CHILDREN'S TUMOUR FOUNDATION
2022 YEAR IN REVIEW

JANUARY - DECEMBER 2022

Our mission is 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.

Together we can #CONQUERNF

CTF.ORG.AU

Flinders St Station, Melbourne lit up blue and green on May 17.

Photo Credit: Thomas Forbes

CEO FORWARD

As we close off 2022, I find myself reflecting on our collective endeavors. We should all be immensely proud of what we have achieved together.

The Children's Tumour Foundation (CTF) team, and you, our community of families, volunteers and supporters rallied this year, and the results speak for themselves.

At every turn we're able to demonstrate increased impact, awareness and understanding for all people living with neurofibromatosis (NF).

The CTF's success over the last 12 months can be attributed to the strength, experience and genuine commitment to the cause by our small, but mighty team, complemented by an equally passionate and engaged Board. It goes without saying that each of you are at the heart of what we do and why we fight so hard to achieve it.

Quite simply, we are a united force.

Our strategic plan continues to be our North Star, ensuring we are in pursuit of delivering upon our three key pillars to;

- Lead Change
- Support and Inform
- Advance Research

The CTF has consolidated relationships and identified new opportunities with state and federal government, to ensure there is an understanding of the needs of the NF community, and how we can deliver best practice support at the highest level. We have also continued to build on our strategic partner relationships with state-based hospitals and NF clinical resourcing.

We've continued to be one of Australia's leading charitable contributors to NF research. With millions of dollars invested into key projects through ongoing advocacy efforts and direct funding over the past decade.

On top of all of this, we've come together through various fundraising initiatives to enable the ongoing need for free support, resources and programs for the 10,000 people living with NF in Australia.

It is our hope that this Year In Review will leave you as encouraged as we are; to do more, know more and give more, in whatever capacity you can, for the betterment of the NF community.

Thank you.

Leanne Dib

Leanne Dib

CEO

Optus Stadium, Perth

NF AWARENESS MONTH

BRINGING NF OUT OF THE SHADOWS

Neurofibromatosis (NF) Awareness Month is held each year in May to improve understanding of the signs and symptoms of NF, to share the stories of real people affected by the condition and to educate Australians on the diagnosis and treatment.

We once again focused on bringing NF "Out of the Shadows" with a series of initiatives that would give us and the condition presence amongst everyday Australians.

SHINE A LIGHT ON NF

In 2022, we lit up even more national landmarks and locations across Australia in the international colours of NF - blue and green. More than 120 locations took on the challenge to help shine a light on NF.

Doubling the number from the previous year.

This initiative was once again coordinated by NF Hero and long-term volunteer, Jasmine Le Tisser who spent the better part of five months reaching out and using her lived experience of NF to encourage participation.

Australia represented around 40% of the total number of buildings to light up globally, including the US.

Key locations included:

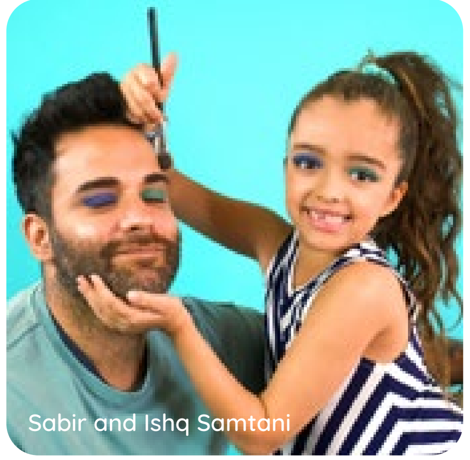
- Flinders St Station, AAMI Park, MCG and Rialto Towers in Melbourne.
- Suncorp Stadium, Story Bridge and Brisbane City Hall in Queensland.
- Optus Stadium, Trafalgar Bridge and Bell Tower in Perth;
- Old Parliament House, the National Carillon and Malcolm Fraser Bridge in Canberra

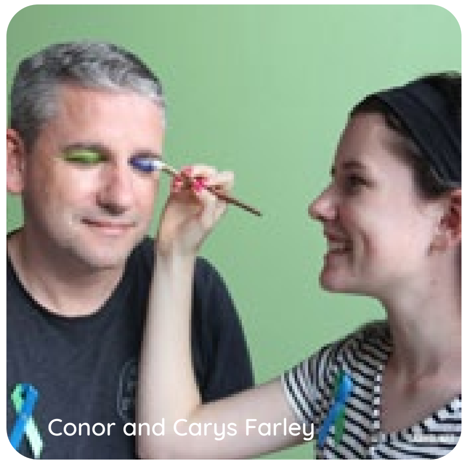
...just to highlight a few.

Lady Nelson Brig
Mount Gambier

Storybridge, Brisbane


Alicia Loxley, Patron


Sabir and Ishq Samtani


Conor and Carys Farley

OPEN PEOPLE'S EYES TO NF

Throughout May, we encouraged men, women and children to pack away the neutral colour palette and embrace a new, bolder look to help bring NF Out of the Shadows.

No one wants to be judged or feel ashamed of something they have no control over, but for many people living with NF, the visible and invisible signs can be debilitating and have a life-long impact on a person's self-esteem, sense of self and ability to connect with others.

As a result, many will avoid the spotlight or participating in activities that may draw unwanted attention to themselves. This includes make up.

By asking every day Aussies to get creative with colours and step outside of their makeup comfort zones, we aimed to help broaden the view of what beauty should look like and who should be represented.

We saw high profile couples like Jules and Cam from Married at First Sight take on the challenge alongside our Patron, Alicia Loxley.

Friends and family of those living with NF, as well as make up artists across the country also got involved, sharing their photos and videos with the hashtag

#OPENYOUREYESTONF

The initiative was picked up by the Daily Mail and shared globally.


Cam Merchant and
Jules Robinson

PLEDGE TO CONQUER NF

We asked our community to send a personalised letter or email using our free downloadable templates to rally their local, state and federal parliament members to make a pledge to conquer NF.

Six Ministers signed the pledge, making a commitment to identify and create opportunities to better support people with NF. This included:

- **David Pocock:** Independent ACT Senator
- **Suzanne Orr:** Labor MP, ACT
- **Leanne Castley:** LIberal MP, ACT
- **Jonathan Davis:** Green MP, ACT
- **Rachel Stephen-Smith**: Minister for Health
- **Fiona Martin:** (Former) Liberal MP for Reid

Special thank you to Brian Shaw for securing and attending each signing in the ACT.

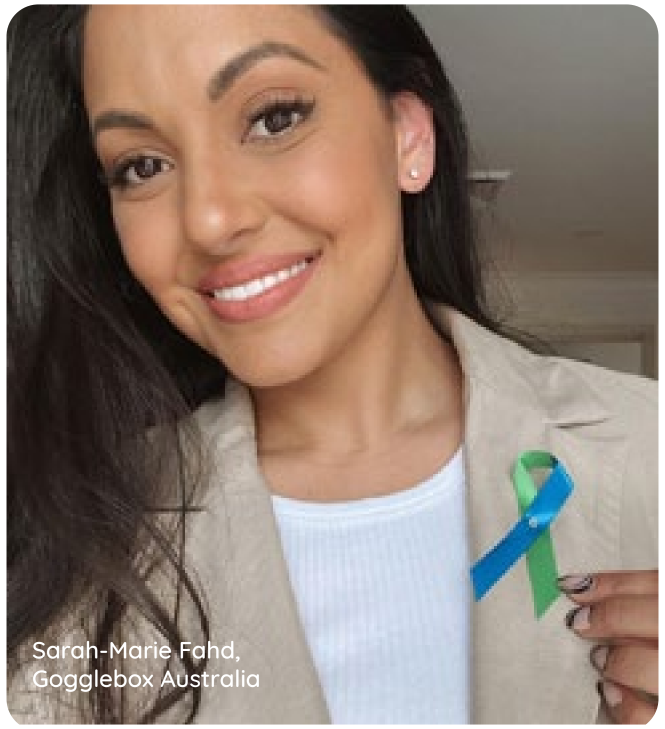
WEAR A RIBBON. SHOW YOUR SUPPORT.

