



NO TYRE LEFT UNTURNED FOR THIS DEVOTED DAD

When it comes to putting your body on the line to raise awareness and funds, Cam Elliott is a force to be reckoned with. Since 2017, Cam has raised close to \$140,000 for the Children's Tumour Foundation in support of his daughter Libby and the thousands of families living their same pain.

Continued on page 4

INSIDE:

- 3 WRAP UP OF THE 2020 NF HERO CHALLENGE
- 6 GROWTH AND IMPACT OF TELEHEALTH
- 10 FEATURE STORY: ELLEN'S AVASTIN JOURNEY
- 18 NDIS APPLICATIONS
- 22 GETTING ON THE GOVERNMENT AGENDA



At the end of every quarter, we come together to take stock of what we have achieved as a team and as a community, and there is always an overwhelming sense of pride. Not just for the difference we make in the lives of people who connect with us, but for the difference that our community makes in the lives of families and individuals who share their fears and anxieties for the future.

Within this edition, we have compiled a wide range of stories, articles and updates that we hope will inspire you, inform you and most importantly, help you to feel more connected and supported as we head into the new year.

On our front cover is one of our favourite photos and epitomises the deep, selfless love of a parent for a child. It seemed only fitting considering the lengths that this father has gone to, to get people talking about NF over the past couple of months as part of the NF Hero Challenge.

We should not underestimate the difference it makes to people's lives knowing there is someone like Cam in their corner too.

We know how important it is to share stories. It helps people feel less isolated (something we could all use a bit more of these days) and more in control of managing their diagnosis.

Our feature story is of a young woman with NF2 who was on the verge of complete hearing loss before starting a new treatment that has helped recover a significant proportion of her hearing in one ear. Further on in the newsletter is another woman's experience of working from home during COVID, the challenges that presented for zoom calls and how she managed her hearing impairment with the help of better technology.

We have also provided updates on many of the support programs, research studies and plans to get NF and the CTF on the government agenda as we head into 2021.

All of which we could not do without the continued faith and support of our wonderful community. It has been a different and difficult year in a lot of ways, but what has remained constant is our drive to improve your world and conquer NF.

Renee Anschau

Head of Marketing and Fundraising

SHOWING NF WHO'S BOSS IN 2020!

We have always known the strength and resilience of our community, but we love how the **NF Hero Challenge** puts it on display for all to see.

We asked you to pick an activity or task that would challenge you physically, mentally or emotionally during the month of September and raise funds to ensure support is always available to those who need it.

We applauded the creativity of our participants, particularly when faced with lockdowns and social distancing.

For those supporting loved ones with NF, we asked you to put yourselves in their shoes for a few minutes, for a day or for the whole month.

For those living with NF, we asked you to show the world how your condition has become the source of your power and not a weakness.

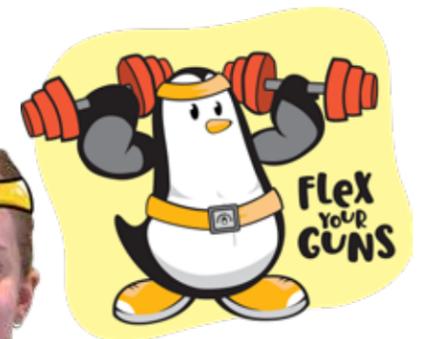
Together we raised close to \$80,000!!!

This means:

- More time spent with parents seeking reassurance and resources
- More opportunities for young people to connect and reduce feelings of social isolation
- More time spent advocating for greater support with government and healthcare professionals
- More funds to be invested into research

We would like to sincerely thank everyone who participated, donated or cheered from the sidelines, including our matched giving partner, Gresham and Prize Partner, Harvey Norman.

This is an incredible achievement and we could not be more thrilled.



No TYRE LEFT UNTURNED FOR THIS devoted dad

When it comes to putting your body on the line to raise awareness and funds, Cam Elliott is a force to be reckoned with. Since 2017, Cam has raised close to \$140,000 for the Children's Tumour Foundation in support of his daughter Libby and the thousands of families living their same pain.

Libby's NF journey began when she was 4 years old. What should have been a simple optometrist appointment for a lazy eye became a diagnosis of NF2, a brain tumour and the start of many years of anxiety, stress and surgeries on both her brain and spine.

As a serving member of the Australian Defence Force, maintaining physical fitness comes with the territory. But for the NF Hero Challenge this year, Cam definitely took it to the next level; raising \$16,285 and becoming our highest national fundraiser.

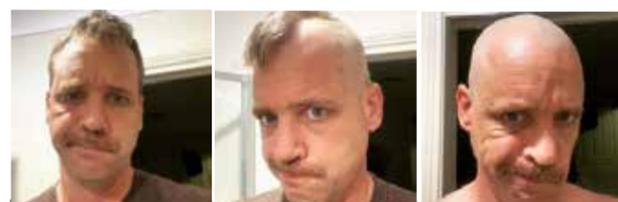
A master in fundraising, Cam set targets to encourage giving and posted regularly to his instagram page @nf2_dad.

\$2,500: Completed a tyre flip per \$100 raised each day till the end of September = 6,500 tyre flips completed.

This was to replicate the burning pain and aches that Libby has due to the tumours she has running the length of her spine.

\$5,000: Grow a mo.

After Libby's first surgery she thought she looked like a monster and wouldn't have any friends because of the way she looked. Cam's mo is intended to represent this.



to maintain a blade smooth shaved head to replicate the effects that chemotherapy can have on a person. Something that many families are going through to try and fight this disorder.

\$10,000: Carry 40kg (2 x 20kg Kettlebells) 100m per \$1,000 raised. This is for the 1 in 40,000 kids that have NF2.



\$12,500: Give up alcohol and soft drink. A personal challenge for Cam and one the represents the many, many sacrifices those living with NF, as well as their families face everyday.

\$15,000: Spend 4 minutes in an ice bath. Not only does Cam hate the cold, but NF causes tumours form on nerves in the body. Plunging into freezing water, his nerves would no doubt have been afire.



On top of these challenges, Cam walked 32.7km - a kilometre for every \$500 raised.

Cam's efforts have been nothing short of extraordinary and we were thrilled to be able to award him a \$2,500 voucher from Harvey Norman for being our highest fundraiser!

Well Dope Cam!

