Children's Tumour Foundation
CONQUERING NF

ANNUAL REPORT

22/23

CONTENTS

WE BELIEVE THAT TUMOURS SHOULD NEVER BE A CHILD'S NORMAL.

Conquering NF is about more than just finding a cure. We are the only patient advocacy and support organisation for people impacted by neurofibromatosis (NF) in Australia.

With greater awareness comes earlier diagnosis and improved access to supports, which leads to better health outcomes.

OUR VISION

A life **without limitations** for everyone living with neurofibromatosis.

OUR 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.

OUR WORK

- 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.

FROM THE CEO
LEANNE DIB

It's a humbling experience to come to work at the Children's Tumour Foundation every day. In the past year since joining the team, I've met so many incredible professionals committed in various ways to conquering NF, from physicians, clinicians, politicians, and researchers.

Together, we're all working to better understand the condition, its many symptoms and ultimately improve health outcomes.

Their expertise and compassion inspire me, but it's the families I meet that are truly amazing. Through the most challenging of times, even when the outcomes from regular MRIs, doctor appointments or NDIS applications is not what anyone hopes to hear, they don't give up.

We continue to be inspired by the resilience of this community and are grateful for the impact we can have on their journey.

Over this past year we've made incredible strides in our goal to make NF a national priority. Our programs continue to expand, with more NF Connect sessions and camps than ever before.

We welcomed more guests at our symposium and information day than years gone by, and our support interactions continue to grow, as more families reach out for support.

We are proud to be the peak body and support service in Australia for everyone with NF, but the realities facing families mean there is still work to do to make life more equitable.

Sadly, too many lives are still being limited, or lost to this condition. On page 14, you'll read the courageous story of young Julia, who lost her battle with a complex malignant tumour this year.

Together, we are not just envisioning a better future for everyone with NF, we are creating it. These advances are not possible without you. Thank you for your support of the Children's Tumour Foundation.

Leanne Dib
Chief Executive Officer

"WE ARE COMMITTED TO MAKING SURE EVERYONE WITH NEUROFIBROMATOSIS RECEIVES THE SUPPORT THEY NEED AND WE CONTINUE TO SERVE AS A LIFELINE FOR THOUSANDS OF AUSTRALIAN FAMILIES FACING COMPLEX HEALTH ISSUES."

FROM THE CHAIR
PETER DOWDING

For most of us, the last few years have been a challenging and unpredictable time, but for those living with neurofibromatosis (NF), a life of disruption and uncertainty is normal. Their lives are often filled with the anxiety and cost of multiple therapies, scans, surgeries, and ongoing health surveillance.

Every year, the foundation's support team is connecting with new families confronted by a reality they weren't expecting.

Thanks to our supporters, these families have someone to turn to during their diagnosis, throughout treatment and beyond.

The variability of neurofibromatosis (NF) means each family we meet is having a unique experience, because NF is often complex, and always unpredictable. Our team continues to respond to the evolving needs of the community we serve, and maintains a person-centered approach to care.

There were so many highlights this year and milestones we're proud to share in this report.

We were so pleased to see the updated terminology and diagnostic criteria shared this year, providing greater clarity for those diagnosed with the rarest kinds of NF.

Collaboration and advocacy was a key focus this year, meeting with many stakeholders to drive forward our goal to improve health outcomes.

Most excitingly, our support services, the core of our organisation, grew many programs, and supported more families than ever before. The feedback in our community surveys has also been overwhelming positive, demonstrating the impact our services provide families living with this complex condition.

We are deeply grateful for your support and partnership and hope you enjoy reading about all the advances you are helping to make possible.

P. Dowding

Peter Dowding
Chair of the Board

"THE FOUNDATION HAS ESTABLISHED ITSELF AS A TRUSTED AND KNOWLEDGEABLE NON-CLINICAL SERVICE PROVIDER WHO WORKS TO ENSURE EVERYONE IMPACTED BY NF, CAN ACCESS BALANCED INFORMATION AND SUPPORT WHEN THEY NEED IT."


OUR PROGRAMS
AND SERVICES

NF IS UNPREDICTABLE, PROGRESSIVE AND HAS NO KNOWN CURE.

NOONE SHOULD FACE A LIFETIME OF UNCERTAINTY ALONE.

Hundreds of individuals and families across Australia call on our support every year. Many people come to us while facing difficult times, while others just like to feel connected and part of a community that understands them.

Despite being called the Children's Tumour Foundation (because NF is most often diagnosed in childhood), we support adults as well as parents and carers.

SUPPORT

Beyond the need to treat the physical symptoms of NF, we create opportunities to learn and to come together in safe and supportive spaces.

THE IMMEDIATE OUTCOMES

Increased health interventions from support navigating support systems.
Improved wellbeing from connecting with others on the same journey.
Increased health literacy and personal advocacy skills.

ADVOCACY

Our goal is to make life more equitable for those living with this complex genetic condition.

THE INTERMEDIATE OUTCOMES

Earlier diagnosis through increased awareness among health professionals.
Increased access to other supports, such as learning and financial supports.
Reduced burden of disease through earlier access to treatments and therapeutics.

RESEARCH

We are one of Australia's leading charitable contributors to NF research with millions of dollars invested into key projects through on-going advocacy efforts and direct funding.

THE LONG-TERM OUTCOMES

Improve predictability of symptom development.
Reduce disease severity through effective treatments.
Support discovery about NF and eventually a cure.

SUPPORT AT EVERY STAGE

Every family impacted by NF faces unique challenges, but there is a common place to turn. We help navigate care, school, connect online and get away from it all at camps.

NATIONAL HELPLINE

A diagnosis can come as a shock to many families. Or it may have been expected. The first place families from all across the country turn to, is to our support team.