Blue and green are the two colours that represents NF around the world. Throughout May, we sell ribbons through our online store, encourage schools and businesses to run fundraisers and for the first time, we partnered with two retail partners, Kidstuff and The Trybe to sell ribbons in store.

We often hear how frustrating it can be to have to explain NF to people who have never heard of it, again and again.

For this reason, each ribbon contains information about neurofibromatosis for community to keep in their wallet or to share with someone they think would find this information helpful.

Throughout the month, we encourage celebrities, politicians and our community at large to wear a ribbon to show their support and invite a conversation about NF.


Sarah-Marie Fahd,
Gogglebox Australia


West Tigers players wear ribbons to
support NF Awareness Month

6,352 NF ribbons were sold across Australia in May 2022

More than 35 schools, pre-schools and businesses went blue and green in May

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Over 20 new fundraisers to raise funds and awareness in May

Matty Johns,
Sunday Footy Show with Matty Johns

KIDSTUFF STORES TURN BLUE AND GREEN ON MAY 17

On World NF Awareness Day (17 May), Kidstuff stores nationally turned blue and green in support of those living with NF in Australia.

With around 55 stores nationally, our partnership enabled thousands of people across the month to hear the word "neurofibromatosis" and ask the question..."what is that?" and potentially even buy a ribbon.

But on May 17, the red Kidstuff branding was overshadowed by bold blue and green colours.

On the day and over the course of the month, more than $14,000 was raised in ribbon sales and donations. An additional $10,000 was donated by the organisation. That meant $24,000 was given in support of families impacted by NF in Australia.

There are many reasons that partnerships like this one are important, but one of the biggest is the opportunity to have a national exposure.


Kidstuff Bondi


Kidstuff Mona Vale


NF Hero, Ishq
at Bondi Kidstuff on May 17

In a collaboration between Kidstuff and parenting platform, Kiindred, we were fortunate to be able to bring two amazing partners together to talk about NF.

Emmy from Kiindred (Mum to NF Hero, Ishq featured above) joined us at Kidstuff Bondi to talk about her experience as a NF Mum and how Kiindred are helping to spread the word alongside the Children's Tumour Foundation.

NF Hero Ishq stole the show, but the important message to take away from this chat is that talking about NF as much as possible for as long as possible with as many people as possible is the key to improving understanding.

CLOSE TO 200 STORIES FEATURED DURING MAY AND JUNE

Thanks to the efforts of our PR partner, BuzzGroup close to 200 stories about NF, NF Awareness Month and people's experiences of living with the condition featured across online, press, magazines, radio and tv across both May and June.

Cumulatively reaching more than 80million people.

This included platforms including, Nine News, WIN News in Canberra and NBN Newcastle. Stories also featured across national mastheads such as 9Honey, Fairfax Media and News.com, as well as local press and magazines.


Island life

Bec aims to shine light on a rare condition

In May, Julia Sandlant met with Steph Anderson from 9News Melbourne with a clear message - "listen to your body".

Julia's story was a powerful reminder of knowing the signs and symptoms to look out for and see your doctors if any of these or other unexplained symptoms arise.

Unfortunately, within a few short months Julia passed away.

At just 23 years of age, Julia was a daughter, sister, granddaughter, friend, colleague and teacher. She was a lover of cats, all things shiny, sunflowers, ice cream and adventure.

She also had NF.

In the words of her friends, "Julia was fierce and a fighter. She said what she thought and did what she planned. The loyalty and commitment shown to her loved ones was enviable, as was the determination and pursuit she had for life."

She was also a huge advocate for the NF community and it was a privilege to be able to support her dream to share her story and message with the world.

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.

It was discovered after surgery that the lump was in fact an aggressive, malignant sarcoma.

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 rib.

A CT scan confirmed that the sarcoma was back and had metastasised and on Monday 10 October 2022, she lost her battle.

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.

With the support of her village, Julia had helped raise more than $23,000 for the CTF this year, including $8,000 at a trivia night held in her honour in Queanbeyan in July.

A legacy we will continue to honour.

OTHER HIGHLIGHTS FROM MAY

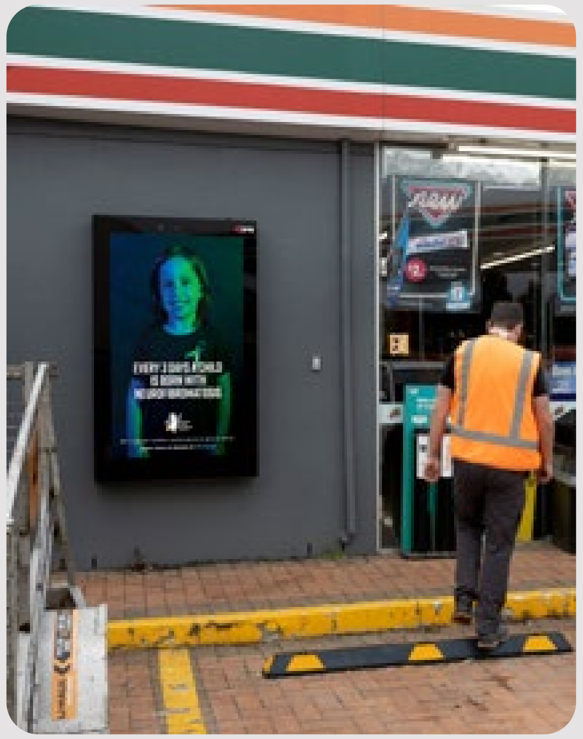
DIGITAL OUTDOOR MEDIA THANKS TO OUR MEDIA PARTNER, QMS

Neurofibromatosis and the Children's Tumour Foundation has been elevated to mainstream advertising space.

Thanks to our outdoor media partner QMS, the general public were able to see our campaign creative on digital billboards outside of 7-Eleven in NSW and on large format sites in Victoria, Queensland, South Australia and Western Australia across the month of May.

This had the potential to reach thousands of eyeballs daily and help take our efforts to shine a ligh on NF.

It represented more than $200k in probono media.



GENERAL NOTICE OF MOTIONS AT NSW PARLIAMENT ON MAY 17

In recognition of World NF Awareness Day and on behalf of the Children's Tumour Foundation, Mr Jihad Dib MP (Member for Lakemba and Shadow Minister for Emergency Services, and Shadow Minister for Energy and Climate Change) addressed the NSW Parliament with a statement of intent as part of the General Notices of Motions.

SCHOOLS & PRE-SCHOOLS GO BLUE & GREEN ON MAY 17

Amongst many others who got involved, Possums Community Preschool in Northern NSW pulled off a huge "green and blue" day to raise funds for the Children's Tumour Foundation.

There was nail painting, coloured hair spray and lots of green and blue in general.

NF Hero Penny had a ball being the centre of attention and even shared her NF Hero book with her friends at preschool.

THE TRYBE GET BEHIND RIBBON SALES IN NSW

Throughout May, customers of The Trybe stores in NSW were able to purchase NF Ribbons at point of purchase.

It was comforting to know that with every pair of shoes that walked through those doors, another person heard the word "neurofibromatosis" and learnt a little something about the condition.

We are grateful to the teams at these stores for supporting the campaign.

BENCHMARKING RESEARCH STUDY

BRAND AND CONDITION AWARENESS

One of our strategic goals is to elevate NF in the national consciousness, ensuring every Australian impacted is supported and every Australian not impacted is made NF aware.

In order to measure our progress, we partnered with insights consultancy, Nature, to conduct a randomised survey with 500 people to better understand our overall brand health. The study was completed probono.

The results showed that both brand and cause awareness is on the rise.

