

THE CHILDREN'S TUMOUR FOUNDATION OF AUSTRALIA

# NF QUARTERLY

A NATIONAL CONVERSATION TO CONQUER NF

SUMMER EDITION: OCTOBER - DECEMBER 2020



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Read all about the progress being made to advance our cause with Government, stories of overcoming fears and how our community has continued to rally after such a difficult year!

[WWW.CTF.ORG.AU](http://WWW.CTF.ORG.AU)



Winston Churchill once said, *“to improve is to change; to be perfect is to change often”*.

There is no doubt that life in 2020 has changed the world and us along with it. But in many ways, it has accelerated improvements to services; making our world feel smaller, more intimate and more connected.

By the end of March, we were no longer able to offer camps, community days or even run fundraising events. Funds that had been designated for these activities needed to be repurposed, and as a result we have been able to connect with more people, more often, in more locations around Australia.

NF Connect was born out of COVID, community training programs were launched online, including a peer support service and a Tuning Into Kids (TiK) parenting program. Both of these programs were piloted this year for the first time, but reworked to run online. This allowed us to connect with people nationally, and not just in Sydney.

In spite of a global pandemic, some major in-roads were made in both Australia and the US that have left us feeling hopeful that NF research and investment into more effective treatments will continue to be prioritised as we head into the new year.

As we turn our faces to tomorrow, we are energised by the conversations we’ve had with key members of parliament during 2020, including the Hon. Greg Hunt MP (Federal Minister for Health), the local member for Reid, the Hon Dr Fiona Martin, as well as Dr Mike Freelander MP for Macarthur.

Our focus for 2021 will be progressing our work with all levels of government and we will need your help to create one very loud voice.

We are confident that with the continued support of the NF community, expertise of our board and passion and commitment of this small, but mighty team – we will start to see real change in the NF space.

While 2020 was a tough year for everyone, as an organisation our focus is on what lies ahead and creating better outcomes for everyone impacted by NF.

Renee Anschau

Head of Marketing and Fundraising



# MEET OUR 2020 WESTFIELD LOCAL HEROES!

Westfield Local Heroes is a recognition and awards program that connects and enriches communities. The program discovers and celebrates individuals who make a positive impact to their local community by awarding a \$10,000 grant for finalists' affiliated organisation to support their work and programs.

## CONGRATULATIONS TO DONNA ROBERTS (WA) and AMY O'ROURKE (QLD)

We are pleased to announce that we had three finalists and two winners this year from thousands of entries.

Each now carry the honour of being a Westfield Local Hero in their area and have helped the Children's Tumour Foundation Australia secure an additional \$20,000!

These funds will be directed towards two projects:

**A CAMP FOR FAMILIES IMPACTED BY NF** - the first to be run in Western Australia.

Most NF families are under stress and many also experience social disadvantage and isolation. These camps have a proven positive impact on the mental health of the entire family and we are delighted be able to bring this to WA in 2021.

**A NEW NF PATIENT REGISTRY** - to help identify both adults and children who would benefit from clinical and support services, as well as future research initiatives.

We aim to build a database containing relevant information that will assist research both nationally and internationally, as well as gain a better understanding of the impacts of NF on people in Australia.

A mammoth effort by all to reach this point, including our third short-listed nominee, Zoe who is without doubt an amazing Mum to NF Hero Emme, and a constant source of support and understanding to many in the community.

**Thank you to everyone who voted, shared or liked our posts, as well as those of our nominees. It takes a village and we certainly gave them that!**



# Christmas Appeal

RAISES \$50,000  
FOR NF RESEARCH

## WHAT A WAY TO END THE YEAR!

We knew we were setting ourselves an ambitious goal in asking our community to help us raise a final \$50,000 for the TiNT MEK Inhibitor Clinical Trial, but in the final hours of 2020 we managed to scrape through and even exceeded our goal!

We got into the festive season with a new donation page that enabled both donations and gifts to be purchased in honour of loved ones - with every donation represented by a beautiful bauble!