INFORMATIVE RESOURCES

All forms of NF are complex and knowledge can be lacking among health professionals. We provide personalised and accessible information, to empower families with the information and guidance they need.

NF CLINICS

NF Clinics ease the burden of managing NF by coordinating multiple specialist appointments in a single visit. In locations where clinics can't be accessed, families utilise our healthcare database to connect with informed specialists.

WEBINARS

We invite industry experts to join our online information webinars focusing on topics of interest to the NF community, ranging from general wellbeing, to specific areas of concern related to the condition.

INFORMATION DAYS

Staying up to date with new clinical information, research trials and treatment methods is made easy by our information days that provide numerous presentations on NF.

INDIVIDUAL ADVOCACY

NF can impact a person physically, as well as their learning and development. Our team support families with NDIS applications and inform educators of individual needs.

NF CONNECT

Each month, facilitated virtual peer support groups bring the community together from the comfort of their own homes. Outside of these sessions, our FB group is a place to share updates, questions and support.

COMMUNITY DAYS

Spending time with others who share the condition promotes inclusion and allows families to relax, learn and expand their support network.

CAMPS

These specials weekends allow kids, their siblings and families to have a break from the complications of NF and provide a chance to get back to the joy of family time.

ADVOCACY

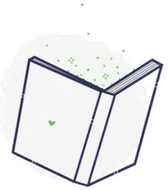
As we advocate to make NF a national priority, many families share their lived experience and attend parliamentary meetings and events.

RESEARCH

Families are kept informed about developments in treatments and investigative studies, as well encouraged to participate in clinical trials that are recruiting participants.

PARENTS AND CARER SUPPORT

When possible, we offer our community the opportunity to take part in facilitated courses, such as the parent support program, Tuning Into Kids.



CONNECTION

Living with a rare and relatively unknown genetic condition can be isolating. We provide opportunities for connection that help improve the well-being of those impacted by neurofibromatosis, expanding their networks and ensuring parents, carers, friends and siblings feel informed and supported too.

Our services are available for anyone impacted by NF1, NF2-related schwannomatosis (NF2) and all forms of schwannomatosis (SWN) and span all ages, from children all the way through to adults.

OUR HELPLINE SEES AN INCREASE IN NEED

For many, the first point of connection is with our support services team. We provide non-clinical support and guidance via telephone, email and video call consultations, to discuss individual needs and solutions, or for those just looking for a supportive companion during their journey.

Our team is made up of four support staff who have a wealth of information about the condition, while bringing with them experience in nursing, speech pathology and counselling.

This year, we saw in increase in the need for our support, with interactions increasing by 9%.

"The feeling of community at camp is hugely valuable. It made us feel less isolated."

Camp attendee

COMMUNITY CAMPS ARE BIGGER THAN EVER

This year, we were so pleased to be able to finally resume many of the in-person activities that formed part of our service pre-Covid-19, while maintaining and even expanding many of the offerings that were developed to keep our community connected online.

Three camps were held:

- The Grampians, Victoria (Nov 2022)
- Middle Swan, WA (March 2023)
- Redland Bay, QLD (June 2023)

Over 100 individuals attended a camp, more than ever before in a single year!

100% OF CAMP ATTENDEES SAID THEIR WELL-BEING IMPROVED

NF CONNECT EXPANDS POST-COVID

Our virtual peer support program, NF Connect continues to be a valuable opportunity for the NF community to come together virtually.

Sessions were held once a month for:

- Teens/young adults (18-30yo),
- Adults with NF; and
- Parents and carers of children with NF.

"I joined the NF Connect sessions and found a community of people who understood what it was like to be me. Since then I have felt happy and supported within this amazing community."

NF Connect attendee

EDUCATION

We keep families informed at every stage, from diagnosis, treatment and beyond.

Managing a complex and unpredictable condition can be stressful and confusing, and we know that no two cases of NF are ever the same.

We want to ensure everyone impacted by NF has access to balanced information to improve health literacy and ensure those impacted can manage this condition through understanding appropriate maintenance protocols and treatments.

NEW RESOURCES SUPPORT PERSONAL ADVOCACY

This year we expanded our resources to include a new school presentations for primary school and secondary school.

We also developed a NF information card to be used as a quick and easy way to introduce a member of the public to the condition.

A referral pad was developed and shared within our known healthcare network to promote our services to their patients.

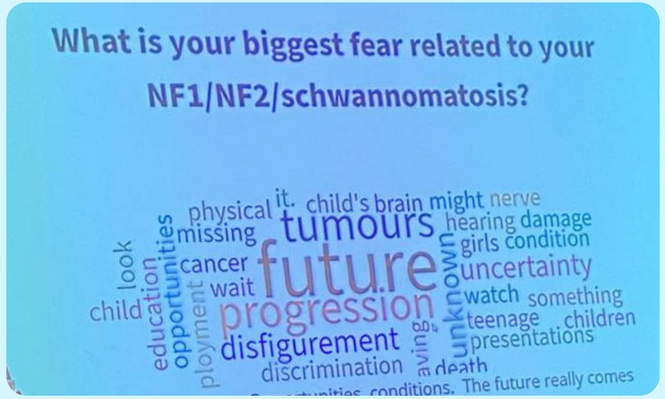
INFORMATION DAY REACHES NEW HEIGHTS

In August 2023, over 120 community members, attended a free, hybrid information day.

More than 11 presentations by clinicians and researchers provided updates on new clinical information, research trials and treatment methods. This event is the only informative session of its kind for families living with all forms of neurofibromatosis.

Key topics included:

- Managing adults with NF
- Role of Neuropsychologist
- Speech, language and NF
- The role of a paediatrician in NF Care
- Selumetinib (tumour-shrinking drug)
- Becoming an adult, the transition process



WEBINARS BRING NEW KNOWLEDGE

We are proud to play host to an Australian based neurofibromatosis webinar series.