KEY OUTCOMES

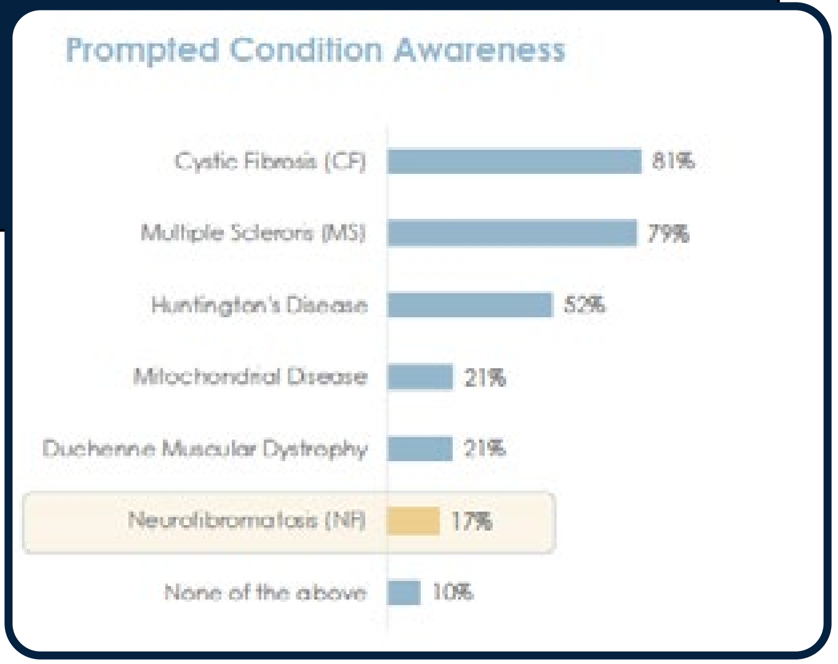
PROMPTED CONDITION AWARENESS

17% of participants surveyed had heard of NF.

PROMPTED BRAND AWARENESS

6% of participants had heard of the Children's Tumour Foundation, which is an increase of 4% on the previous year.

Nature:



22 MAY = $22,000 MATCHED

We are so grateful to PBK Management and Eucalyptus who jumped on board in May to match every dollar donated to the value of $22,000 as a way to mark NF2 Awareness Day.

MEDIA STORIES

CONNECTING & SHARING ALL YEAR ROUND IN THE MEDIA

As an organisation one of our strategic goals is to advocate and lead change in an effort to make NF a national health priority. In order to achieve that goal, we need to collaborate with local and international partners, as well as the NF community to leverage and maximise impact.

A big part of what we do at regular intervals throughout the year is drive media opportunities through our partnership with Buzzgroup.

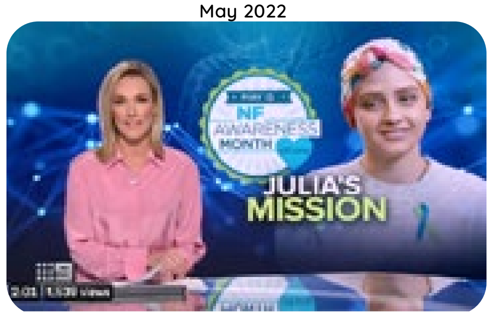
Over 12 months, we have secured more than 300 news articles, including tv and radio interviews; local, national and international online news coverage, and 15 magazine stories across titles including, Good Weekend, That's Life, Take 5 and New Idea.

Below is a few highlights from 2022.

NBN NEWS NEWCASTLE
May 2022

Hunter-based researcher is leading a ground-breaking study to find a treatment, which could one day help a Cessnock youngster.

NINE NEWS
May 2022



Julia shared her story with Stephanie Anderson at @9News Melbourne, which was syndicated across all markets, except Sydney.

NINE NEWS
November 2022

Coverage of inaugural Conquer NF in Colour fun run at Wentworth Park in Sydney on Sunday 13 November.

TWO OF US: GOOD WEEKEND
February 2022

TAKE 5 MAGAZINE
May 2022

DAILY TELEGRAPH
June 2022

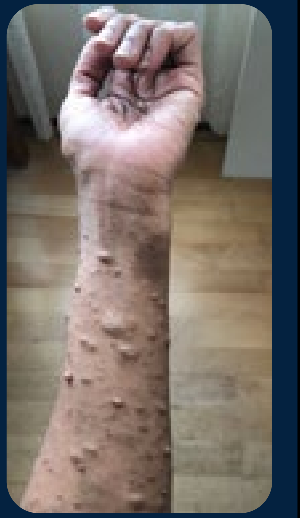
THAT'S LIFE
August 2022

CRISIS MANAGEMENT

AUGUST 2022

NOT ALL BUMPS ARE THE SAME: MONKEY POX IS NOT NF

As the monkeypox outbreak started attracting increased attention both in the news and social media, individuals with neurofibromatosis (NF) who had cutaneous neurofibromas were reporting a range of reactions both online and in public – from outright harassment to quizzical looks, and more.



In response, we reshared the statement put out by the CTF in the US and worked with Buzz Group, A/Prof Mimi Berman and two members of the NF community to develop a media alert to help set the record straight.

It was picked up by Newsltd and syndicated across all mastheads nationally.

CLICK THE LINK TO READ THE STORY

AWARDS IN ADVOCACY

CREATE CHANGE VICTORIAN YOUNG ACHIEVER AWARD

At the end of April, Jasmine Le Tisser was awarded the Create Change Victorian Young Achiever Award for her commitment to the 2021 Shine A Light on NF lighting initiative.

Jasmine has volunteered her time for two years to this initiative, appeared in tv interviews and helped others in the community see their stories and experiences validated.

Jasmine has been instrumental in making NF visible and creating positive change.

RARE CHAMPIONS IN ADVOCACY: CHILDREN'S TUMOUR FOUNDATION

In June we were thrilled to learn that the Children's Tumour Foundation had been nominated for a RARE Champions in Advocacy (Foundation) Award.

Every year Global Genes, a leading, global patient advocacy organisation in the rare disease space, asks the community to nominate those deserving of recognition for their extraordinary efforts in rare disease to bring awareness to rare disease patients, their families or community.

This year, we are one of 190 nominees across seven categories to be nominated.

As a small organisation, with some pretty BIG goals, it is wonderful to know that we are moving in the right direction to help shine a light on neurofibromatosis. Unfortunately we were not successful, but encouraged by the acknowledgement amongst so many other worthy organisations.

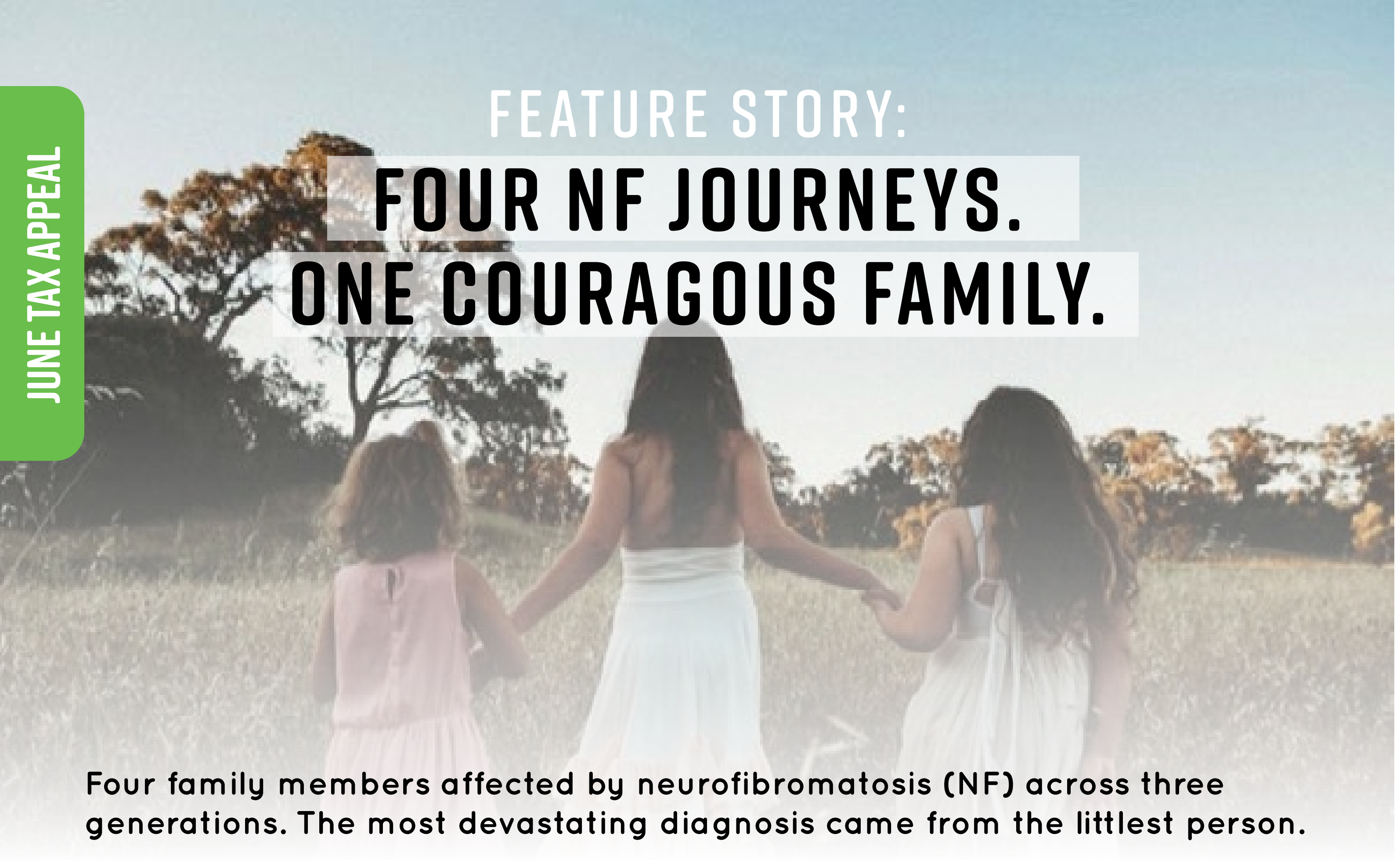
ORDER OF AUSTRALIA YOUTH COMMUNITY SERVICE AWARD