Thanks to your generosity and those of your friends and family, not only did our tree look gorgeous, we raised \$50,156!!!

For three days starting on Tuesday 1 December (Giving Tuesday) every dollar donated or gifted was TRIPLED thanks to our matched giving partners, J Farren Price Jewellers to the value of \$20,000.

Why? Because every 3 days a child is born with NF in Australia.

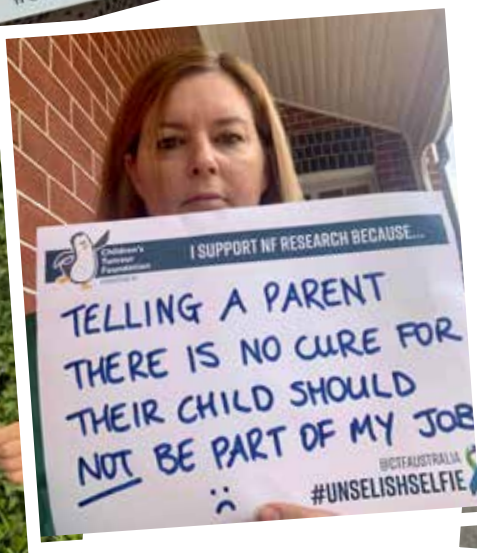
To grow our footprint and awareness, we asked every one who donated to share an **#UNSELFISHSELFIE** on their socials telling the world why they support NF Research.

Through the social campaign, we were able to reach many more people with personal accounts of why funding of this clinical trial and others just like it are so important.

Thank you to everyone who lent their voice to ours throughout December and contributed to this initiative. With this funding in place, we are looking forward to creating positive change in 2021.







I SUPPORT NF RESEARCH BECAUSE....



# WELLBEING WEBINAR: TRIALING TRAMETINIB FOR NF1 TUMOURS

Our final NF Wellness Webinar for the year focused on the promising MEK Inhibitors and Australasia's upcoming Trametinib in Neurofibromatosis Tumours (TiNT) trial which will commence early 2021.

The webinar was presented by Dr Geoff McCowage on Wed 2 December and was very well attended.

Dr Geoff McCowage is a senior paediatric oncologist at the Children's Hospital Westmead, is CEO of Australasian Children's Cancer Trials and is the lead clinician for the TiNT trial in Australia.

This was a unique opportunity for the community to hear directly from the person responsible for this trial and covered topics:

- What is a MEK inhibitor
- How do MEK inhibitors work in NF
- Prior research into MEK Inhibitors
- Timing and eligibility criteria.



You can watch the webinar anytime on our YouTube page or via our website.

**CLICK HERE TO VIEW**

## UNDERSTANDING HOW MEK INHIBITORS WORK

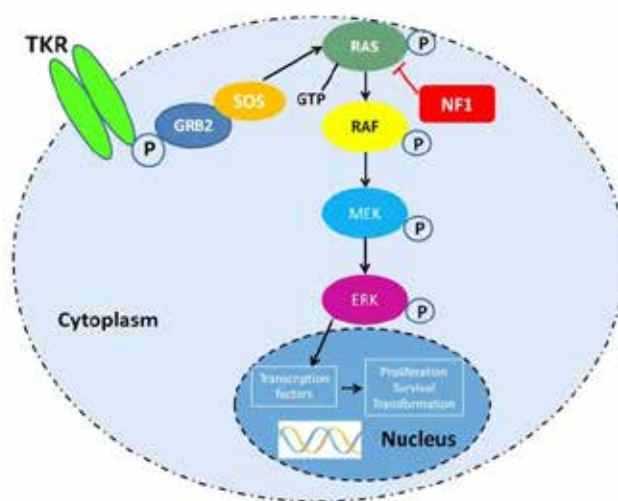
The protein produced by the NF1 gene exists on a RAS biochemical pathway and is designed to prevent tumours from growing by working as an "off switch".

For those diagnosed with NF1, that off switch is broken, resulting in tumour growth.