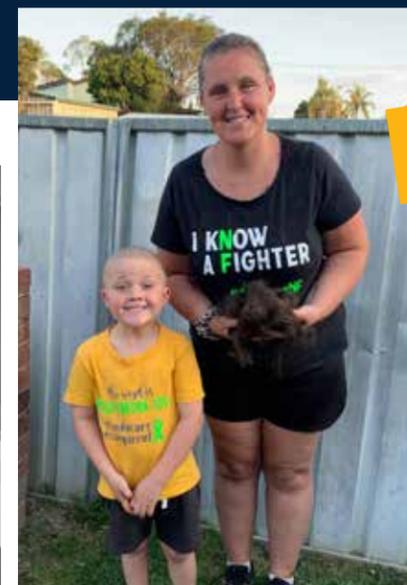
We have watched you complete your challenges with awe and gratitude, a reminder of how much stronger we are when we raise our voices together.

We have seen everything from...

- 10,000 steps a day all the way to 15km a day
- thousands of tyre flips, burpees and pushups
- Ice baths and showers
- Head shavings, hair dying and even a mohawk
- Competition to win a \$1500 tattoo as a way to raise funds
- Commitments to train, give up coffee or sugar every day for a month

PLUS so many, many more.

THANKYOU





THE GROWTH AND IMPACT OF TELEHEALTH DURING A PANDEMIC

The last six months have been tough on everyone, and so many things we take for granted and consider “normal” have changed for better or worse until such time as we can get back to some semblance of normal.

Telehealth has been around for a long time, but until the COVID-19 pandemic, it had limited capacity and use due, in part, to the preference and need for face-to-face appointments.

“This rapid shift meant that our health system was not fully prepared to adapt in the way that it needed to.

We heard about the increase in purchases of surgical grade masks, other PPE and other necessities like ventilators, but little was said about a shift to virtual appointments and what that meant.

However, Medicare quickly adapted the MBS framework to include more flexibility with regards to telehealth services prior to the nation’s lockdown in March.

As you can imagine, hospitals, private health providers, doctors and allied health professionals, including those managing patients with NF, were left scrambling to adapt to a very foreign way of operating. This was all happening while also adapting to working from home, remote learning and social distancing.

As expected, there were teething problems with an en-masse shift to platforms not designed to hold the weight of the health system at once, let alone having the wider workforce and community working remotely.

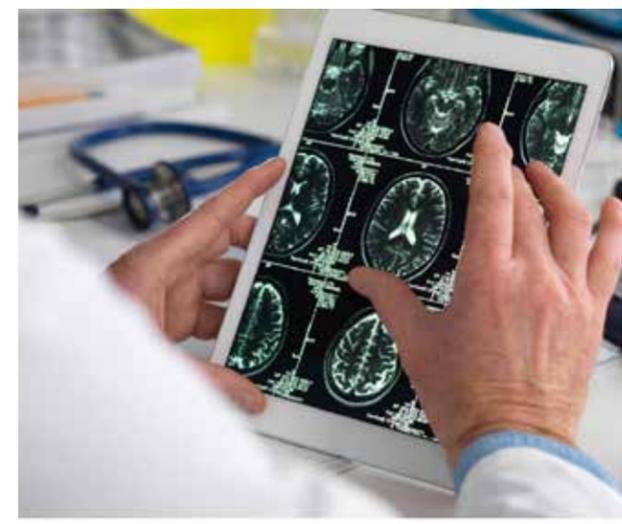
Along the way, the challenges that telehealth has always presented have become more apparent, and new ones have arisen too.

Less expectedly though, there have been benefits to this virtual mode of appointment delivery which has resulted in a shift in thinking within the health industry that will likely see telehealth incorporated into medical practice into the future.

With the effects of the pandemic extending for months rather than weeks, in many instances there have been no immediate plans for a return to in-person appointments. Lending strength to the idea that telehealth may be here to stay at some level.

With that in mind, we thought it might be time to take a look at telehealth in more detail for families impacted by NF, and what you need to know for future appointments.

You may have already had a telehealth appointment or two (or even lots) for your ongoing monitoring and management of symptoms, but many people have also deferred their appointments waiting for a time when in-person appointments can go ahead.



We recommend going ahead with scheduled telehealth appointments as there are several benefits (aside from those relating to COVID-19):

- It allows you to keep a relationship going with your clinical team so
- You know where to turn if anything changes
- Your team can keep across any changes to your condition and intervene early if necessary

Any questions can be answered and concerns can be addressed with a follow-up plan put in place to:

- Attend in person if physical examination is required
- Attend your local GP with specific requests
- Referrals can be made to other specialists
- Present to ED
- Have scans booked and undertaken

It can be done from the comfort of your own home (or wherever works for you), which also means travel time is eliminated from appointments, so they are easier to work around.

- Costs for regional and remote families are reduced as only urgent appointments need attendance in person.
- The approach taken during appointments is often more holistic rather than just the nuts and bolts stuff covered in clinic appointments.

These benefits obviously don’t eliminate the constraints with this delivery model. For example, a doctor cannot view or touch neurofibromas or perform an eye exam.

- However, clinicians have found ways to engage within the space to get the best outcome for their patients.
- It might be that they ask you to send them a photo of any concerning NFs so they can review them for you.
- They may test eye movements while you are looking at the camera
- Asking you specific questions or to use objects around home to assist with assessments to determine whether further testing is required at this time.

While telehealth does have the drawback of not allowing for a physical examination or the use of equipment such as ophthalmoscopes to complete assessments, the doctors can gather a lot of information from a telehealth appointment to track how you’re going and make future plans.

This is particularly true if you have uncomplicated NF and just need to check in from time to time.

While some of the NF Clinics are starting to transition back to face to face appointments slowly, telehealth is still being utilised in all clinics and the feeling is that this will continue into the near future.

FUNDING NEW PAEDIATRICIAN AT ROYAL MELBOURNE CHILDREN'S HOSPITAL

In 2019, we were awarded \$20,000 in funding from the Westfield Local Heroes grants initiative to be used to fund a new Developmental Paediatrician in the NF Clinic at the The Royal Children's Hospital, Melbourne.

There was concern that the general paediatric and development care of patients with neurofibromatosis was too fragmented. To address this need, an experienced paediatrician was engaged to fill the role in February 2020.