In September, NF Hero Edward Hayek was nominated and awarded the Order of Australia Youth Community Service Award for 2022.

This Award recognises the significant service performed by Year 11 and 12 students beyond their school boundaries in the wider community. Nominations are considered by a judging panel of three Order of Australia Award recipients who selected the 26 Awardees this year.

Amongst his many achievements, Edward has been an advocate for those living with neurofibromatosis, generously sharing his experience at Children's Tumour Foundation events,

Diagnosed at age two, Edward has faced and overcome many of the challenges of his condition through the support of his family, medical team and the CTF. He has raised funds and raised the spirits of other young people facing similar journeys with optimism and grace.



FEATURE STORY:

FOUR NF JOURNEYS. ONE COURAGOUS FAMILY.

Four family members affected by neurofibromatosis (NF) across three generations. The most devastating diagnosis came from the littlest person.

NF affects everyone differently and there is no way to predict how mildly or severely someone will be affected, even within the same family.

Half of all cases of NF arise in families with no history of the condition, but for Natasha and Scott, they always knew there was a possibility their children would be born with NF.

This worry became a reality in the form of two beautiful daughters, the youngest is now living with a very rare, incurable brain cancer at just 6 years of age. Their middle daughter does not have NF, but she certainly lives with it.

NF IS UNPREDICTABLE, PROGRESSIVE AND THERE IS NO CURE. BUT THERE IS HOPE.

Natasha's story with NF started before she was born. It was a world her father was born into. She and her brother were the next in their lineage to be born with the same condition. At 10 years old she would sit in the bath tub and try to scrub away her spots.

She has childhood memories of regular specialist appointments, a history now replaying itself in her daughter's lives.

It often tears her father to pieces knowing their NF started with him, but he is a beautiful Nonno and a wonderful support to his NF grandchildren.

No family should have to deal with a diagnosis of NF alone. Its impact can reach well beyond the person living with it.

AT FIVE WEEKS SHE NOTICED THE FIRST BIRTHMARK, IT WAS THE BEGINNING OF ANOTHER NF JOURNEY FOR THEIR FAMILY.

Natasha and her husband Scott welcomed three babies in just four years.

Their first daughter Matilda was born with multiple café au lait birthmarks, a tell-tale sign of NF.

Natasha was instantly faced with the harsh reality that her brand new baby would soon be diagnosed with NF.

Next came Georgia, no spots, no signs of the condition, she does not have NF.

A false sense of security washed over the family with Matilda thriving as a toddler and meeting all of her milestones and enjoying being big sister to Georgia.

Danika was born next with no visible signs of NF at birth, but at five weeks her first cafe-au-lait spot appeared.

It was the beginning of yet another NF journey for their family, but it was also a stark reminder of how varied this condition can be - even within the same family.

Diagnosis is rarely straightforward when it comes to NF. Particularly as both Matilda and Danika met all of their milestones in their first few years of life. Matilda started to struggle at school, and Danika started to complain of headaches that induced vomiting and was diagnosed with unrelated hereditary abdominal migraines...Natasha wasn't convinced.

> “After months of nausea and vomiting, I requested a brain MRI. It was then they discovered Danika had a 5cm mass on her cerebellum. This news crushed the world we lived in, and we were naturally scared and devastated”, said Natasha.

DANIKA UNDERWENT AN 8-HOUR SURGERY TO "DEBULK" THE TUMOUR AND DECREASE THE PRESSURE THAT WAS CAUSING HER LITTLE BODY SO MUCH PAIN.

Within 7 weeks the migraines reappeared.

Another MRI revealed the devastating news that the tumour had grown back. They feared for their brave daughter as she was rushed away for a second lengthy surgery.

DANIKA'S BIOPSY RESULTS REVEALED EVERY PARENT'S WORST FEAR, CANCER. BUT IN THIS CASE, IT WAS A VERY RARE STAGE 3 BRAIN CANCER.

A third operation was not considered at this point, instead Danika was placed on a brand new drug and so far, this miracle drug has kept her tumour stable, but her condition remains incurable.

Until we find better treatment options or a cure for this devastating condition, thousands of Australian families could be confronted with a reality they were not expecting.

> “*When Danika's health news became our living reality, Meredith from the CTF support team was the friendly voice among the medical jargon who would check in with us every week.*
>
> *But maybe most importantly, I know the Foundation is there advocating, rallying government support, and committing donor funds toward research that has the potential to change the lives of all people touched by this genetic condition.”*

Of course, their eldest daughter, kind, giving, patient Matilda who also has NF has watched this all unfold.

One day shortly after Danika's diagnosis Natasha was sitting on Matilda's bed and she asked if this could happen to them. “Will we get a brain lump this scary?”

Natasha remembers her heart shattered because she didn't want to lie.

> “*I know NF is unpredictable, but I reassure her that there are so many people in her corner, doctors, specialists and the Children's Tumour Foundation who are keeping a very close eye on us.”*

Thanks to the generosity of families like Natasha's in sharing their stories, as well as matched giving partners like Whiteley, we were able to raise $60,000 in June as part of the annual tax appeal.

Matilda, Eye Scan

PERSONALISED, ACCESSIBLE & FREE

SUPPORTING YOU AT EVERY STAGE OF YOUR JOURNEY

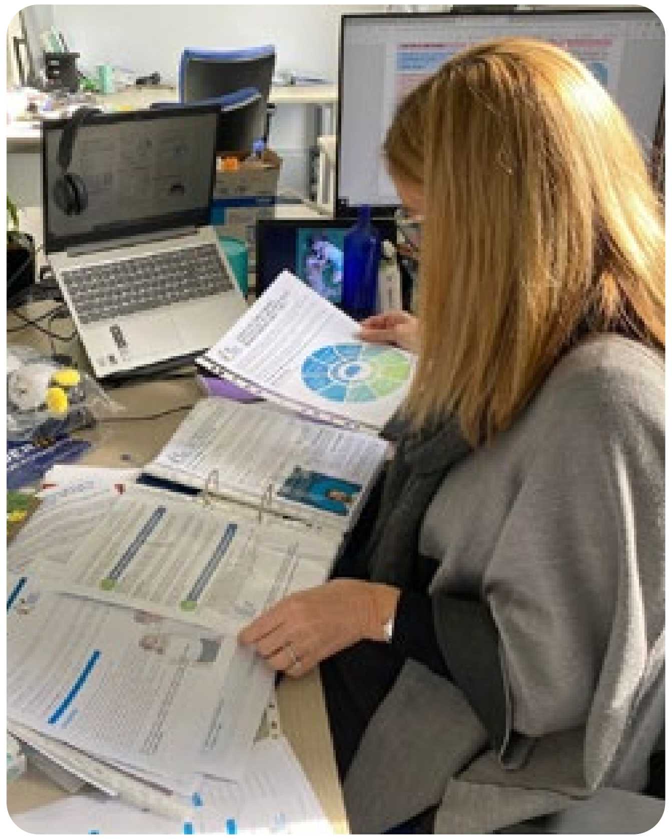
Providing access to free, personalised, and confidential support services for people impacted by NF in Australia is at the heart of what we do.