MEK1 and MEK2 are products created by this same pathway. Therefore, by stopping the MEK proteins it might affect how the NF1 gene does its job (by using a MEK inhibitor).

The use of these drugs has been proven to be useful in the treatment of melanoma, therefore it was predicted that they could also have a positive effect on tumour development in NF1.

**The clinical trial is planned to commence in early 2021.**



# TRIAL UPDATE: TINT MEK INHIBITOR CLINICAL TRIAL

The Children's Tumour Foundation has been advocating and raising funds to support the trial since 2019 and with the help of additional funding from the Federal Government in June 2020, it is now within reach.

**Main Study Aim:** To investigate the effectiveness of Trametinib for the treatment of plexiform neurofibromas and optic pathway gliomas in NF1 patients, while also monitoring the improvement in pain, brain and body function, as well as social development.

## ELIGIBILITY CRITERIA

Enrolments are expected to begin as early as January 2021 for up to 60 patients from hospitals around Australia and New Zealand and will occur directly through existing patient lists. To be eligible for the trial, a patient will need:

- to be aged between 3 months and 25 years when they start the trial;
- to have NF1;
- to have an optic pathway glioma where the tumour has continued to grow or the vision tests have deteriorated after treatment such as chemotherapy; or
- to have a plexiform neurofibroma which is causing significant problems and where surgery is not an option. This could include symptoms like nerve pain, cosmetic issues, nerve or spinal compression and other problems.

## HOSPITALS INVOLVED IN THE STUDY



### Australia

- Sydney Children's Hospital, Randwick
- Sydney Children's Hospital, Westmead
- The Royal Children's Hospital, Melbourne
- Monash Children's Hospital, Melbourne
- Queensland Children's Hospital, Brisbane
- Women's and Children's Hospital, Adelaide
- Perth Children's Hospital
- John Hunter Children's Hospital, Newcastle
- Royal Hobart Hospital



### New Zealand

- Starship Children's Hospital, Auckland
- Christchurch Children's Hospital

[CLICK HERE FOR MORE INFORMATION](#)

2020 provided more recognition for NF than ever before in both Australia and the US. With Selumetinib now on the market for treatment of NF1 in the USA, we reached out to pharmaceutical company AstraZeneca at the end of the year to discuss access to these trial medications here in Australia.

We hope that by engaging with AstraZeneca now we can ensure the Australian community is kept up-to-date on progress regarding access and to ensure that the consumer voice is taken into account throughout the lengthy regulatory process.

We have also reached out to Roche with regards to equity of access to Avastin for treatment of NF2, and hope to engage further with other pharmaceutical companies across the year.

These discussions will continue throughout 2021, and we will provide updates as and when they are available.

# FEATURE STORY: **THE POWER TO MOVE MOUNTAINS**

It was suspected that Alex had NF1 as early as 6-months of age following the appearance of multiple cafe-au-lait spots, amongst a number of other indicators.

Since then, Alex has only ever known a life of appointments, surgeries and disruption.

Despite these set backs, he is a bright, affectionate and resilient 8-year old boy and his mother is on a mission to draw attention to this complex and often misunderstood genetic condition.

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

Alex's family are Melbourne natives, but just as investigations into his health began, the family was preparing to relocate to rural New South Wales for work.

The management and treatment of NF requires a highly specialised and skilled medical team who understand the many complexities of the condition, so this meant establishing a new team within a different health system.

Alex was referred to the Sydney's Children's Hospital at Westmead and spent his first birthday in the company of the Clinical Genetic Service who offered the family genetic counselling and testing.

Alongside Mum Shelly, Alex was making regular flights to Sydney for appointments that the rural hospital did not have the resources or expertise to support.

In between one of these visits, Alex was hospitalised for a severe respiratory infection that was not improving.

So, within nine months of re-locating, the family returned to Melbourne.





## ALEX'S SEVERE RESPIRATORY INFECTIONS WERE CAUSED BY AN UNDERLYING HEART DEFECT.

They recognised how important it would be for Alex to be close to a hospital with the network of specialists and resources he would need in his lifetime.