This year, we collaborated with wonderful experts to help deliver our series, which included:

- How headspace can help, with Senior Clinical Advisor, Jennifer Lobb
- Siblings Support with Kate Strohm of Siblings Australia

"No longer do I feel that I have to put up with rude people staring at me. I can just say "here" and hand them a card. Thank you CTF for making me feel more confident in my outings."

NF Information Cards recipient

NAVIGATING CARE

Living with a rare and relatively unknown genetic condition can be isolating. We provide opportunities for connection that help improve the well-being of those impacted by neurofibromatosis, expanding their networks and ensuring parents, carers, friends and siblings feel informed and supported too.

Our services are available for anyone impacted by NF1, NF2-related schwannomatosis (NF2) and all forms of schwannomatosis (SWN) and span all ages, from children all the way through to adults.

NF CLINICS $500K MILESTONE

The Children's Tumour Foundation funds two paediatric specialist roles at two major children's hositals to support families coordinate multi-disciplinary care by allowing patients to see a number of specialists on the same day.

- The Children's Hospital at Westmead (NSW)
- The Royal Children's Hospital (VIC)

2022 marked more than half a million dollars gifted in total to the Sydney Children's Hospital Foundation, including support of the NF Clinic and Learning Clinic at The Children's Hospital at Westmead.

UPDATED TERMINOLOGY AND DIAGNOSTIC CRITERIA

The diagnostic criteria for NF1 and NF2 were previously established at the National Institutes of Health (NIH) consensus meeting in 1987, and the diagnostic criteria for schwannomatosis was established in 2005.

Since that time, and thanks to the arduous work of so many CTF-funded researchers, there has been a tremendous increase in knowledge about these genetic disorders.

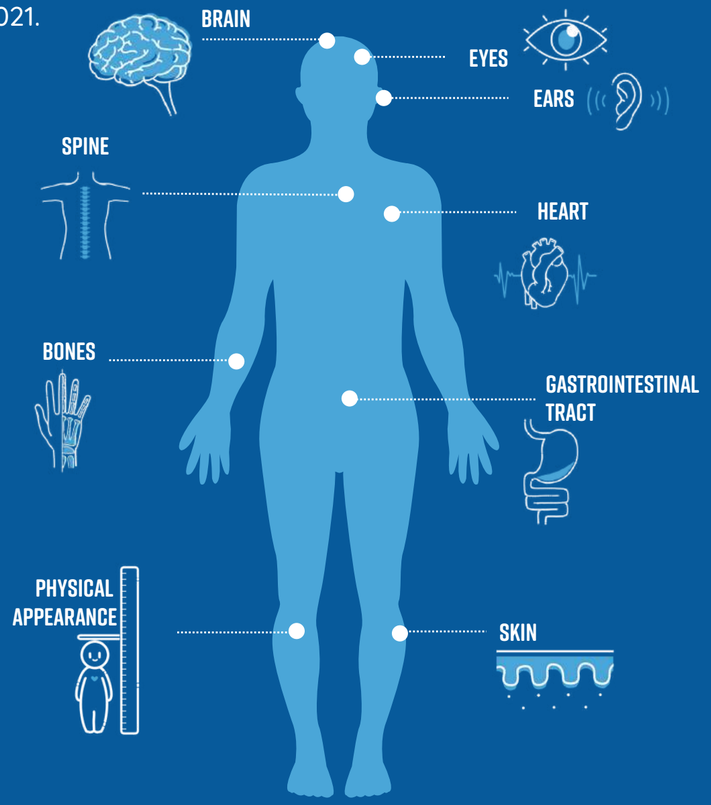
The diagnostic criteria for NF1 was updated in 2021.

In 2022, terminology and diagnostic criteria was updated for the genetic conditions formerly referred to as neurofibromatosis type two (NF2) and schwannomatosis.

These updates followed a multi-year process led by the Children's Tumor Foundation (US) that included 32 international experts.

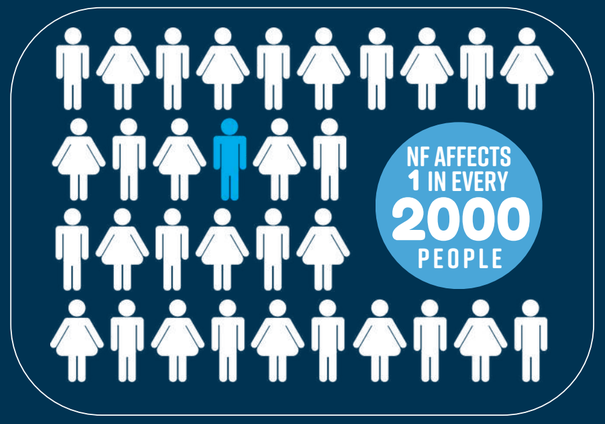
The updates were published in the Genetics in Medicine, the official journal of the American College of Medical Genetics and Genomics (ACMG)

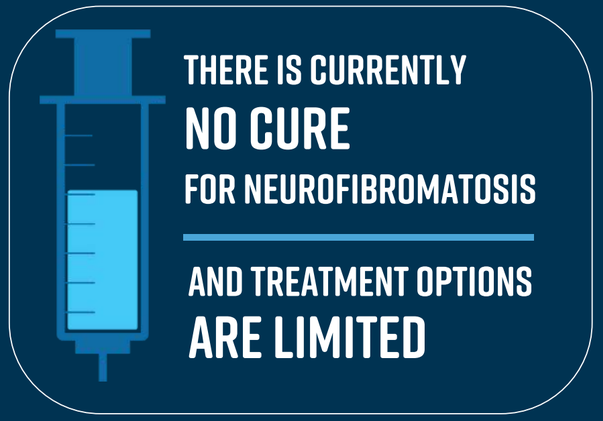
In part, this update helps address the confusion and overlap in the diagnosis of all types of neurofibromatosis and schwannomatosis, and the updated criteria is intend to improve patient care by reducing misdiagnosis.