Hundreds of individuals and families across Australia call on our support every year. Many people come to us at breaking point, while others just like to feel connected to the outside world and love a chat.

We adapt as the situation requires it, but most importantly we understand NF in a way that even close friends and family may not.

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

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 social work.



1600+

interactions with community throughout the year, including phone calls, online enquiries and referrals.

100+

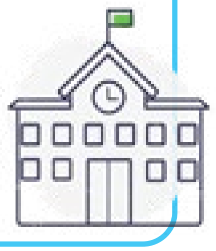
health management kits distributed to parents of young children, teenagers transitioning to adult care and adults with NF.

50+

support letters for **NDIS applications** provided to parents of children with NF, as well as adults living with the condition and in need of funding.

180+

parents and teacher toolkits, distributed directly to schools, carers and educators to support kids in the classroom who struggle with learning.



33 NF CONNECT SESSIONS

hosted across the year for teens and young adults, adults with NF and parents or carers of children with NF. This represents 66 hours of engagement with more than 200 participants throughout the year.

THE TRUE IMPACT OF NF CONNECT

NF Connect has become a core part of our service provision since we launched the program in 2020 in response to COVID.

A virtual destination for people in the NF community to come together for a chat, check in and learn something new, it has represented a unique opportunity for individuals from across the country (and even across the ditch to NZ) to form strong ties.

Across each session, topics range from addressing the challenges of knowing how to discuss NF with children, as well as when and what to tell them; how to advocate for educational supports; challenges of explaining NF to others and just general chit chat about popular topics.

There is something really comforting about talking to other parents about the challenges of parenting across the different life stages from toddlers to young adults or sharing goals for the future with another teenager who understands a life of appointments and the anxiety that follows.

Featured below is a group who met online during COVID in our NF Connect Teen and Young Adults sessions. The Victorian camp in November 2022 was their first chance to connect in real life, with two participants even flying down from Sydney.

Hosting NF Connect sessions in the office with our support team

> "I made my own family with the most amazing friends who I originally met on NF Connect"

NF CONNECT WILL RETURN IN FEB 2023

NF CLINICS

$500K DONATED TO SYDNEY CHILDREN'S HOSPITAL FOUNDATION

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.

NF is a complex condition and requires input from many different medical specialties. Access to a centralised hub where patients and their families can see multiple doctors and receive support coordinated by the NF Specialist Nurse/Support Officer has a huge impact on their lives.

On average, this vital multi-disciplinary clinic supports more than 500 patient visits and telehealth appointments a year and is critical in reducing the significant anxiety caused by the condition.

In addition to the investment in this role at Westmead, the Children's Tumour Foundation are also funding a clinical nurse specialist role at the Royal Children's Hospital in Melbourne; a position we have funded for several years.

The clinic supports clinical services for families impacted by complex neurofibromatosis, including NF1 and NF2.

The investment in both services has been made possible thanks to our generous community through appeals and events, as well as the NSW Government for Sydney state-based services.

Photo Left to Right:
Leanne Dib, CTF CEO, Peter Dowding, CTF Chair and Dr Manoj Menezes (SCHW)

WEBINAR SERIES

Throughout 2022, we hosted a regular webinar series to provide an ongoing opportunity for our community to hear directly from medical professionals, researchers, and those with a lived experience of NF.

- **Skin Issues in NF (Part 1)** : A/Prof Mimi Berman, Royal North Shore Hospital
- **The NF1 Cutaneous Neurofibroma Project**: A/Prof Tracy Dudding-Byth, University of Newcastle
- **Feelings and Fun, how to support emotional well-being in children and teens**: Josh Langley
- **Introducing Headspace**: Senior Clinical Advisor, Jennifer Lobb
- **Supporting siblings of children with chronic illness:** Kate Strohm, Siblings Australia

2022 NF CLINICAL SYMPOSIUM

In August we hosted the first Australian NF Clinical Symposium in over two years.

More than 100 doctors, clinicians, researchers, scientists, and allied health professionals from around Australia came together in person or online to learn about the latest in NF medical management, treatment, and research.

The event was hosted at Melbourne's Library on the Dock with 16 local and international speakers sharing their insights, interactions and work into neurofibromatosis.

The Children's Tumour Foundation looks forward to continuing to play this leading role in bringing together the brightest minds in the NF space for the benefit of our community moving forward.

We are incredibly grateful to our sponsors Whiteley and Alexion Pharmaceuticals, for supporting this important meeting of minds and to our Medical Advisory Panel for their guidance.

WATCH THE VIDEO

SPEAKERS & TOPICS COVERED

- **Associate Professor Mimi Berman:** Revised NF1 Diagnostic Criteria
- **Dr Sue-Faye Siow:** NF Model of Care Project - a statewide NF service
- **Associate Professor Andrew Ellisdon:** Structure of Human Neurofibromin
- **Dr Natalie Pride:** Characterising sleep disturbance in children with NF1
- **Associate Professor Jonathan Payne:** New evidence around ASD in NF1
- **Dr Jane Flemming:** The impact of cutaneous neurofibromas on quality of life
- **Martin Good:** Nurse-led care as an appropriate and acceptable model of care
- **Associate Professor Ruth Webster:** Accessing the Medical Research Future Fund
- **Professor Kate Drummond:** Transitioning to multidisciplinary care for adults with NF
- **Dr Geoff McCowage:** Update on TiNT Clinical Trial
- **Dr Jim Whittle:** Komet Trial Update
- **Dr Gabriel Dabscheck:** Is early diagnosis MPNST possible?
- **Jonathan Lau:** Comparison of 3D imaging devices for the measurement of CNs
- **Associate Professor Tracy Dudding-Byth:** International NF1 Project
- **Professor D. Gareth Evans:** Update on NF2 in the UK
- **Nicholas Hall:** Hearing preservation options in NF2

2022 COMMUNITY INFORMATION DAY

LIBRARY AT THE DOCK, MELBOURNE

Approximately 150 people attended the 2022 Neurofibromatosis Community Information Day - both online and in person.

We were fortunate to be able to bring together 10 speakers, talking on a range of topics and disciplines, including clinical care in Victoria, latest updates on treatments and understanding neurodevelopmental disabilities in children with NF1.

It was also a great opportunity for anyone impacted by NF to learn more about the role of the Children's Tumour Foundation as the only non-clinical support service provider in place to help manage their condition.

We had an amazing group of volunteers with us on the day, including Jasmine Le Tisser; Sidney and Ben, students of the Master of Genetic Counselling at the University of Melbourne, as well as students Melissa, Lauren, Grace, Connor and Claudia from the Genetic Support Network of Victoria.