The cause of Alex's respiratory infections became clear only upon his return to Melbourne. He had an underlying heart defect; a condition picked up while still in utero, but dismissed by cardiologists at the time.

He was now suddenly fighting for his life and undergoing emergency heart surgery.

While in hospital, Alex's medical team noted other issues related to his NF that would come to require ongoing intervention.

At 18 months, Alex was still non-verbal and had not yet started walking. He was diagnosed with a global developmental delay and in the years to come, would add Autism and ADHD to his growing list of labels.

Over 20% of children with NF1 are diagnosed with Autism or ADHD and require early intervention to support their learning and socialisation.

Alex has attended weekly therapy sessions with an occupational therapist and speech pathologist, as well as regular reviews with a physiotherapist since he was 18 months. However, with the sudden appearance of a number of café-au-lait marks,

Alex was born with several unique body characteristics that didn't suggest anything sinister when considered in isolation, but with the sudden appearance of several café-au-lait marks, collectively, all signs led to an ultimate diagnosis of NF.

This rigorous program put him in the best possible position to start school in 2018 and continues to assist him to integrate into everyday life. But not all families can afford the extensive outlay of costs associated with this type of treatment.

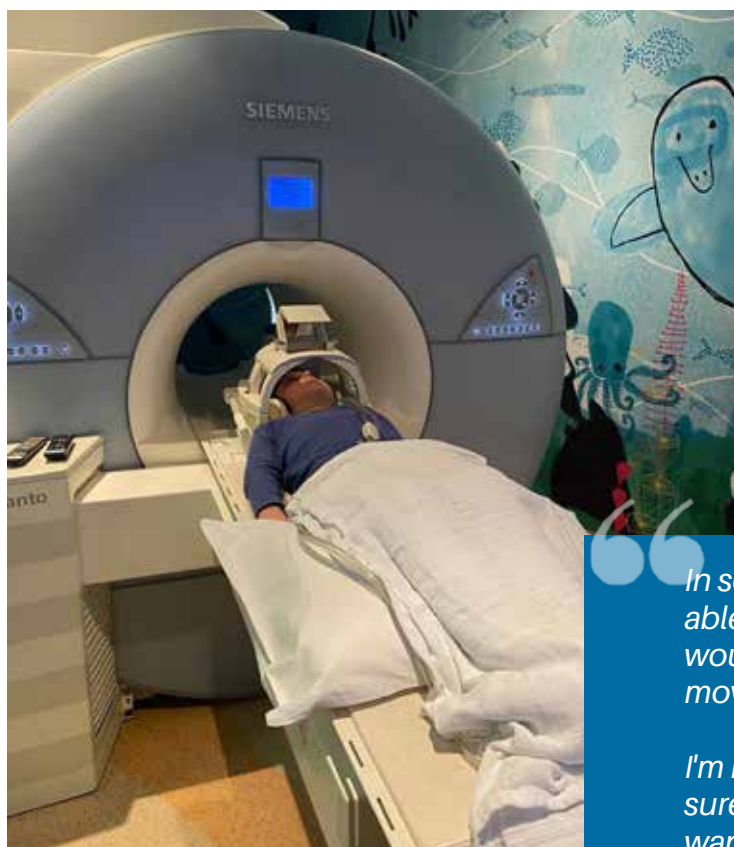
Alex was fortunate to be approved for the NDIS to assist with the costs, although they still have large gaps to cover for all of Alex's allied health and medical needs.

Shelly is a staunch advocate for all families with NF in Australia and is lobbying government for nationwide support. She describes her family as being “extremely lucky” as she has access to NDIS and lives in a city with a specialised NF Clinic funded by the Children’s Tumour Foundation.