UNDERSTANDING NEUROFIBROMATOSIS

A child is born with NF every 3 days. It can affect anyone regardless of ethnicity or gender.





Around 1 in 5 children with NF1 will develop a brain tumour

On average, lives are shortened by 10-15 years

Incidence of breast cancer is five times more likely in women with NF1 aged 30-50 years

Up to 80% of children with NF1 will experience learning and behavioural difficulties

Approx 25% of children with NF1 will be diagnosed with Autism Spectrum Disorder

THE CHALLENGES

A SINGLE GENE CHANGE CAN CAUSE A LIFETIME OF TUMOURS

The condition can often impact a person physically, mentally, academically, financially and socially.

Lives are often disrupted by numerous specialist appointments, surgeries and ongoing health surveillance, which extends well beyond the person living with it to include parents, carers and siblings.

PREVALANCE BUT OBSCURITY

Despite being one of the most common genetic conditions, awareness is low and funding for supports and treatment options are lacking.

VARIABILITY OF SYMPTOMS

NF can cause tumours to grow on any nerve ending in a person's body and therefore each person will face different challenges and potential complications depending on the size and location of the tumours and their rate of growth.

DELAYED DIAGNOSIS

30% of Australian adults living with a rare disease are impacted by a diagnostic delay of more than 5 years. This is even greater for those with less common forms of NF, with some waiting 10 years.

UNCLEAR PROGNOSIS

The slow progress of investigation into the condition to understand the predictability of symptoms impacts thousands of Australian families, and millions more globally.

LIMITED EXPERT KNOWLEDGE

Most doctors and pediatricians have never heard of NF before and are therefore unaware of the diagnostic criteria or management plans for monitoring symptoms and tumour growth.

INCREASED RISK OF CANCER AND DEATH

NF is a cancer predisposition syndrome and persons with NF1 are known to have up to a 4-fold increased risk of malignancy throughout their lifetime compared to the general population.

REMEMBERING JULIA

When Nicole Sandlant noticed her toddler Julia had a bow in one of her legs, she couldn't have known it was a sign of the condition that would claim her daughter's life.

Julia was diagnosed with a rare genetic condition called neurofibromatosis type 1 (NF1) before her second birthday, but no one in the family had ever heard of it.

A bright little girl who was always quick with a smile, Julia made the most of her childhood, even when tumours did develop and she had to undergo surgery to remove them.

One appeared on her hand, and grew until it wrapped around nerve endings all the way up to her elbow when she was in school, then another large mass appeared on her neck.

By the time she reached her 20s, Julia had been through multiple tumour removal procedures and though she was always positive, it was hard for mum Nicole.

"IT'S JUST HORRIBLE BECAUSE YOU DON'T KNOW WHERE THAT NEXT TUMOUR OR COMPLICATION IS GOING TO BE, AND YOU JUST HAVE TO TACKLE THEM AS THEY COME UP"

"WE HAD SO MANY QUESTIONS OVER THE YEARS, BUT THERE WERE SO FEW ANSWERS TO BE FOUND."

In 2021, Julia had been aware of some pain in her left thigh and put it down to a sporting injury, however, the pain got worse as time went on and a lump was discovered.

Surgery revealed that the lump was in fact an aggressive, malignant sarcoma.

Despite receiving such devastating news, Julia used her time and influence to ensure other people living with NF would always have the treatment and care needed throughout their journey.

Julia completed six weeks of daily radiation and was told she was in the clear. Some weeks later she found herself in excruciating pain around her ribs.

A CT scan confirmed that the sarcoma was back and had metastasised. Sadly, on Monday 10 October 2022, she passed away.

With the support of her village, Julia had helped raise more than $23,000 for the CTF.

ADVOCACY

NF is progressive, painful and unpredictable. Our goal is to make life more equitable for those living with this complex genetic condition.

Our advocacy efforts focus on working with State and Federal Governments to improve access and quality of care and educating health care professionals on the condition to improve diagnostic times and treatment options. In addition, we collaborated with leading therapeutic organisations to gain earlier access to treatments and therapies. We also support personal advocacy efforts for individuals and families, at work, school and in the larger community.

MEDICAL ADVISORY PANEL

The Medical Advisory Panel exists to provide professional guidance and advice on the medical and scientific aspects of the information services provided by CTF as well as any research grants made by CTF.

This year, there were 8 members, many whom provided considerable support in the planning and lead up to the NF Clinical Symposium.

Members included:

- A/Prof Mimi Berman (Chair)
- Dr Colin Derrick
- Dr Kate Drummond
- Dr Tim Hassall
- Dr Gargi Pathak
- Dr Geoff McCowage
- Dr Katrina Morris
- A/Prof Jonathan Payne

COMMUNITY ADVISORY PANEL

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.

Members included:

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

ADVOCACY MEETINGS

Building relationships with Government
In early April, our CEO, Leanne Dib and Head of Support Services, Ruth Lindsay met with Dr Mike Freelander MP for Macarthur. Dr Freelander worked as a paediatrician in Campbelltown, dedicating his life to making sure kids got the best start in life, including children with neurofibromatosis.

Evolving the partnership with Sydney Children's Hospital, Westmead (SCHW)
In April, our support services team presented to the Neurogenetics Department at Children's Hospital Westmead to provide an update on the non-clinical role we play to support the NF community, including client advocacy, government liaison and NDIS access.

Supporting efforts to enable greater access to Selumetinib in Australia.
In November, Alexion Pharmaceuticals submitted an application to the PBAC to have the tumour-shrinking drug, selumetinib,added to the PBS.
While this application was not approved at the time, the PBAC invited the CTF to attend a meeting to offer the collective consumer perspective of what a drug like selumetinib will do for the NF community.