SPEAKERS & TOPICS COVERED

Dr Gabriel Dabscheck

NOW AND NEXT: AN INTERACTIVE SESSION ABOUT NF CARE IN VICTORIA

Jamie McCarthy

BECOMING AN ADULT: THE TRANSITION PROCESS

Professor Kate Drummond

TRANSITIONING TO MULTIDISCIPLINARY CARE FOR ADULTS WITH NF

David De Bruin

HEALTH AND THE NATIONAL DISABILITY INSURANCE SCHEME

Dr Jim Whittle

SELUMETINIB

Louise Healy

SUBMITTING A CONSUMER COMMENT TO THE PBAC

Dr Deena Parbhoo

NEURODEVELOPMENTAL DISABILITY IN NF-1

Miya St John

SPEECH AND LANGUAGE AND NF

Hayley Darke

THE ROLE OF A NEUROPSYCHOLOGIST

Kylie Clarke

WHAT TO EXPECT FROM NF CLINIC AT RCH

> **It was wonderful to see so many passionate professionals and I really appreciate all the hard work from the CTF team to bring the day together. Well done!**

WATCH THE VIDEO

RETURN OF NF CAMPS AFTER TWO YEARS

ROSES GAP RECREATION CENTRE, VICTORIA

Connecting the NF community with information, services and each other is a huge part of what we do. Events like camps are designed to empower, educate and create critical points of connection.

But, for two years our ability to bring people together in this way has been restricted by COVID, so when we say we were eager to bring our community together for a camp, we genuinely mean it.

On the last weekend of November, close to 70 people from 19 unique groups travelled to Roses Gap Recreation Centre in The Grampians seeking connection.

A 3-hour drive from Melbourne, the campsite is nestled in the Victorian bush. Surrounded by mountains, an abundance of friendly kangaroos and limited access to mobile reception - it represented and became a place of true escape.

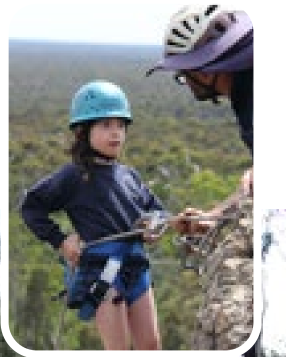
Kids, teenagers and adults alike found freedom, friendship and a fearlessness withing themselves that empowered them to believe they could - so they did.

Everyone found an activity that challenged or excited them in equal measure. There was abseiling, canoeing, flying fox, a giant swing and crate stacking. But it was perhaps the final run into the lake at the end of a long day of activities that showed just how comfortable everyone had become within such a short space of time.

> *It was so good to be able to do something that was connected to my child's NF that wasn't an appointment, forms, or additional worries and burden.*
>
> *It was so lovely to finally be able to do something FUN that we could only do because he has NF1.*

The camps do more than just connect families with each other, they also create friendships and peer support opportunities that wouldn't happen without the Children's Tumour Foundation.

"NF Camp is the single best thing to happen this year."



The staff at Roses Gap not only donated their time, cost of food and activites to the Children's Tumour Foundation, they were without fault. Nothing was too much trouble and we can't wait to return in 2023.

CAMPS ANNOUNCED FOR 2023

Western Australia, 10-12 March 2023
Queensland, 2-4 June 2023

REGISTER INTEREST

COLLABORATING WITH ALEXION TO ADD SELUMETINIB TO THE PBS

Alexion, AstraZeneca Rare Disease has been seeking to have Selumetinib (Koselugo®) funded by the Pharmaceutical Benefits Scheme (PBS) for the treatment of neurofibromatosis type 1 (NF1) paediatric patients aged two years and above, who have symptomatic, inoperable plexiform neurofibromas (PN).

Earlier in the year, the Pharmaceutical Benefits Advisory Committee (PBAC) invited patients, caregivers, family members and friends to share their views via their online portal, to better understand the impact of the condition and the challenges patients and families face.

Consumer comments are a way for the PBAC to understand issues that are important to patients and caregivers, and comments that contain specific information about why treatment is important based on lived experiences, needs and preferences can impact the PBAC's advice.

The Children's Tumour Foundation appealed to the NF community to submit their personal experience of living with inoperable plexiform neurofibromas over July to September. We provided guidance and support to those individuals who decided to make a submission, while also submitting a submission ourselves.

Unfortunately, Alexion did not receive a positive recommendation from the PBAC at the November meeting.

Although this is disappointing to us all, we can be encouraged by the PBAC's acknowledgement that Selumetinib addresses a high and urgent unmet clinical need for children with inoperable PNs and the lived experience of our community was critical in building that awareness.

Alexion has advised us that they will continue to work with the PBAC and the Department of Health and Aged Care to secure access to Selumetinib and will keep us informed of the next steps in that process.

Whilst this is difficult news for all involved, the pathway to funded access to new medicines for rare conditions such as NF1, with inoperable PNs is complex, and it is not unusual for the PBAC not to recommend a first submission.

It is important not to lose hope as we must continue to advocate for access to treatment options where there are no alternatives, and support clinical trials and efforts to extend access to the adult population as well.

WHY IS YOUR VOICE IMPORTANT?

Evidence Matters

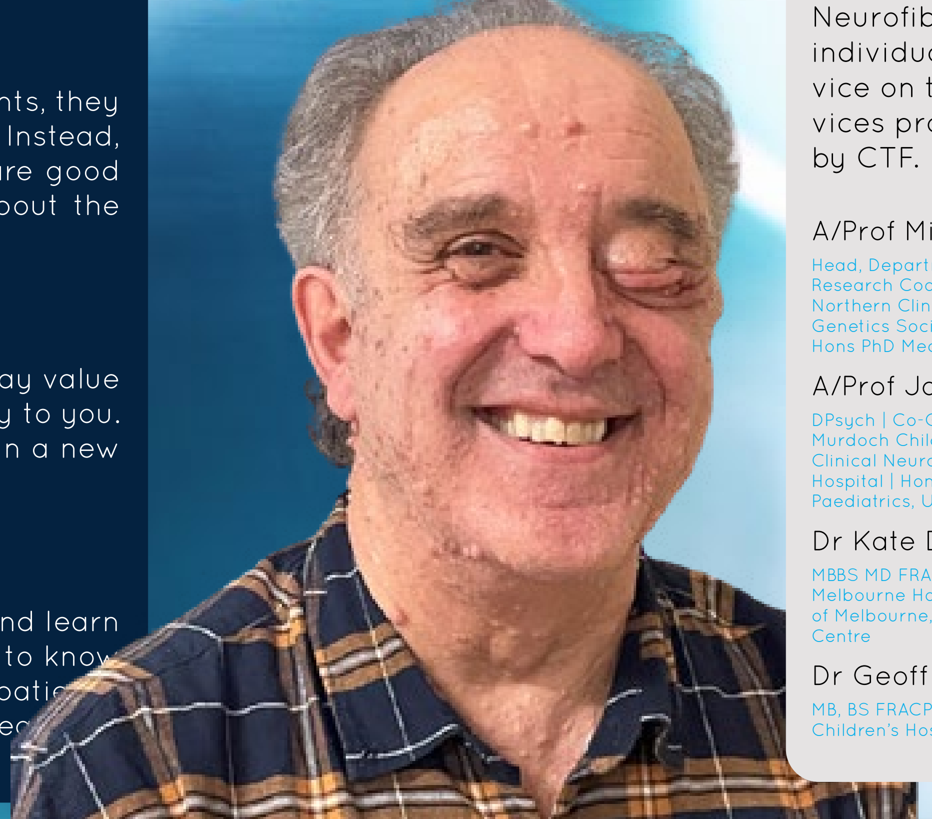
When governments make decisions about investing in healthcare and new treatments, they take into account the cost. However, decisions are not made based on price alone. Instead, they try to maximise the benefit to the community by choosing treatments that are good value. Evidence from clinical trials and economic models provides information about the value of a treatment.

Weighing Up Outcomes

Good value means different things to different people. For example, a researcher may value an outcome of treatment differently to a doctor who in turn, may value it differently to you. This is why decision-makers need your input when they are considering investing in a new treatment or changing the way treatment is provided.

Make Better Decisions

Decision-makers need to know what matters most to patients and carers like you and learn from your insights about how and when a treatment may best be used. They want to know if treatments have value beyond clinical trials and if they will make a difference to pati daily lives. Patient and carer input can help them understand the true value of a trea and make better decisions.



SUPPORTING RESEARCHERS TO RECRUIT PATIENT GROUPS FOR THEIR STUDIES

Associate Professor Tracy Dudding-Byth was one of four projects to receive funding though the Medical Research Future Fund following our advocacy efforts to secure dedicated research funding from the Federal Government in 2020.