Not all families have this opportunity,

*“Before the NDIS, I found it frustrating that all the literature said early intervention is key to allow children with NF to integrate into mainstream society. But if I can’t pay for it, how am I supposed to do it? It was a frustrating battle,” Shelly said.*

## NF IS COMPLEX. HAVING A SERVICE THAT BRINGS ALL OF THOSE SPECIALITIES TOGETHER IN ONE PLACE IS CRITICAL.



NF is often described as a “tick-ing time bomb”. There is no way to predict when, where or how severely a tumour will impact function and so families live in constant fear of what they cannot see.

Something we are all a little more familiar with these days.

Shelly said that there were a lot of unknowns with NF and she often wonders how Alex will fare as an adult.

*“In some areas he’s so highly intelligent, but he’s not able to articulate himself, and I wonder how that would translate when he’s an adult and wants to move out of home.*

*I’m not going to be around forever so I want to make sure he’s looked after. He’s a beautiful kid and I just want the best for him.”*

Alex is scheduled for a gastroscopy procedure later this year, as well as surgery in early 2021 to remove his tonsils and adenoids to help with his sleep apnea. Both of which are a likely complication of his NF. But overall he is doing well.

If you asked Alex his name, he more than likely would reply:

**“MY NAME IS ALEXANDER JAMES NEAMONTIS, THE GREAT.”**

**Alex IS great. Alex is a NF Hero.**



# MEETING WITH MINISTER FOR HEALTH, THE HON. GREG HUNT

In early October, members of the CTF Support Team had the privilege of meeting with the Federal Health Minister, Greg Hunt and his senior Medical and Research Advisor, Kylie Wright.

This meeting was orchestrated by one of our fabulous community members, Shelly Lynde (Mum to NF Hero Alex featured in this report) following direct correspondence with the Minister's Office earlier in the year.

We sent Minister Hunt three documents prior to the meeting as a way of introduction to NF and the people it affects, including a fact sheet and two stories.



We had the Minister's undivided attention for nearly an hour (during a pandemic!!) and were able to share knowledge of Neurofibromatosis, what we do at the Children's Tumour Foundation (CTF), the importance of changing how NF families access NDIS funding and the need for greater research to be investigated here in Australia.

He was very receptive and asked many questions, which we took as a positive sign of his interest in support the NF community more into the future.

Following this meeting and at his suggestion, the CTF have tendered a proposal and we are eagerly awaiting the outcome of our submission.

Whilst we are not yet at liberty to discuss the details of the conversations, we are confident that the Minister has a new understanding of the impacts of NF, the critical need for local research and the difficulties experienced when trying to access the NDIS and navigate the complexities of the health system.

We are indebted to Shelly for her tenacity, generosity and willingness to share the spotlight with us.

## WHAT'S NEXT?

We recognise that we need to continue the fight on both sides of the aisle and will need to collective support of the wider NF community to be heard.

In the coming months, we will soon be requesting your assistance in raising awareness amongst other politicians by sharing your stories.

Every experience of NF is different, so it will be important to demonstrate how broad the need is and where the most effort should be made.

Stay tuned to our social media pages or sign up to our e-newsletter for any updates as they come to hand.

[CLICK HERE TO SIGN UP](#)

Virtual  
 CUPID'S UNDIE RUN

# TAKE THE CUPID'S UNDIE RUN 2021 CHALLENGE



WALK



RUN



CYCLE



DO IT YOUR WAY

Cupid's Undie Run is going virtual! Help us raise money for the Children's Tumour Foundation and those living with Neurofibromatosis by taking the Cupid's Undie Run 2021 Challenge. February 14 – 28.

**FEBRUARY 2021 / ENTRY IS FREE**

Register and buy merchandise at [cupidsundierun.com.au](https://cupidsundierun.com.au)

PROUDLY  
SUPPORTED BY

 **morgans**

  
The  
Athlete's  
Foot



**Harvey Norman**



# MAKE A DATE FOR FEBRUARY 14

Virtual  
CUPID'S UNDIE RUN

The countdown is officially on for Cupid's Undie Run, the cheeky fun run that raises funds to support adults, children, and their families impacted by Neurofibromatosis (NF).