RESEARCH

We are one of Australia's leading charitable contributors to NF research with millions of dollars invested into key projects through on-going advocacy efforts and direct funding.

Our research efforts focus on funding Australian treatment and clinical trials and supporting investigative studies into the many complexities of NF. Due to our vast connection with the Australian NF community, we also engage in research participant recruitment. We regularly bring health professionals and researchers together at NF Clinical Symposium, the only event of its kind in Australia.

NF CLINICAL SYMPOSIUM FUELS NEW IDEAS

In August 2022, 89 health professionals and researchers came together, in person and virtually, to network and discuss the latest in medical management, treatment and research into neurofibromatosis in Australia and around the globe. The Children's Tumour Foundation is proud to host this event that stimulates new collaborations, showcases progress and fuels new ideas to conquer NF.

"The Symposium provides an opportunity to meet with colleagues who are all interested in improving the lives of patients with NF1."

Symposium attendee

RECRUITMENT REACHES NEW LEVELS

Throughout the year we were approached by researchers seeking more participants for their clinical trials.

Recruiting projects included:

- International NF1 Cutaneous Neurofibroma Consortium Project
- Health concerns of individuals with neurofibromatosis: Supporting Reproductive Decision Making in Neurofibromatosis (NF SURE)

FUNDED PROJECTS:

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.

YEAR IN NUMBERS

2048
support related interactions by phone and email

30+
New clients engaged in supportive interactions

2
webinars hosted and attended by close to X attendees

50+
health management kits sent to newly diagnosed families

1000+
members within the NF support FB group

3
new resources developed on condition education

30+
NDIS applications supported by the CTF

30
patient submissions for a tumour-shrinking drug to be added to the PBS

200+
media stories across the year showcasing the diversity and complexity of NF

21
advocacy meetings

100%
of camp attendees said their well-being improved

89
Attendees at the NF Clinical Symposium

114
Attendees at three community camps

100+
buildings lit up blue and green in support of NF in May

33
NF Connect sessions held with with more than 150 attendees

1000+
patient visits to an NF Clinic

70+
parent or teachers toolkits shared

127
Attendees at the NF Info Day


RAISING FUNDS
AND AWARENESS

NF AWARENESS MONTH

Neurofibromatosis (NF) Awareness Month is held each year in May to educate, advocate and elevate – and raise funds to help bring NF out of the shadows.

SHINE A LIGHT ON NF

IN 2023, NATIONAL LANDMARKS AND LOCATIONS LIT UP ACROSS AUSTRALIA IN THE INTERNATIONAL COLOURS OF NF - BLUE AND GREEN. 97 LOCATIONS TOOK PART TO SHINE A LIGHT ON NF.

$105,000+
Raised in May + June

70,000+
Social Media Reach

19,954
Website hits in May alone

$261,000
In pro-bono ad space thanks to QMS

4,468 RIBBONS WERE SOLD AND WORN ACROSS THE MONTH, IN RETAIL STORES AND THROUGH INDIVIDUAL AND SCHOOL FUNDRAISING EFFORTS!

OUT OF THE SHADOWS

65+ RETAIL STORES TOOK PART IN SPREADING AWARENESS BY PLACING POSTERS IN STORE, RIBBON BOXES AT POINT OF SALE!

PEBBLES THE PENGUIN

Children's Tumour Foundation
CONQUERING NF

X

Kidstuff
EST. 1969

A PLUSH PARTNERSHIP

Pebbles was lovingly created in partnership with Kidstuff, who understand how important it is that every child and adult living with NF experience comfort and a sense of belonging.

Why Pebbles? Penguins know a good pebble when they see one. Some species offer their loved ones small pebbles to acknowledge the relationship and show their commitment.

Something we aim to offer our community too - unwavering support and hope for a better tomorrow.

DAN EWING BECAME AN AMBASSADOR!

RAISING AWARENESS

SBS INSIGHT

NF Ambassador Janu shared her thoughts on body positivity as part of an episode of Insight SBS in April. Janu discussed the challenges she faced, issues with balance and coordination; and how learning difficulties put her at a distinct disadvantage.