The project NF1 Cutaneous Neurofibroma Consortium (NF1 Project) seeks to identify genetic modifier pathways driving variation in cutaneous neurofibroma burden experienced by adults with NF1 and the team are looking to recruit 2000 people to the study.

As the leading charitable authority for NF in Australia with direct links with a large number of the required patient body, we have been working with Tracy and her team to help grow awareness of the study and secure the participation numbers she needs.

Utilising our social media platforms, we have run advertising to promote the study to our broader community. At the time of writing this report, advertising had been running for 4 weeks and the team has seen a significant increase in traffic to the website and conversions.

Advertising is paid for by the study, but is managed by the Children's Tumour Foundation.

We would like to extend these opportunities to other researchers and clinicians who are seeking an expansion of their existing resources to secure participation.

MEDICAL ADVISORY PANEL

One of out strategic objectives is to bring together a panel of world leading clinical and scientific experts in the field of neurofibromatosis. Their purpose is to assist the CTF with specific, objective clinical and scientific expertise where the evidence is unclear, or the expertise is outside the scope of the CTF management and staff.

We are pleased to be able to announce that we established a Neurofibromatosis Medical Advisory Panel in 2021 and those individuals have been providing professional guidance and advice on the medical and scientific aspects of the information services provided by the CTF, as well as any research grants made by CTF.

A/Prof Mimi Berman

Head, Department of Clinical Genetics | MD Research Coordinator, University of Sydney Northern Clinical School, Vice President, Human Genetics Society of Australasia, BMBS FRACP BSc Hons PhD Medicine | Clinical Geneticist (HGSA)

A/Prof Jonathan Payne

DPsych | Co-Group Leader, Brain and Mind, Murdoch Children's Research Institute | Senior Clinical Neuropsychologist, Royal Children's Hospital | Honorary Principal Fellow, Department of Paediatrics, University of Melbourne

Dr Kate Drummond

MBBS MD FRACS | Director of Neurosurgery, Royal Melbourne Hospital | Other affiliations: University of Melbourne, Victorian Comprehensive Cancer Centre

Dr Geoff McCowage

MB, BS FRACP | Senior Paediatric Oncologist Children's Hospital at Westmead

Dr Tim Hassall

MBBS, FRACP (Paed, Med Onc) | Senior Staff Specialist in Paediatric Oncology, Children's Hospital Queensland HHS

Dr Katrina Morris

Neurologist, Staf Specialist Concord Repatriation General Hospital, VMO Neurofibromatosis Clinic Dpt Genetics, Royal North Shore Hospital, Neurologist, Sydney Neurology at BMC

Dr Colin Derrick

MBBS, FCPead | Consultant Paediatrician, Department of General Paediatrics, Perth Children's Hospital

Dr Gargi Pathak

Clinical Geneticist | Genetic Services of Western Australia, Women and Newborn Health Service, Agnes Walsh House | King Edward Memoral Hospital.

SHAKING UP THE FUNDRAISING CALENDAR IN 2022 & BEYOND

The Children's Tumour Foundation is proud of the strength of our community and supporters.

Through active participation in events, social media following and sharing, fundraising and volunteering, you have enabled the CTF to deliver more services and fund more research.

As we grow, we learn more about the impact we make and how we represent NF to health professionals, scientists, government, funders, general public, and our community.

We want to continue to grow and support the 10,000 Australians living with NF every day, but sometimes change is needed to propel us forward.

As an organisation, it is important that everything we do strengthens our brand, reinforces our messaging and ensures the NF colours, the CTF and the condition become interconnected.

CUPID'S UNDIE RUN WILL NOT RUN IN 2023

There are a lot of fond memories that surround an event like the Cupid's Undie Run (CUR). For ten years, we have asked you to take to the streets in your undies with thousands of fellow runners to raise awareness and funds for people living with NF.

Resplendent in red, we started important conversations about the physical and social challenges many with NF face; helping to spread the message that stripped down, we are all the same.

Fearsome. Fabulous. Strong.

But the last three years have been tough on an event that performs best in front of an audience, not at home.

In 2020, we cancelled just 10 days out from the run (as advised by Australia's Chief Medical Officer) but were thrilled with how superbly everyone welcomed the idea of going from the "streets to the screen".

It was a concept we sought to replicate to a degree in 2021, and again in 2022, despite our best efforts to run the event in-person. Opportunities for fundraising have declined alongside these unforeseen and uncontrollable changes.

Unfortunate as these circumstances have been, it has also presented an opportunity for reflection and growth as we look to move the organisation forward.

The unofficial, but now very accepted colours for NF globally are blue and green. By aligning with our international counterparts, we help ensure greater consistency and recognition internationally.

With so much positive momentum building around the new branding, it has become increasingly clear that our best path forward lies in identifying opportunities that align with and strengthen the Children's Tumour Foundation brand.

It is in this spirit that we have decided to not move forward with Cupid's Undie Run in 2023.

We have not taken this decision lightly and recognise the time, effort and love that has gone into its execution every year by our race directors and volunteers, as well as the bravery of those who have dared to bare for us. **We cannot thank you enough.**

WE PILOTED A BLUE & GREEN COLOUR RUN

"CONQUER NF IN COLOUR"

On Sunday 13 November, we hosted our inaugural CONQUER NF IN COLOUR fun run at Wentworth Park in Sydney.

It was a spectacular day that was a perfect expression of who we are as an organisation - it was boldly blue and green, inclusive, accessible and full of positive energy for the NF community.

It was everything we want to be known for as we work to build awareness and understanding of neurofibromatosis, connect the condition to the colours of blue and green, and raise the profile of the Children's Tumour Foundation amongst the general public.

We had close to 350 participants, volunteers and spectators in the NF Village and on ground running 2km, 4km or 10km in the heart of Sydney. We were visible and visibly having fun, which we hope will inspire others to make next year even bigger and better.

We are so grateful to everyone who embraced and supported us by running and fundraising, through sponsorship, by volunteering, or by gifting their time, influence and talent, including Dan Ewing, Kevin Sullivan and Peter Deppeler.

Thank you to our event partners at Bendigo Bank - Darling Square, Gresham Partners, Wentworth Park Sporting Complex Trust, Edge Agency and Onsport for their generosity and participation.

More than $60,000 has been raised through fundraising and sponsorship, $200k in probono ad space thanks to Edge Agecny and hundreds of thousands of people have been exposed to news articles and tv over the period thanks to the Buzz Group.

A video of the day was compiled by the talented team at Plazitas Creative which can be viewed HERE.

Tamara from @vanlifeshots participated in the event and created a vlog that can be viewed HERE.

Our goal was to pilot a new fundraising event that strengthens the Children's Tumour Foundation brand, is accessible and appealing to a broad audience and demonstrates scalability. We definitely achieved that.

INTRODUCING DINE & DISCOVER NF
LUNCHEONS

In May, we hosted the first of our new Dine and Discover NF Luncheons in Sydney and Melbourne.

These events are designed to give existing partners, friends of the organisation and potential new supporters the opportunity to learn about neurofibromatosis in a more intimate setting.

Hope for a better future for the community we support is why we host events like this.

To give guests an understanding of the condition, it's impact and potential treatment options, a member of the NF community is invited to speak, as well as a medical professional working with NF patients.

We held our first event at Ventuno Restaurant in Walsh Bay, Sydney on the 24 May, followed closely by our first Melbourne luncheon on the 30 May at Fitzroy Town Hall Hotel.

We hosted a second event in Sydney at the end of November at the same venue.

With guests and board members purchasing tickets to support the event, the intimate setting enables better conversations, which has already led to some wonderful new partnerships and donors.

We are so grateful to our speakers who have contributed to each event, including medical professionals A/Prof Mimi Berman (RNSH), Dr Gabriel Dabscheck (RMCH) and Dr Manoj Manezes (SCHW), as well as community members Claudia Hopday, Shelly Lynde and Simon Carroll.

THE POWER OF TWO

Our campaigns could not have been as successful throughout the year without the support of our matched giving partners, who inspire our donors to give more, knowing it will be doubled and go further.