## IT'S ALL ABOUT CELEBRATING DIFFERENCE

This Valentine's Day, we're daring Aussies around the country to show a little flesh – in the name of charity – **by recreating our iconic undie run at home!!**

Whether you do it running in a tutu, walking the dog in your Wonder Woman outfit, or prefer to ride a bike with your undies over your cycling shorts, this is your chance to help **make a date for a cure**, while supporting the 1 in 2,500 Aussies who suffer from NF.



## TAKE A PEEK AT SOME OF THE CHALLENGES!



### I TAKE MY PANTS OFF FOR CHARITY

Grab your friends, grab your undies and recreate your own undie run! Share online and win!



### "MUM! WHERE ARE MY UNDIES? CHALLENGE



### PUT YOUR BIG BOY/GIRL PANTS ON CHALLENGE



### SUPREMES: "STOP IN THE NAME OF LOVE"



### CUPID'S "EMBRACE" CHALLENGE

Share why you "embrace" your body and tag us in celebration of our newest ambassador, Taryn Brumfit and in recognition of the @bodyimagemovement that unites us!



### CUPID'S COCKTAIL CHALLENGE



### BEST FUNDRAISING PITCH CHALLENGE



### CUPID'S "GET FIT" CHALLENGE



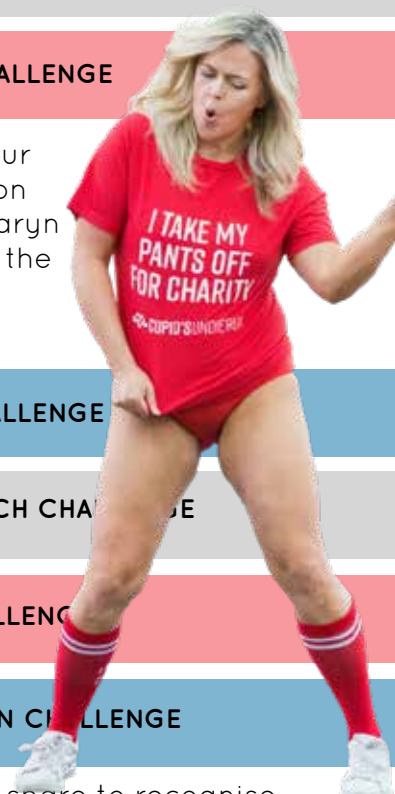
### "I SEE YOU NF2" AUSLAN CHALLENGE

Learn a phrase in Auslan and share to recognise those with NF2 and hearing loss.

"I see you, NF2"

**THEN JOIN OUR VIRTUAL SUNDAY SESSION ON SUN 28 FEBRUARY, HOSTED BY THE ONE AND ONLY RICHARD REID!**

**WHAT BETTER WAY TO CELEBRATE?**



# TUNING INTO KIDS

There is no right way to parent and no right way to cope with emotions, but what we do know at the CTF is that we love talking about both of those things, which is why we decided to trial a six-week parenting course called Tuning in to Kids (TiK).

TiK is an evidence-based, emotion focussed parenting program aimed at providing parents and carers with skills in emotion coaching. This includes:

- Recognising and understanding your own and your child's emotions
- Coping with and managing your own feelings, so you feel more in control of whatever challenges come your way
- Developing the skills and language that can support your child's emotional development.

**All of which is particularly relevant when dealing with an NF diagnosis.**

For six weeks, the parents who registered spent a couple of hours a week sharing experiences, learning and listening and hopefully picking up some tips and tools along the way.



There were also plenty of tears and laughter and thanks to all attendees who were patient when technical hitches happened, as it was our first remote learning experience.



**Listening and sharing with the group about real life situations we have felt difficult to solve and how we handled it."**

If you missed this session, our support team is always available to discuss parenting or emotional challenges, so please get in touch if you ever feel like talking, or send us an email at

**support@ctf.org.au.**

We have resources and links that might be able to help you, along with other parents facing similar challenge whom we can connect you in with.