THE DOG HOUSE

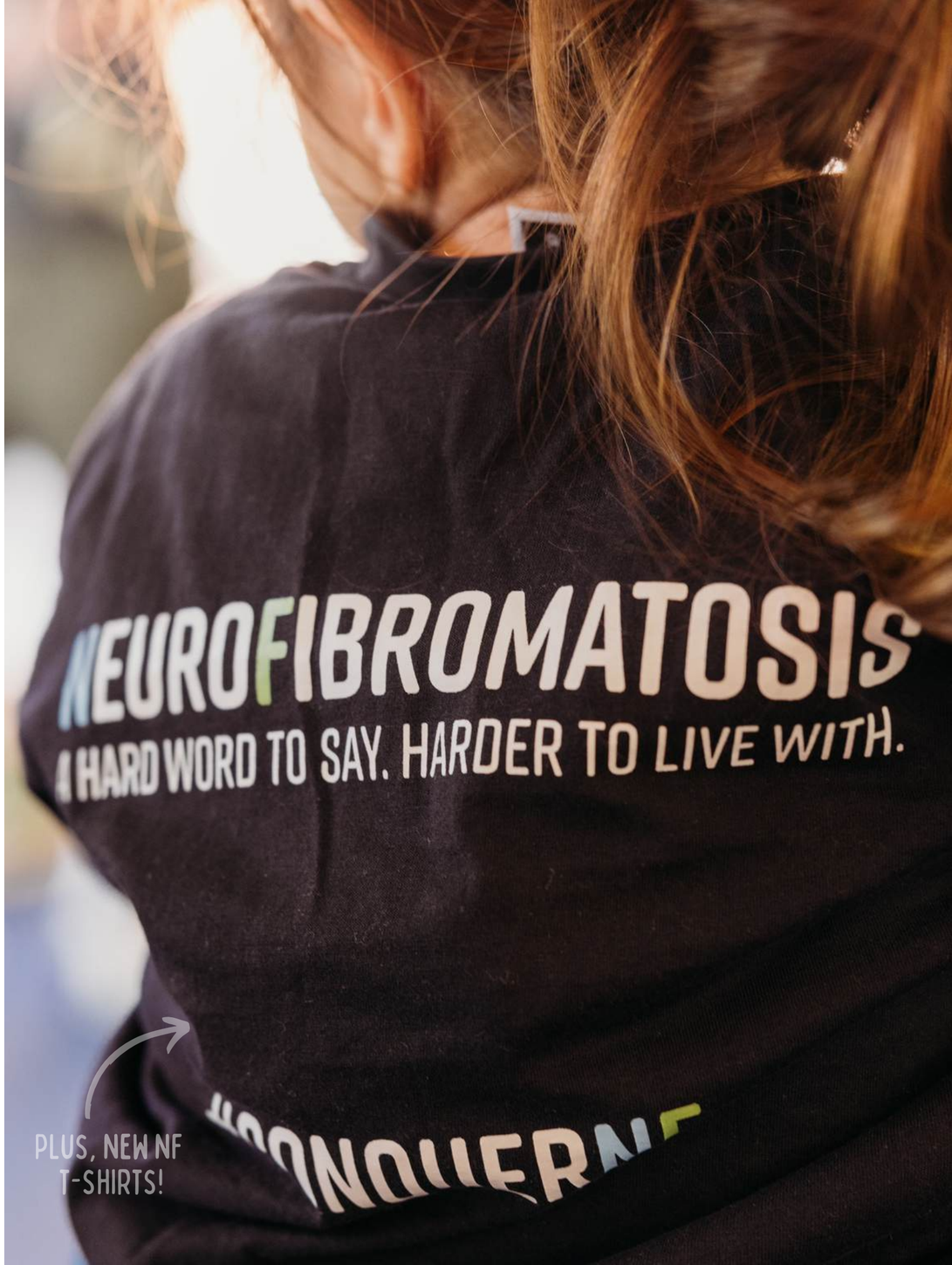
NF Hero Alex and his family appeared on an episode of The Dog House, meeting their new beloved family member, Tess. Not only did they have a wonderful experience, but it has afforded them the opportunity to shine a light on NF on commercial television.

NEW BLUE AND GREEN SOCKS

We introduced new eye-catching socks with one green and one blue sock to represent NF's global colours, and of course complete with our penguin mascot.

SOCIAL IMPACT VIDEOS

Two new videos were released in May, featuring NF heroes Emme and Grayson. The videos show the diversity and complexities in NF.



RAISING FUNDS

PETE "THE INTERN" DEPPELER MC'D!

CONQUER NF IN COLOUR

On Sunday 13 November, we hosted our inaugural Conquer NF in Colour fun run at Wentworth Park in Sydney. The event aimed to connect the condition to the international NF colours of blue and green.

Close to 350 participants, volunteers and spectators in the NF Village and on ground running 2km, 4km or 10km. More than $60,000 was raised through fundraising and sponsorship.

STEPS TOWARDS A CURE

Steps Towards a Cure was introduced during NF Awareness Month as a virtual challenge that raises funds specifically for NF research. Over 173 individuals and 28 teams chose to step, stride or ride, a distance of their choice over the month of May, collectively raising over $80,000 from more than 1,000 donations. Together, we made progress possible.

CHAIRMAN'S GOLF DAY

Alongside Peter Dowding (Chair of the Children's Tumour Foundation), in January we hosted our inaugural Chairman's Charity Golf Day, at the exclusive Elanora Country Club golf course in the Northern Beaches of Sydney. Attended by 62 people, over $31,895 was raised from the event. Federal Member for Mackeller, Dr Sophie Scamps also dropped in!

DINE AND DISCOVER

Across the year, we hosted two Dine & Discover NF luncheons, the first in Sydney at Venturo in Walsh Bay and the second at Spencelys in Clifton Hill in Melbourne.

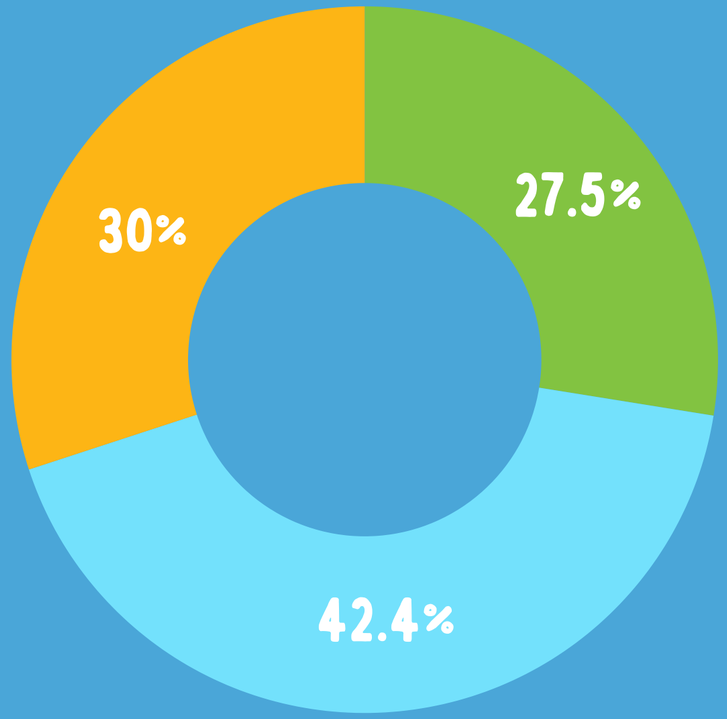
These intimate dining experiences are an opportunity to provide insight into what it means to live with NF, the services we provide, while thanking our partners, and strengthening new relationships.