In just over six months, Dr Parbhoo has engaged with approximately 60 patients over 18 clinic dates and has been a welcome voice of maturity and insight when it comes to managing patients with complex medical conditions.



She has particularly focused on patients with developmental difficulties, autism and attention issues, while also working alongside the neuropsychology team and community services to help provide more holistic care for some of our NF Heroes down in Melbourne!

In what can only be described as a challenging year, we are proud to have helped the Department of Neurology and the Neurofibromatosis team maintain the highest quality care for patients during this time.

Through funding of a dedicated NF Clinical Coordinator at the Royal Children's Hospital Melbourne, the Children's Tumour Foundation has supported hundreds of families across wider Victoria access multi-disciplinary care.

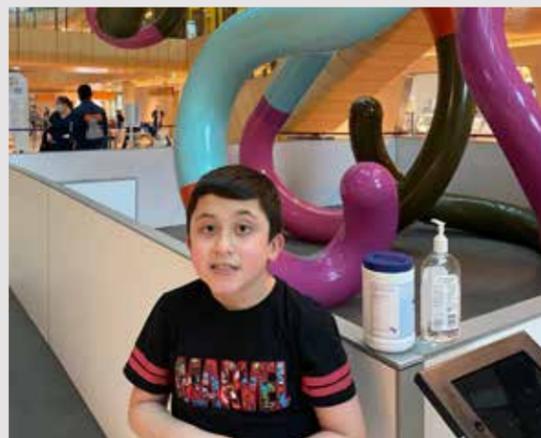
Below are the numbers for FY20:

335 IN-CLINIC APPOINTMENTS

165 TELEHEALTH APPOINTMENTS

OVER 1200 SUPPORT-RELATED INTERACTIONS

21 TRANSITIONED INTO ADULT CARE



DEVELOPING BEST PRACTICE PRINCIPLES ADULT NF CLINIC AT ROYAL MELBOURNE HOSPITAL

While there are a number of specialist NF clinics at leading neurological centres around the world, most provide initial assessment and referral services, but do not continue life-long care.

Using principles of evidence based and research-led care, this project will provide a best practice framework for the life-long multi-disciplinary care and follow up of adult patients in a public hospital setting.

Funded by InsituGroup, the project aims to set up individualised templates for each patient attending the clinic and will include:

- A triage plan for waiting referrals
- A first attendance assessment template
- A clinical pathway
- A clinical passport for GPs
- A health passport for attending patients

The clinic is currently run quarterly with around 40 patients accessing these services.

We are currently halfway through the project which is expected to be completed by mid-2021. It is at this point that we hope to support the introduction of more frequent clinical dates.

If you would like to find out more about how to access the Adult NF Clinic in Melbourne or find out more about this project, please contact our support team at support@ctf.org.au

In a population health survey recruited through the CTF and managed by the Royal North Shore Hospital (RNSH), it was identified that only 40% of adult patients with NF1 are accessing regular health reviews despite guidelines recommending annual reviews.

Whilst this was in line with similar studies in the US, only 43% of patients knew where they could go to access care.

Transitions from paediatric to adult care are difficult, as they are for many rare diseases, with many young adults with NF1 not receiving regular care or not understanding the importance of continued monitoring through adulthood.

FEATURE STORY: ELLEN'S AVASTIN JOURNEY

My hearing journey has felt quite like a rollercoaster since I was diagnosed with NF2 at 15. It started with mild hearing loss in my left ear which led to an MRI scan which revealed multiple spinal tumours, as well as bilateral acoustic neuromas (AN), also known as vestibular schwannomas. The left acoustic neuroma was slightly larger and impacted my hearing more.



For the next 5-6 years, NF2 was on the sidelines and didn't play a huge part in my life at that point. My hearing was not so bad as to have a significant impact on my life.

It wasn't until I started university straight after high school that my ENT specialist recommended I start wearing a hearing aid on my left ear so I would cope better throughout my studies and not miss out on any information in lectures/ tutorials.

My specialists at this time occasionally brought up a hopeful new drug called Avastin that was being trialed for NF2 primarily in the US and the UK but did not mention any use for me at this point. Will I

be able to teach them to drive? Pick out a formal dress?

Celebrate their graduation? Buy them their first legal drink? Or even watch them get their first job?

My tumours were relatively stable in size up until 2017, my final year of university, where follow up MRI's started to show that they had started to grow again.

It was at this point that we made the decision to remove the larger left acoustic neuroma to create some more space in my brain and minimise the high likelihood of serious complications such as seizures.

They were unable to remove it completely but did debulk it.

I was left profoundly deaf in my left ear post surgery.

It was said a cochlear implant could possibly be useful but this could not be determined yet as it depended on the functioning of my hearing nerve which was impacted from surgery and the tumour itself.



The 6 monthly follow up after this surgery again showed that my AN's had continued to grow. During this time the hearing in my right ear plummeted.

It slowly got worse and worse and I relied on wearing a hearing aid in this ear to communicate. But even then, the hearing aid wasn't very helpful in understanding sounds, particularly speech, but more so amplified sound and I became reliant on lip reading.

My doctors suggested that they remove the remainder of my left AN and look into starting Avastin which was now being used on some NF2 patients in Australia.

“Going into major brain surgery the second time around felt less daunting as I had already experienced it before and felt I was able to cope with the recovery”.

My surgeons were very comforting and reassuring which made it all the more easier. The surgery was a huge success. It took 12 hours, and they removed the remainder of my left AN. Along with approaching the tumour through a cut behind my ear, they also removed part of it that had grown into my inner ear - which damaged my inner ear and essentially ruled out the possibility of a cochlear implant.



Once I was recovered from surgery, the process for getting onto Avastin began. I was referred to neurologist Dr. Katrina Morris at the NF Clinic at Royal North Shore Hospital. Dr Morris referred me to see an oncologist, kidney specialist and fertility specialist to prepare for Avastin treatment.

As this was during the beginnings of the Covid-19 pandemic, the process to starting treatment was quite long and took a few months.

I was incredibly excited to start Avastin and had done a heap of research myself which showed some promise in essentially buying hearing time and delaying the need for future surgeries. I was told that a majority of patients find that their tumours stabilize in size, and a proportion of them experience tumour shrinkage and a small return in hearing.

“During lockdown period, the hearing in my right ear plummeted further. This made communication even more difficult. I gained a new sense of confidence in my hearing and condition during this time”.



