muscular Dystrophy and Huntington's Disease combined, 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 services entitlements. We are also a referral source that connects our community to medical and allied health professionals who have experience treating people with NF. We work with State and Federal Governments, advocating for improvements in availability and cost of diagnostic scans, medications and improved treatment options.

COMMUNITY ADVISORY PANEL

In June 2021 we established the NF Community Advisory Panel (CAP) to assist the Children's Tumour Foundation with:

- Ensuring the diverse views of the broader NF community are heard and considered when decisions are being made by the CTF team
- Providing advice on the development and implementation of new and revised community information, programs and events
- Advocating for effective support services in line with the CTF's strategic goals
- Promoting the work of the CTF across appropriate channels.



2021 CAP Members:

Alexa Brown
Naomi Elkin-Jones
Holly Parryman
Brian Shaw
Kylie Webb
Jacqui Duong
Claire McKenzie
Danielle Rego
Rebecca Spry
Kirsty Whitehead

ACKNOWLEDGEMENTS

GOVERNMENT

The Hon. Greg Hunt MP,
Federal Minister for Health and Aged Care

The Hon. Brad Hazzard MP,
NSW Minister for Health and Medical research

The Hon. Fiona Martin MP,
Federal Member for Reid

The Hon. Mike Freelander MP,
Federal Member for MacArthur

MAJOR GIFTS

Peter Ketley
Dr. Greg Whiteley

PATRONS AND AMBASSADORS

Alicia Loxley
Amoss McKinley
Cameron Merchant
Eddie and Melanie Listorti
Felicity Egginton
John Hughes
Josh Langley
Jules Robinson
Justyna Kalka
Kevin Sullivan
Nick Greiner
Taryn Brumfitt

FOUNDATIONS

Morgans Foundation
Syd Stass Perpetuity Fund / LATMA Australia

CORPORATE

Insitu Group
Essential Energy
Gresham Partners
J Farren-Price
Manor Real Estate
PBK Management
Plus Fitness
QBE Insurance Group
Scentre Group
Whiteley Corporation

CORPORATE GIFT IN KIND AND PROBONO PARTNERS

Assta Label House
Ativa
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Harvey Norman
Herbert Smith Freehills
Hyperactive Merchandising
Immediate Communications
Ink Media Group
Kiindred
Owen Hodge Lawyers
QMS Media
Scott Ehler
The Athlete's Foot
Yoghurt Digital

EVENT SUPPORT

Adelaide Oval
Once Upon a Time Children's Entertainment

COMMUNITY CLUBS

Cabra-Vale Diggers
Campbelltown Catholic Club
Campbelltown RSL
Canada Bay Club
Kemps Creek Sporting and Bowling Club
Kingsgrove RSL

VOLUNTEERS

Alex Maitland
Benita Milicich
James Clark
Jasmine Le Tisser
Manjit Narula

INTERNS

Abbey Clarence
Andrew Coventry
Laura Barth

COMMUNITY FUNDRAISERS *RAISED OVER $4K

NF Hero Challenge 2020
Cameron Elliott
Carey Russell
Grayson's NF Challenge (Jennifer Pearsall)
Jacob Gwynn
Kay Muir
Paul Verhoef

NF Awareness Month 2021
Charlie & Lachie's Shave for NF (Charlie Phelan)
Ouse District School (Vanessa Triffitt)
Out of the Shadows for Grayson (Jennifer Pearsall)

Cupid's Undie Run 2021
Nirmal Hansra
Andrea & Rick McKenzie
Captain Cary's (Carys Farley)
Emme's Cupids (Zoe Rehbein)
Happy as Hamish (Vanessa Streitberger-sams)
Jess McKinnon
Tonya Constable

SPECIAL THANKS

Carys Farley
Casey Burgess
Claudia, Arthur and Zoe Hobday
Ellen Dimanoski
Janu Ddhayanathan
Jasmine Le Tisser
Joshua Alexis
Kirsty, Jackson and Shelby Whitehead
Naomi Elkin-Jones
Richard Reid

Children's Tumour Foundation
CONQUERING NF

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Full Children's Tumour Foundation Australia financial statement is available online and by request. ABN 26 1488 155 34

REGISTERED CHARITY
acnc.gov.au/charityregister