FINANCIALS

REVENUE

In 2023, fundraising revenue was **$1.18m**

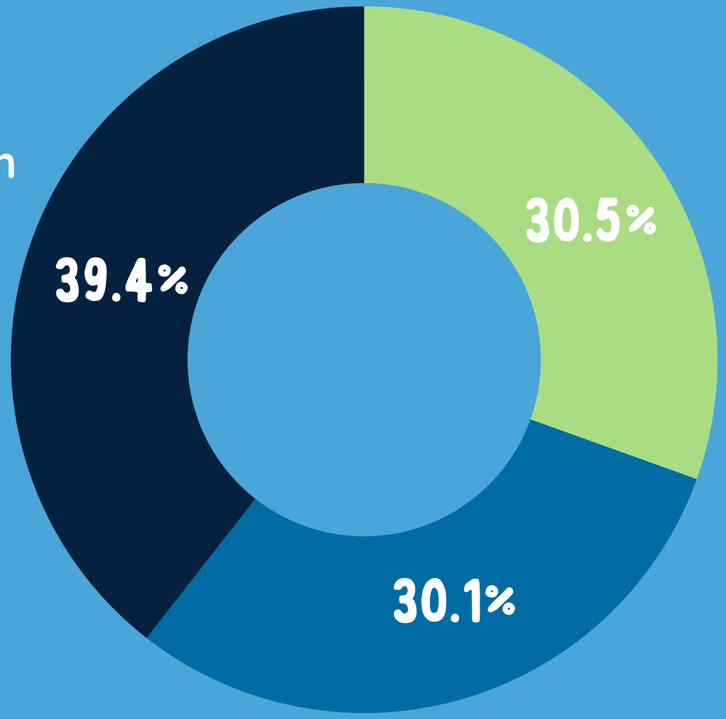
- DONATIONS AND BEQUESTS
- FUNDRAISING
- GOVERNMNET



EXPENSES

In 2023, operating expenses were **$1.35m**

- RESEARCH AND SUPPORT
- EMPLOYEE EXPENSES
- ALL OTHER EXPENSES



THE POWER OF US ALL

GRESHAMS CONTINUED GIVING

Gresham Partners have been long term supporters of the Children's Tumour Foundation, including another $8,000 this year to inspire greater giving through matched donations during our Conquer NF in Colour fun run in November.

BENDIGO BANK GIVES BIG

Bendigo Bank Darling Square joined the CTF as a new partner this year, promtply donating $50,000 to support our support initiatives from providing immediate support, to advocating and investing in promising research.

MORGANS TEAM VOLUNTEERS

Long time supporters, Morgans Australia, sent a team to support NF Awareness Month preparation activities! They set aside a full day to help prepare 100 ribbon boxes and assets ready for posting to our retail partners to sell in May, while also supporting with $30,000!

BRIAN TEN PIN BOWLS

NF Hero Brian and the Hurricane Tenpin Bowling Club donated $1 for every strike that players achieved and $0.50 for every spare. Fellow members, kindly topped up the donation by $625 to make it an even $2000 and another donor generously matched the League's amount of $1375.

END OF SEASON FUNDRAISER

Pittsworth Junior Danes Rugby League Club raised over $2,000 for the CTF at their end of season match. One of their littlest members is NF Hero Levi who was diagnosed with NF1 when he was just over a year old. There is no family history of the condition and so it came as a complete shock.

#TEAM CTF AT THE CITY TO SURF

The World's Largest Fun Run, the City2Surf was back on again in August 2022. Amongst the 80,000+ people who descended on Sydney to participate were five ladies, who ran in support of the Children's Tumour Foundation. Capes and all.

WHAT A WONDERFUL YEAR

THANK YOU!

GOVERNMENT
NSW Government
Australian Federal Government
The Hon. Greg Hunt MP
The Hon. Brad Hazzard MP
The Hon. Fiona Martin MP
The Hon. Mike Freelander MP
The Hon. Sally Sitou
The Hon. Jihad Dib MP
The Hon. Mr David Pocock MP
The Hon. Suzanne Orr MP
The Hon. Leanne Castley MP
The Hon. Jonathan Davis MP
The Hon. Rachel Stephen-Smith MP

MAJOR GIFTS
Peter Ketley
Dr. Greg Whiteley
Tim Doyle

PATRONS & AMBASSADORS
Alicia Loxley
Dan Ewing
Eddie and Melanie Listorti
Janu Dhayanathan
Josh Langley
Kevin Sullivan

INTERNS
Ben Smith
Sidney Ruthven

MARKETING ADVISORY COMMITTEE
Alison Hallworth
David Stretch
Kieran Gallagher
Zoe Rehbein

CORPORATE PARTNERS
Alexion
Bendigo Bank Darling Square
Essential Energy
Eucalyptus
Gresham Partners
Insitu Group
Kidstuff
Nexia
PBK Management
The Trybe
Whiteley

CORPORATE GIFT IN KIND AND PROBONO PARTNERS
Buzzgroup
Crowe Australasia
Edge Agency
Elevencom
Herbert Smith Freehills
Hyperactive Merchandising
Ink Media Group
Kiindred
Nature
PIXO
Vanlife Shots
QMS Media
The Athlete's Foot
Yoghurt Digital

EVENT / VENUE SUPPORT
Roses Gap Recreation Centre
Wentworth Park Trust

FOUNDATIONS AND COMMUNITY GRANTS
Canada Bay Club
Carlingford Sports Club
Guildford Leagues Club
Morgans Foundation
Rotary Club Sydney Cove