Completing studies from home and online was a silver lining for me as communicating via Zoom was much easier as I would wear my hearing aids, noise cancelling headphones, and be able to lip read everybody much easier.

I think it forced everybody to speak one at a time and made it much easier to track the person who was talking. Normally keeping up with a group discussion would be quite impossible for me.

Even though I struggled in daily life with group conversations and phone conversations; listening to music, podcasts and TV, I was content with my hearing staying at the level that it was as it felt manageable.

But I could not imagine a world where it continued to get worse. I experienced a lot of anxiety about my hearing and was often embarrassed of mishearing, which made me limit my interactions with many people.

After a couple of months of waiting to hear from specialists, I finally had an appointment to see a kidney specialist. They checked my kidneys were healthy and functioning normally as there is a risk of kidney damage with Avastin treatment.

I was then referred to the fertility clinic at RPA as I would need to have my eggs harvested before starting due to the chance of fertility issues after treatment.

Going through the fertility preservation process was an emotional process and made me think about my future relationships.

My appointment with oncology at St George Cancer Care Centre was also filled with nerves and anxiety. Primarily because I knew that Avastin isn't listed under the Pharmaceutical Benefit Scheme (PBS) for NF2, meaning that it would not be automatically approved and would likely come with a huge out of pocket cost.

They reminded me of this during the appointment and said they would write a letter to the PBS asking for some subsidy as I would likely benefit from it. I was told that they could cover every one in three infusions - which sounded really helpful although that still leaves a huge fee.

A couple of days after this appointment I received a call from oncology while I was on my way to work. They informed me that PBS had approved 6 months of Avastin free of charge! I was overjoyed to hear this and made everything feel more real.

“Hearing this news made me feel like things were finally going to get better and I was quite optimistic that I would benefit from Avastin, with the idea of even a small amount of hearing returning being miraculous.”

My first infusion was on the 10th of July at St George Cancer Care Centre. Before starting the infusion, they gave me an education session to remind me of the side effects to look out for, the need for regular blood tests and extra care that would help me keep healthy. The first infusion lasted about 2 hours to ensure that I did not have

an allergic reaction to the medication and that my body could tolerate it.

It went well and I just left the clinic feeling quite tired - fatigue being a main symptom to be expected.

The first couple of days after the first infusion, I noticed that my hearing felt unexplainably different.

On the third day post first infusion, I had gone into work and noticed that the environment felt too loud and everything seemed to echo. I had to turn my hearing aid down which was crazy because I had always learnt that I needed to constantly increase the volume in order to understand.

The day after this, I had forgotten to put my hearing aids in - something that absolutely never happens because they became my crutch! I noticed I was able to communicate much better at work, home and socially, almost as well as I remembered my hearing to be before I started losing it in my right ear.

From this point, I completely stopped wearing my hearing aids and called my audiologist to get a hearing test done to confirm that my hearing had actually improved.



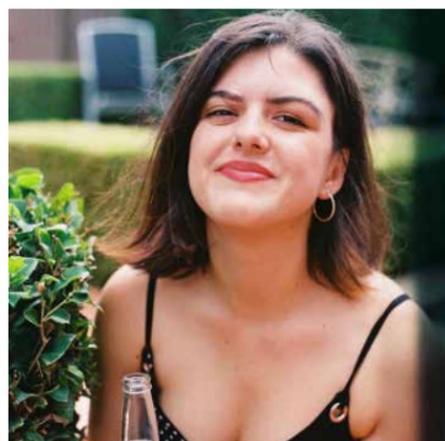
My audiologist was amazed when she did my hearing test and it showed that the hearing in my right ear had definitely improved, something that she said never happens in the audiology world.

At its worst, the hearing in my right ear was a moderate-severe mixed hearing loss. The follow up hearing test revealed that this had improved to a mild mixed hearing loss localised to the lower frequencies. Learning that my hearing had improved from a moderate-severe loss to a mild loss was incredible and I definitely noticed a huge change that this had created in myself.

I felt like I could be social again, I regained so much confidence, and began listening to music non-stop!

As stressful as it was getting started on Avastin; being concerned about the finances, the possible side effects and going through the fertility preservation process and not knowing if it would actually work - I am incredibly grateful with the quality of life that it has returned for me in such a short amount of time.

I have become extra attentive and cherish all the sounds I can hear, taking notice and enjoying the details that I hadn't experienced in years.



The next step from here is to continue with fortnightly infusions until the end of the year at which point I will have my 6 monthly MRI which should hopefully confirm that my right AN has shrunk, explaining the huge return in hearing. There is the concern that PBS may not provide future Avastin treatments free of charge, however I am again optimistic that the benefits I have gained will be enough evidence to continue with infusions.

So far, the only negative side effect is fatigue on the day of and the day after the infusion and some dryness. I hope to continue on this for as long as possible and as long as the benefits outweigh the side effects.

I don't want the level of my hearing to stop me from living life to the fullest. I want to continue learning sign language and immerse myself in the Deaf community to be able to communicate with as many people as possible.

I know the sudden return to "normal hearing" may not be permanent and that the reality of living with NF2 is completely unpredictable, but I am thankful for this newfound hearing, sense of life and insight that I have gained.

FROM PROMISING POTENTIAL TO PLATFORM CLINICAL TRIAL FOR NF2: INTUITT-NF2

The Children's Tumor Foundation (CTF) in the US announced back in May a significant advancement in care for neurofibromatosis type 2 patients with the launch of a new clinical trial called INTUITT-NF2, an innovative platform trial which will evaluate multiple treatments simultaneously.

The name INTUITT-NF2 stands for 'Innovative Trial for Understanding the Impact of Targeted Therapies in NF2', and its innovation is in responding to - and acting against - specific traits unique to NF2 patients.

The INTUITT-NF2 trial will enroll patients with progressive tumours of any type - schwannoma, meningioma, or ependymoma - to allow for the simultaneous study of the various tumour types, rather than one tumour type alone.

This approach will accelerate the information gathering and results analysis processes.

The INTUITT-NF2 trial will expand the possibilities for NF2 care in multiple ways.

WHAT MAKES THIS TRIAL DIFFERENT?

In a traditional clinical trial, patients are enrolled to test one drug treatment that will measure response for one specific tumour type (even if patients have more than one type in their bodies, as is often the case for NF2 patients).