**I found hearing what others are dealing with and how the program helped them useful. Also, learning to understand what my child is expressing when he is emotional, not just thinking that he is being naughty."**



**I feel that by applying emotional coaching theory I can solve issues quicker without it turning into a screaming match."**

Thanks to Resourcing Parents for giving us the opportunity to run this course.







NF Connect was born out of COVID-19, a solution that would enable community to stay connected even while apart.

Connecting people with information and with each other is a vital part of our mission, so when our ability to host live events was no longer possible, we developed a new approach that would help meet this need in a different way.

With the support of the QBE Foundation we set up monthly Zoom chats for teens, young adults and adults living with NF, as well as parents and carers of children with NF.

Each group has its own unique dynamic, which can change from month-to-month depending on who is attending.

The sessions ranged in size, with some becoming quite large, while others were a bit more intimate. But like most things, it is not the size that counts, but the quality of the conversation.

“The NF connect session I was a part of made me realise that I’m not alone in anything I go through. There are other teens and young adults who are riding the same rollercoaster.

Having access to NF connect sessions makes you feel like you are a part of a movement and a family.

It is something that makes you feel at home”

**Jasmine Le Tisser, 2020 NF Connect participant**

As tired as we all are of Zoom, the benefits of this way of working and connecting has often outweighed the downsides.

## UPCOMING DATES IN 2021

### TEENS & YOUNG ADULTS

- Mon 8 February at 8pm AEDT
- Mon 8 March at 8pm AEDT
- Mon 19 April at 8pm AEDT

### ADULTS WITH NF

- Wed 10 February at 11.30am AEDT
- Wed 10 March at 11.30am AEDT
- Wed 21 April at 11.30am AEDT

### PARENTS/CARERS OF CHILDREN WITH NF

- Thu 11 February at 11.30am AEDT
- Thu 11 March at 11.30am AEDT
- Thu 22 April at 11.30am AEDT

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

[WWW.CTF.ORG.AU/NF-CONNECT](http://WWW.CTF.ORG.AU/NF-CONNECT)

We’ve connected with people throughout the year that have not been able to attend events hosted by the CTF before and we’ve seen friendships grow within the groups that never would have happened unless we had connected virtually.

We don’t record the sessions as they are designed to be a private, safe space where people can come along and share feelings, some laughs, or to talk about the impact that NF is having on their life.

### Why join in 2021?

At times it can be hard to find people who understand NF.

Family and friends are often a great support, but being in a space where you don’t have to explain NF and you know that everyone gets it, is also very powerful.

# NEW RESOURCES

With students across the country returning to school, we have been working hard (with the help of a small team of Genetic Counselling students from Melbourne University) to create and update a range of new teacher toolkits.

Each document is designed to educate and inform school teachers about the impact of NF1 and NF2 on a young person's learning and development, while also providing strategies to help support them while in the classroom.

Living with a genetic condition comes with a unique set of challenges, but we believe that educators can have a hugely positive impact on their life.

If you are interested in any of the following documents, you can request a copy from our Support Services team.

- NF1 Toolkit for Teachers
- NF2 Toolkit for Teachers
- Addressing Attention Difficulties in students



If you need more detailed resources, these can be discussed with a Support Coordinator and tailored to your specific needs.

**Email:** [support@ctf.org.au](mailto:support@ctf.org.au)

**Phone:** 02 9713 6111

Or visit the [RESOURCES](#) section of our website

## New information sheets on

- Gamma Knife Surgery (NF2)
  - Itch in Neurofibromatosis (NF1)
- are also available on our website.



# MEET SOME OF OUR FUNDRAISING HEROES!

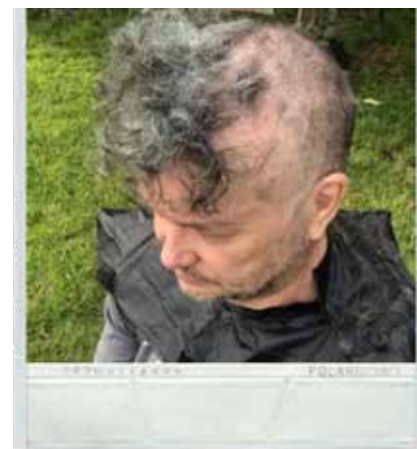
Do you have fundraising idea?