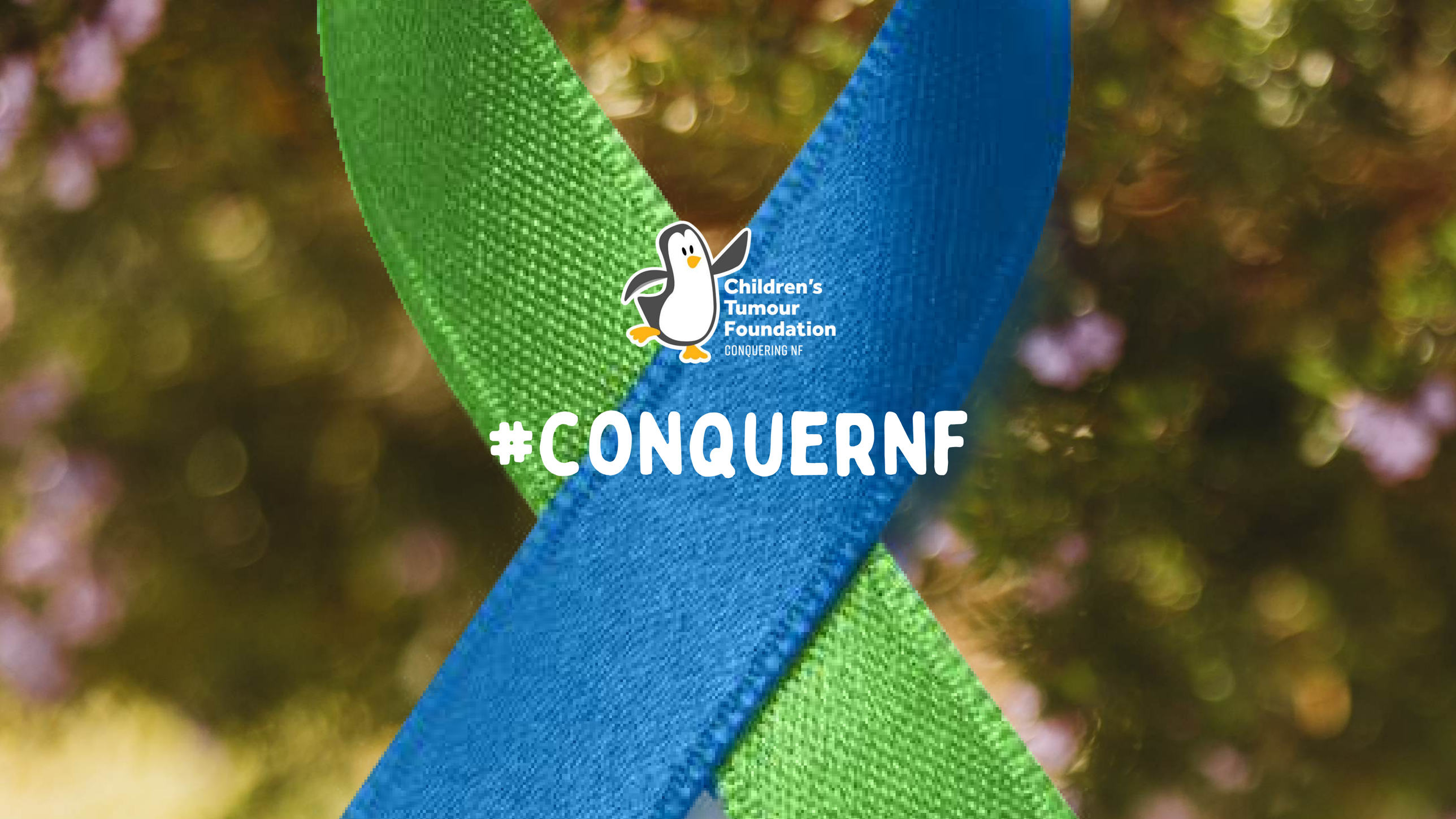
PRIZE PARTNERS
Archie Brothers
Bunnings
Chilcott's Butchery
Cucina Espresso
F45 Ashfield
Harvey Norman
Novotel
Onsport.com.au
Perfetti
PSI Cycling
Sydney Football Club
Sydney Seafood School
The Card Network
West Tigers Club
The Athletes Foot The Fenwick

COMMUNITY ADVISORY PANEL
Alexa Brown
Brian Shaw
Claire McKenzie
Danielle Rego
Holly Parryman
Jacqui Duong
Kirsty Whitehead
Kylie Webb
Naomi Elkin-Jones
Rebecca Spry (Chair)

MEDICAL ADVISORY PANEL
A/Prof Mimi Berman (Chair)
Dr Colin Derrick
Dr Kate Drummond
Dr Tim Hassall
Dr Gargi Pathak
Dr Geoff McCowage
Dr Katrina Morris
A/Prof Jonathan Payne

BOARD MEMBERS
Peter Dowding (Chair)
Alex Maitland (former CS)
Brooke Smith
Donna Player
Hugo Dudley-Smith
Jessica Illich (Company Secretary)
John Bishop
Laurence Dell
Luke Goldsworthy
Nirmal Hansra (retired in Dec 22)
Peter Krideras
Wes Lambert

VOLUNTEERS
Alexander Sas-Pele
Audrey Faith
Brendan Chan
Caitlin Dunton
Deb Vass
Emma Pritchard
Fhilipe Scoutti
Jasmine Le Tisser
Jason Gauthier
Janu Dhayanathan
Karenza De Leon
Kathryn Wheatley
Lachie Wrenford
Manjit Narula
Sky Camarce
Sheree Corrales-Vargas
Sophie Rothery
Tracey Galanos
Tung-Ling Li (Donna)
Zara Coorey


Children's
Tumour
Foundation
CONQUERING NF
#CONQUERNF