If that tumor type does not respond to the treatment, then the trial potentially fails, and patients wait as the development process has to restart again, perhaps with a different drug, or with a new process that looks at a different tumour type.

The "one tumour type, one drug at a time" approach slows down the development of treatments for NF2.

Leading the INTUITT-NF2 trial are Scott Plotkin, MD, PhD of Massachusetts General Hospital and Jaishri Blakely, MD, of Johns Hopkins University.

The goal of this new trial is to rapidly and efficiently screen multiple therapies simultaneously so as to enable faster approval studies that have the highest indication for success.

By contrast, the INTUITT-NF2 trial will enroll patients with schwannomas, meningiomas, and ependymomas. For a given drug, the study will determine whether any one (or more) tumour types respond better than the others.

This novel approach provides the opportunity to find active drugs for tumour types that have never been eligible for clinical trials previously.

In this model, a patient whose tumours grow on brigatinib could be eligible to receive treatment with another drug within a short period of time.

To find out more, head to www.ctf.org

PLASMA BIOBANK UPDATE

People with NF1 are at a risk of developing malignant peripheral nerve sheath tumours (MPNST); an aggressive form of cancer that often originates in plexiform neurofibromas.

With the support of funding partners like InsituGroup and the scientific expertise of doctors at the The Royal Children's Hospital, Melbourne campus, this project aims to proactively develop a biobank of plasma containing cell-free DNA - a process that has proven effective in detecting and tracking changes to a person's DNA over time.

Samples from patients with NF1 will be collected periodically in the hope of giving future researchers access to an established database from which to compare tissue samples in those patients who go onto develop a MPNST.

Whilst the project is currently still being reviewed by the Human Research Ethics Committee, it is hoped the biobank will become pivotal to the early detection of these aggressive malignancies without the need for more invasive discovery methods.

This is a joint funding initiative between the Children's Tumour Foundation and



Flicker of Hope, with funding from our partner going towards the cost of sample collection and storage.

Due to COVID-19, significant restrictions have been placed on clinic operations and research which has pushed back timelines, but we are hopefully that this project will get up and running in 2021.

If you would like to keep up to date on the progress of this project, please contact our support team on support@ctf.org.au



NF Connect is a virtual destination for people in the NF community to come together have a chat, check in and learn something new.

We've had some special guests make appearances over the past few months too, including:

- Sally Maspero; Clinical Nurse Co-ordinator at Westmead Children's Hospital
- Heather Rehtlane; body positivity and fitness influencer and
- CTF Ambassador and children's author Josh Langley, who shared his own story about anxiety and had us all singing, sharing our creativity and laughing (a lot) by the end of the session.

The sessions are normally quite informal and give everyone a chance to feel heard.

Make sure you register for any of our upcoming sessions!

UPCOMING DATES & SPEAKERS

TEENS & YOUNG ADULTS

- Mon 9 November at 8pm AEST
- Mon 7 December at 8pm AEST

ADULTS WITH NF

- Wed 11 November at 11.30am AEST with guest speakers, A/Prof Mimi Berman and Dr Rebecca Saunderson of RNSH
- Wed 9 December at 11.30am AEST

PARENTS/CARERS OF CHILDREN WITH NF

- Thu 12 November at 11.30am AEST
- Thu 10 December at 11.30am AEST

IT'S FREE AND A SAFE SPACE TO CONNECT AND SHARE YOUR EXPERIENCE

WWW.CTF.ORG.AU/NF-CONNECT



BREAST SCREENING STUDY FOR WOMEN WITH NF1

Women with NF1 have a higher risk of breast cancer at a younger age, than someone without NF1. Finding a breast cancer early increases treatment options and improves outcomes.

The CTF funds the Centre for Translational Excellence at Royal North Shore Hospital who have been working with the Cancer Institute to develop eviQ guidelines for NF1 that include MRI screenings from 35 years.

The team are nearing completion of a study examining effectiveness and accessibility of breast MRIs for young women with NF1. The data collected provides meaningful evidence regarding the feasibility and challenges of introducing screenings for young women with NF1 into an already established risk management clinic.

NEED HELP WITH YOUR NDIS APPLICATION?

Putting in an NDIS application can feel like a huge hurdle that just seems to high jump over, and if you've managed to take the leap and your application is rejected it can feel particularly devastating. However, if you feel that gaining access to funding and support for you or your child is something you would like to pursue then we encourage you to get in contact with us.

Over the past year, our Support Services Team have had great success helping families access NDIS funding; many of which have involved appealing rejected applications.

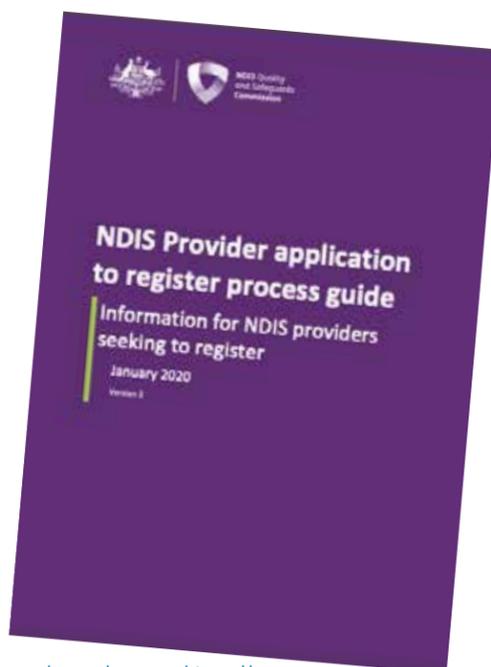
NF is a complicated condition and having a diagnosis does not automatically mean you will receive NDIS funding, but with a support letter written by the Children's Tumour Foundation, we know from experience that it can add weight to your application.

If you've been thinking about applying for NDIS, but it's felt too overwhelming, now is a good time to get started, and we are here to help guide you through the process.

- We can write a letter explaining NF in a way that is tailored specifically to the needs of the child/person who to receive the support. So it's not just a standard letter!
- We will highlight the particular needs of your child (or yourself) to support your application as every person's funding needs are different.

The CTF Support team are ready, willing and able to provide you with assistance. Simply send us an email at support@ctf.org.au and we can call you back at a time that is convenient for you to discuss the process.

We'd love to hear from you.