Throughout the year, we have been supported in this way by Morgans Foundation, Whiteley, Gresham Partners, PBK Management and Eucalyptus.
Kidstuff and Essential Energy also promoted matched giving internally to inspire their employees, for which we are incredibly grateful.

CIRCLE OF SUPPORT

Help build a Circle of Support around families impacted by neurofibromatosis.
Become a Regular Giver today.

CTF.ORG.AU/REGULAR-GIVING

COMMUNITY SPIRIT IS STRONG

FUNDRAISING FOR NF

We have been so impressed with the fundraising ideas that people have come up with and executed, raising thousands of dollars for the Children's Tumour Foundation in the process.

ALEX'S NF HERO FUNDRAISING STORY


Emily and NF Hero, Alex

Over my 13 years of life, NF has caused some challenges for me. When I was about six, I had to have a plexiform neurofibroma removed from my head. That surgery was no big deal, but that was the same year that my vision loss began.

Fast forward a few months, I was having a regular eye test when to everyone in the room's surprise, I could not read the letters in my right eye. So I had a MRI and they discovered a optic pathway glioma on my optic nerves. I had a mediport put in and I started chemo immediately.

Then a few years later we noticed on an MRI that the tumour had grown. So I restarted chemo. Then fast forward to age 11, I noticed that it was hard to see the words in a book. So I tried reading some different font sizes and found out I could not read much so off to the hospital I go.

They gave me some steroids and fluid reduction medicines and told me my vision would be resolved in a few weeks. It did not work. I started at a school for blind and vision impaired kids.

At the school, I had to relearn a lot of things. I learnt braille and how to use a white cane to get around. I graduated and went to a high school with staff from the school to help kids with vision impairment.

At the same time, I did a fundraiser for the Children's Tumour Foundation and raised around $4,620 riding my tandem bike - 1km for every $10 donated up to 100km.
I was overwhelmed by the response. That was a great experience and I enjoyed it very much".

Pittsworth Junior Danes Rugby League Club nominated the Children's Tumour Foundation Australia to be the recipient of funds raised at their end of season match this year.

One of their littlest club members is NF Hero Levi who was diagnosed with NF1 when he was just over a year old. Despite some challenges, Levi is doing well. He is making his mark on the world by ensuring his community are educated on what it means to live with this condition.

Not only was Levi on field to welcome the U16s team on the day wearing his NF Hero cape, but the entire team and support base wore a specially designed jersey with the CTF logo and branding across the front, back and side of the shirts.

As a club, they raised $2000 for the CTF and we are so grateful for their support and that of Levi's entire family.

GOGGLEBOX STARS LEND THEIR SUPPORT

MALIK HAS HIS FIRST HAIR CUT FOR KIDS WITH NF

Any parent of a toddler will know just how significant that first haircut is. Hanging on to their baby hair is like hanging onto your baby.. because once you cut it off, you know you will suddenly have a real little person on your hands - with their own personality.

This is something Gogglebox star, Sarah Marie Fahd and husband Matty have now had to come to terms with following the decision to cut their son, Malik's hair.

Introduced to us by NF Mum, Emmy from Kiindred who has been friends with Sarah for 15 years, she wanted to do something to support Emmy's daughter Ishq (and the thousands of other NF Heroes out there).

Sarah decided to use this moment to also help raise funds and awareness of NF.

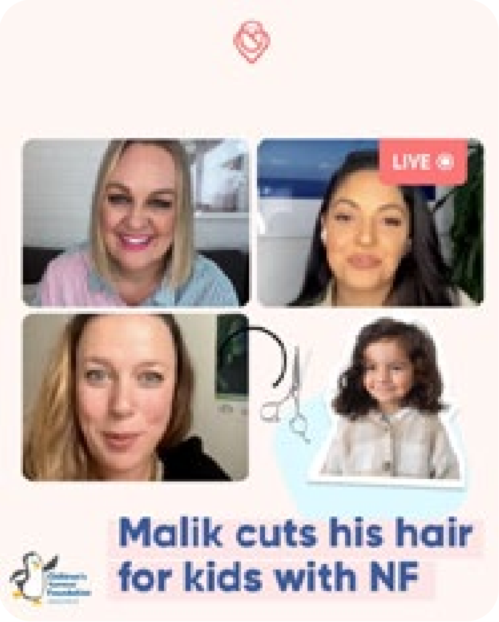
The fundraiser kicked off with a live on instagram between Emmy and Sarah to their collective instagram audiences of over 100k talking about what Sarah planned to do and why.

Our Head of Marketing and Fundraising, Renee joined the call which lasted for almost an hour! Man, those guys can talk.

It was the catalyst that was needed, for within a week and a half, Sarah and Matt had raised more than $11,500!!

On the big day, Malik sat confidently in the barber's chair to have his first hair cut and definitely came out even more handsome.

We are so grateful to Sarah and her family for using their platform to raise much needed awareness.



KAY'S ANNUAL MORNING TEAS ARE A CROWD FAVOURITE

Every year, the wonderful Kay hosts a morning tea to help raise funds in honour of her grand-daughter and in support of the Children's Tumour Foundation. 2022 was no exception.

On World NF Awareness Day, 40 guests gathered at her home and together they raised $2000 for the CTF, as well as additional funds for the Cancer Council of Australia.

Kay has helped raise more than $20,000 over the years through her morning teas and participation in NF Hero Challenge.

CHRISTMAS TIME GIVING

ECARDS NOW AVAILABLE

Imagine discovering your child's cute birthmarks were also a sign of a lifelong genetic condition with no cure and few treatment options. Progressive and unpredictable, tumours form on nerves in the body, including the brain and spine.

This was the reality for Mel and Lee Shrimpton and thousands of other families whose child has become the first in their family to be diagnosed with NF.

In half of all cases of neurofibromatosis, there is no family history and it comes without warning.

When Melinda's son Jack was diagnosed with neurofibromatosis type 1 (NF1) at eight months old, the news was devastating and unexpected, but thanks to donors like you, they had the support of the Children's Tumour Foundation at every stage of their journey.

Now five, Jack has had more MRIs, needles and specialist appointments than any person should have in their lifetime.

Jack was born with a bowed leg, which they later learned was actually Tibial Dysplasia - a rare symptom of NF1 occurring in around 1 in 150,000 births.

As soon as Jack was old enough to stand and begin to walk, he required an AFO (Ankle Foot Orthotic) to support his leg bone. As he grew, he watched his peers run, jump and climb. He wished he could keep up.

By the time Jack was four years old, he had already undergone three surgeries on this leg to correct bone bowing, which had reached 85-degrees at the time of his first major surgery.

Recently, Jack has experienced some challenges with his eyesight, and will require an MRI every six months.

"As parents, it's horrible this feeling of hopelessness against a condition that has many symptoms that can arise at any time. This fear of the future consumes part of me every day" Melinda shares.

As the only non-clinical service provider, we work to ensure anyone regardless of location, NF type or financial position can access balanced information and personalised support free of charge, while also enabling important connections with community and healthcare professionals.

There are many unknowns when it comes to NF, but your gift at Christmas (and any other time of the year) will continue to help fund vital support programs and research into better treatment options.

We are incredibly grateful to Morgans Foundation for jumping on board as a matched giving partner and the Shrimpton family for opening up to us and sharing their experience of NF with the world.

FOR THE FIRST TIME, WE HAVE BEEN ABLE TO SEND ECARDS AT CHRISTMAS!

This has been made possible by our web service providers at PIXO who chose us to partner with to test this new technology.

We are so grateful to everyone who gave a donation or gifted one to their loved one this Christmas.

ACKNOWLEDGEMENTS

WE COULD NOT DO IT WITHOUT ALL OF 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

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Peter Ketley
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Tim Doyle

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PIXO
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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

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Danielle Rego
Holly Parryman
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Kirsty Whitehead
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Rebecca Spry (Chair)

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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

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Luke Goldsworthy
Nirmal Hansra (retired in Dec 22)
Peter Krideras
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Children's Tumour Foundation
CONQUERING NF

#CONQUERNF