PEER LEADER PROGRAM UPDATE

Peer support can be an important part of the management of a chronic condition like NF. Anecdotal evidence shows the many benefits which have been supported by empirical research.

Peer Leaders have been trained in counselling skills that include active listening, verbal and non-verbal communication, confidentiality and problem solving.

The first group of CTF Peer Leaders have completed their training and are ready to take your calls.

“Peer support is not like clinical support, and it is more than just being friends. In peer support we understand each other because we've 'been there,' shared similar experiences and can model for each other a willingness to learn and grow...”

This allows us to try out new behaviours with one another and move beyond the 'illness culture', where we are defined as sick and disabled, into a culture of health and ability.”

(Mead and Copeland, 2004)

We have Peer Leaders who have a lived experience in NF1, NF2 and Schwannomatosis.

The CTF Peer Leader Program will benefit people by helping to:

- feel connected, understood & heard by someone who shares a similar experience
- reduce feelings of isolation
- deal with anxiety and stress around changes in health and help manage emotions such as loss and grief
- increase confidence, independence and self-management and assist in decision making through sharing ideas, information and tips
- improve advocacy skills & techniques to deal with health professionals
- improved self care and awareness

If you would like to speak to one of our Peer Leaders, please contact the Support Services Team on (02) 9713 6111 or email us at support@ctf.org.au

We are also taking nominations for the next round of Peer Leader training.

If you would like to nominate yourself (or someone else), please also contact us.

BECOME A REGULAR GIVER TODAY

Good things happen when we come together. Great things happen when we do it regularly.

With a regular donation, you'll help better the odds for children and adults with life-threatening tumours, by helping to fund ground-breaking trials and studies, life-changing support programs and enabling more opportunities to build connections.

A monthly donation of just \$25 = year round impact.



At the beginning of September, we kicked off our Wellbeing Webinar Series with guest speakers from Owen Hodge Lawyers talking about the importance of will and estate planning.

Our guest speakers included Ellen Pacelli; a NF Mum and solicitor with expertise in Estate Planning, Deceased Estate Administration, and Estate Litigation, and Dr Malcolm Stoddart; an experienced solicitor and academic with expertise across estate planning, special disability trusts and Supreme Court Equity matters.

Over the years, Ellen and her family have connected with the Children's Tumour Foundation, attending camps and community days. Remo is currently in a stable condition with NF1; however, like many others living with NF, Remo has had multiple surgeries and is continuously required to be monitored by various specialists.

Having a child with a genetic condition can be a stressful and painful journey; however, the unpredictability of NF has only served to reinforce the importance of the work she does in ensuring a person's wishes are honoured and loved ones cared for.



She wanted to take the opportunity to give back to the NF community by sharing her expertise in our first NF Wellbeing Webinar and donating her normal consult fee to the CTF during the month of September for anyone in the community wanting to find out more.

WATCH THE WEBINAR

NF WELLBEING WEBINARS

COMING UP NEXT

Dr Geoff McCowage Clinical Lead for the TiNT MEK Inhibitor trial

Wed 2 December 2020 at 12pm AEDT

FREE.

PERSONAL BLOG:

THE UNEXPECTED CHALLENGES OF COVID



Written by Kylie Webb, Living with NF2

Life as we know it has changed dramatically since March when COVID-19 reared it's ugly head. Gone is our freedom and for a lot of people, our sanity.

As we practice social distancing to prevent spreading of the virus, virtual catch ups with family and friends, virtual staff meetings and Telehealth appointments have become the new normal.

Hearing loss in the current climate has added a whole new dimension of difficulty to what is ordinarily hard enough.

With a lot of staff members from my department working remotely, IT platforms like Teams and Webex are replacing face-to-face staff meetings. Although there is the advantage of being able to see the speakers faces, often there is a delay which makes reading lips impossible and the subtitle function is not always accurate.

The amount of concentration it takes to follow what is being said and try to fill in the missing pieces is draining day-after-day.

The implementation of mandatory face masks posed an even greater challenge. The ability to lip-read is taken away, facial expressions are limited and the sound is distorted. Despite a common misconception, raising your voice does not make the sound any clearer!

Unlike needing a wheelchair for mobility or having a plaster cast for a broken arm, hearing loss is a hidden disability.

The pandemic has certainly highlighted this. For the first time in a long time I have experienced feelings of inadequacy, frustration and loneliness over the inability to communicate.

When I contacted my NDIS Local Area Coordinator (LAC) to see if I could use funds for a headset that would make the virtual calls easier he recommend I contact Job Access.

Job Access exists to remove barriers for employment for people with a disability. The best part was, unlike the NDIS the application and approval process was quick and pain free!

I completed the eligibility form, which included things like diagnosis/impairment, my employment details (including a contact person i.e. manager) and an explanation of the problems I was having. The very next day I had a call from an OT who requested some further information regarding my diagnosis (surprise, surprise she wasn't familiar with it!). The OT then contacted my employer to verify the information I had provided was correct.

Within a week I had a virtual assessment where I ran through the problems I was having with communication especially now I was working from home. Although all I was interested in was the headset, the OT spoke about a range of devices she thought would help with my job role.

I am so incredibly thankful for finding out about this service, for being approved and for how these items will improve my working life. If you are having any problems relating to your disability at your workplace I recommend you get in touch with Job Access.

GETTING NF AND THE CTF ON THE GOVERNMENT AGENDA

In spite of 2020 being a very strange and difficult year, it is ironic that in many ways the opposite has proved true for NF research and recognition.

In June, the Medical Research Futures Fund (MRFF) granted over \$760,000 towards the upcoming TiNT MEK Inhibitor clinical trial here in Australia and signalled to us that **brain and childhood cancers were on the Federal Government agenda.**

It was an opportune moment to dust off advocacy plans that have been on the backburner; awaiting a suitable time to pursue with increased rigour.

It must have been something our community sensed too, with a number of parents taking the initiative to send letters to officials at the very top of the government food chain.

For us, it started with a conversation with our local member, The Hon. Dr Fiona Martin; Federal Member for Reid in NSW.

The passion, dedication and enthusiasm of the team, coupled with MP Martin's familiarity with small community-focused charities resulted in an offer of endorsement be sent to the Minister of Health and Minister for Social Services which soon followed.



Following that discussion, another community member reached out with an offer for us join a meeting with The Hon. Dr Mike Freelander MP, Federal Member for MacArthur.

Dr Freelander went into politics following a career as a paediatrician with experience in diagnosing and managing NF. He provided valuable insight into who within parliament would be favourable to our cause and how to engage these individuals effectively.

Behind the scenes, our Support Lead Natalie began writing submissions for the Disability Royal Commission issues paper looking into Employment and the National Disability Strategy.

The document was submitted in August and gave voice to the concerns of the NF community, as shared with our Support Services Team over the years.

SUBMISSION TO THE DISABILITY ROYAL COMMISSION ISSUES PAPER: EMPLOYMENT

Government policy doesn't write itself, but rather, is formulated upon the views, opinions and needs of the community who provide feedback on the issues at hand.

For too long NF has not had a voice in the policy-making arena, but this has all changed!

Back in August, we submitted feedback regarding questions about employment to the Royal Commission into Violence, Abuse, Neglect and Exploitation of people with Disability.

Within this submission, we covered some of the challenges people with NF face when looking for, retaining and progressing within employment.

This submission also covered the challenges with transitioning between life-stages. In particular, it addressed the impact learning difficulties have on this, the lack of understanding around the need for job supports, as well as harassment and bullying due to physical appearance, amongst other things.

While there was not room to cover off all the issues faced by members of the NF community in employment in this forum, we hope it goes a little way to improving the services afforded people in future.

We hope that this is the first of many contributions to policy that the CTF makes on your behalf.

“Just as ripples spread out when a single pebble is dropped into water, the actions of individuals can have far-reaching effects.” - Dalai Lama

Across the other side of the country, ripples were being made by other members of the community.

Shelby, whose mum's story featured in the previous edition of the NF Quarterly, wrote letters to the Prime Minister and others prior to her life-threatening surgery back in May.

In August we shared the fantastic news that this letter had made it onto the Prime Minister's desk and had not fallen on deaf ears. It had also been passed along to the Minister for Health, The Hon. Greg Hunt MP, for review.

Having seen news of Shelby's letter on our social media, Melbourne Mum Shelly, reached out to Minister Hunt reminding them that it was not the first time NF had crossed his desk, with a request for a meeting.

Her son Alex's journey with NF and the NDIS had been mentioned in Parliament back in 2018.

Her request was granted, with time being made in October to discuss her concerns.

Two members of our Support Services Team were also invited to attend this meeting in support of Shelly and the broader NF community.

While we cannot disclose any outcomes from this meeting at this point, the conversation was very positive and we believe further interactions with the Minister and the Department of Health will be favourable.

The timing was fortuitous, as the whole team have been working hard to launch a new initiative in coming weeks which we hope will create a community ground-swell that cannot be easily ignored.

RUN WHEN YOU CAN, WALK IF YOU HAVE TO, CRAWL IF YOU MUST...JUST NEVER GIVE UP.

WRITE TO YOUR LOCAL MP

Your story matters.

You are in a unique position to be able to make a real impact simply by using your voices and your experiences to ensure people in the right places, with the right resources can take action.

In the coming weeks, we will launch a **“Write to Your Local MP”** campaign in conjunction with Giving Tuesday happening on Tuesday 1 December.

We are making it as simple as possible to ensure we have maximum impact. We will provide:

- Downloadable letter template that you can customise and send to your local MP or to key Federal Ministers
- List and contact details for key ministers in each state and territory, as well as links to your local electorates

OUR GOAL: To appear before Parliament by May 2021 in time for NF Awareness Month.

Will you help us get there?



Back in August, we worked with a beautiful woman to put NF in the spotlight and to recognise the importance of #diversity in beauty and #geneticdiversity.

We may not have been the first, but we certainly won't be the last to recreate the iconic magazine cover to help broaden the view of what beauty should look like and who should be represented.

This cover belongs to Janu. She recalls spending much of her life in the "shadows", never admitting to anyone the difficulties she faced from both a health and an emotional perspective.

Being from a close-knit Tamil community, her family and extended family felt that it was best to keep her diagnosis hidden and as result, she held onto her secret for more than two decades.

She started to develop external cutaneous neurofibromas as she reached puberty which only grew in number and size as she got older.

Noticeable and disfiguring, she often felt isolated and alone, unable to share with others why or even connect with those most likely to understand and empathise, the NF community.

The photo was taken in June last year. Moments afterwards she shaved her head, and raised \$16,000 for the Children's Tumour Foundation Australia. But more importantly, she chose that moment to share her experience of NF with her wider family, friends and colleagues in a positive way.

She was finally free to embrace and talk about every part of herself and feel proud. At no point did she ever expect to raise as much money as she did, but it was an important first step towards breaking down cultural and social behaviours that see a person's imperfections as something to be feared or avoided.

Her condition has become both unifying and empowering - and now she graces the front cover of our **own edition** of Vogue Australia.

She is also a NF Ambassador who wants to use her story to inspire others and help breakdown social barriers.



Janu is also the face of our new video series, NF in Focus: Conversations that Matters. You can follow her on [YouTube here](#).

Christmas Appeal

Parenting a child with Neurofibromatosis can be a stressful and painful journey. Maintaining hope for a better future for that child is critical and at the centre of that hope is research.

There is no doubt that life in 2020 has changed the world and us along with it, but as we head into the new year, it is reassuring to know something good is right around the corner.

The **TiNT MEK Inhibitor Clinical Trial** will commence at the beginning of 2021 with an expected two year roll-out period.

The Children's Tumour Foundation have a final commitment of \$50,000 to the project.

Not only do we want to be able to fulfil our financial commitment by the end of the year, but start to build a dedicated research fund for future studies and trials.

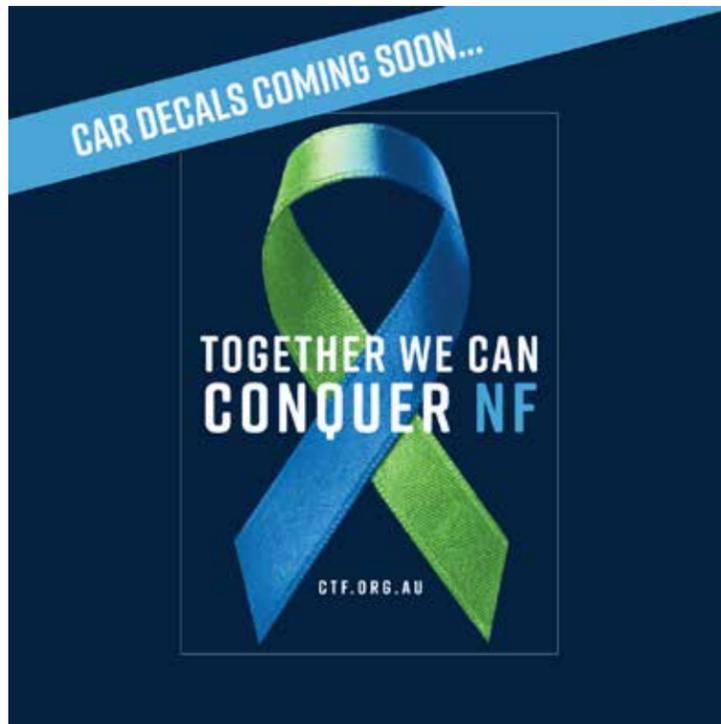
This Christmas, we need your help to wrap this clinical trial up in a big blue and green bow.

Every dollar raised, gifted or donated moves us another step closer to a more hopeful future for our NF Heroes.

Something Good

is right around the corner
this Christmas

www.ctf.org.au/donations



Thanks to our friends at Assta Label House, new car decals for your back window will be available for purchase through our store from mid-November!

When we relaunched the brand back in May, we had a number of people reach out asking for items like this to be made available for sale.

A simple way for the community to help raise the profile of NF to everyday Australians by placing them on the back windows of their cars.

We listened and the decals will be available for purchase for just \$5 by the end of November.

Dimensions: 13.5cm high x 9cm wide

[CLICK HERE TO PRE-ORDER](#)

UPCOMING ACTIVITIES IN 2020

NF Connect for Teens and Adults with NF

Location: Online via Zoom

Date: Mon 9 Nov 2020 at 8pm AEDT

NF Connect for Adults with NF

Location: Online via Zoom

Date: Wed 11 Nov 2020 at 11.30am AEDT

NF Connect for Adults with NF

Location: Online via Zoom

Date: Thu 12 Nov 2020 at 11.30am AEDT

NF Wellbeing Webinar

Topic: Everything you need to know about the TiNT Mek Inhibitor Clinical Trial

Guest Speaker: Dr Geoff McCowage

Date: Wed 2 Dec 2020 at 12pm AEDT

NF Connect for Teens and Adults with NF

Location: Online via Zoom

Date: Mon 9 Nov 2020 at 8pm AEDT

NF Connect for Adults with NF

Location: Online via Zoom

Date: Wed 11 Nov 2020 at 11.30am AEDT

NF Connect for Adults with NF

Location: Online via Zoom

Date: Thu 12 Nov 2020 at 11.30am AEDT

NF Quarterly is the official publication of the Children's Tumour Foundation. All issues are available on our website at www.ctf.org.au

Please direct any questions or feedback to info@ctf.org.au

The Children's Tumour Foundation (CTF) is the only support service for families living with Neurofibromatosis (NF) in Australia. NF is a life-long genetic condition with few treatment options and no cure.

Conquering NF is about more than just finding a cure. The NF journey from diagnosis through to treatment is challenging and most of what people will experience is unknown.

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

NF is unpredictable, progressive and there is no cure, but there is hope.

www.ctf.org.au for more information or follow up on social media (@ctfaustralia)



WELCOME SALLY

There is a fresh face on the team this month! Sally has joined us as our new Fundraising and Events Manager and will be taking on our major events, including Cupid's Undie Run.

We are so thrilled to be able introduce her to our community and with her help, continue to grow as an organisation.



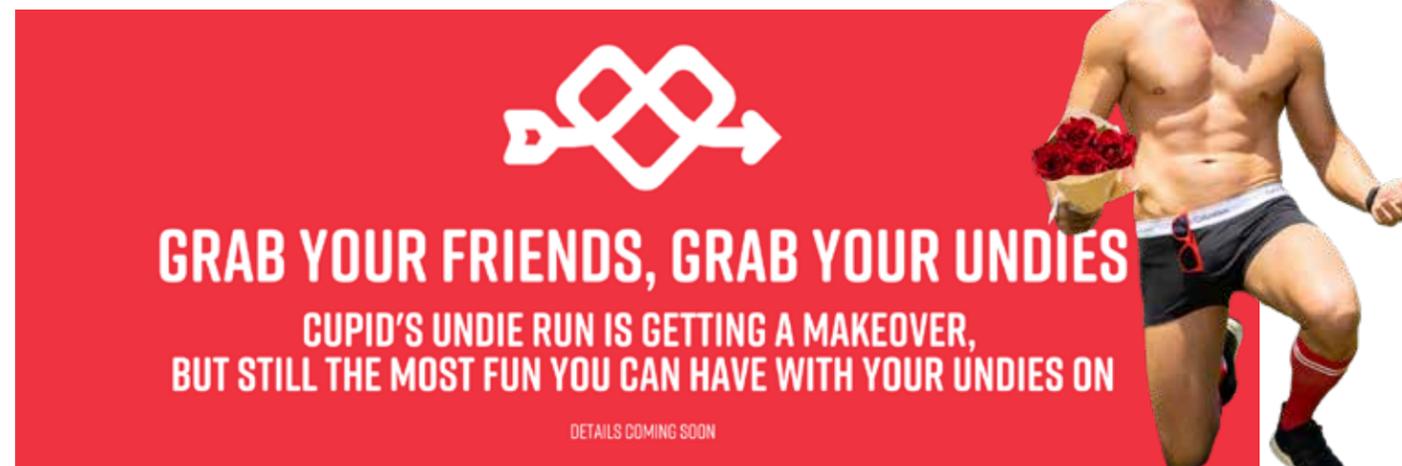
#UNSELFISHSELFIE

We all love a selfie, but what about an #unselfishselfie

As part of our Christmas Appeal this year, we will be running a social media campaign to encourage greater giving and to let more people know why investing in research for NF is so important.

Many people find reasons not to do things, but when the reason TO DO SOMETHING is staring you in the face, how could you say no?

These printable posters will be downloadable from our website from mid-November, so make you follow us at [@ctfaustralia](https://www.instagram.com/ctfaustralia) to get involved.





#CONQUERNF

WWW.CTF.ORG.AU