You don't need to wait for one of our awesome campaigns to fundraise – you can rally your friends, family and local community to be part of the movement any time of the year!

Whether you're a social butterfly or a bit of an introvert, our fundraising kit and resources give you the opportunity to raise funds your way.

- Be Bold. Be Brave. Go Bald.
- Donate Your Birthday
- Organise a Trivia Night

**DOWNLOAD YOUR  
A-Z FUNDRAISING GUIDE**



There have been some great fundraising initiatives happening over the past few months, including one from this committed Dad.

Andrew's daughter, Mykaela was diagnosed with NF1 as a child and now at age 18 will be undergoing surgery to remove a tumour from her scalp that has become problematic.

To support his daughter, who will need to shave her head for the surgery, Andrew will be dying his beautiful "iso" hair-do blue and green for a week, before shaving it all off in support of Mykaela.

Andrew's daughter Mykaela will be heading into surgery soon to have a tumour removed from her scalp and will be next to lose her hair, but in the meantime, this amazing Dad has helped raise more than \$5.600 by shaving his "iso" hair-do.



Every year, NF2 Hero Kylie gets crafty making these fabulous Penguin-themed cards and tags to sell at Christmas time and throughout the year.

She donates 100% of the profits to the Children's Tumour Foundation!

Such a selfless gesture and creative way to give back!

## PERSONAL BLOG:

# TRANSITION FROM PAEDIATRIC TO ADULT CARE



*Written by Jasmine Le Tisser, Living with NF1*

My name is Jasmine, I am 20 years old and I have NF1.

It has been three years since I transitioned from paediatric care into the adult system. Looking back on the experience, I recall feeling incredibly uneasy and even a little scared about the process, but that is because we fear what we do not know.

What I do know is that nerves are normal, feeling anxious is normal and being worried about being able to build a rapport with your new team of specialists is normal.

We wouldn't be human without these fears and it doesn't mean connections between specialists can't be reformed with new people. I spent seven years of the most intense part of my NF1 journey at the Royal Children's Hospital, Melbourne (RCH).

I underwent a year of chemotherapy (once every 28 days) for an optic pathway glioma and developed a benign polycystic astrocytoma in my parietal lobe, before having my first brain surgery to remove the tumour at age 15.

Over the years, I saw an extensive range of specialists from all different departments at the RCH, including neurologists, oncologists and paediatricians.

I saw an epileptologist, neurosurgeon and orthopaedic specialist, as well as my neurofibromatosis specialist. I grew quite attached to this talented team of people whose job it was to ensure my health and wellbeing was met from every angle.

So naturally, it was hard to let go.

I also had the support of a NF Clinical Co-ordinator named Natalie from the Children's Tumour Foundation.

She made sure my family and I were comforted and always knew what was happening.

To this day my Mum still has Natalie's contact card in her wallet, the little NF penguin cheekily poking out.

I believe that good things come from breaking out of our comfort zones. So, when it was time to fly the coop and start a new chapter of my NF journey in a brand new hospital, with brand new specialists, I used this to help me stay focussed and calm...well, as much as I could.

I remember attending my first appointment at the adult hospital. As I clicked the lift button and entered the first floor, I had to swallow the little lump of fear that bubbled up in my throat.

My nerves simmered beneath the surface but having my Mum by my side kept them in check as we walked into the waiting room.

Without support from my paediatric transition nurse, my childhood paediatrician, as well as family and friends, transitioning hospitals would have felt like an impossible and daunting task, but it wasn't.





I walked into my first appointment with a USB stick and a DVD with back up MRI'S, that I was kindly given by Natalie and my team of specialists. This had all my scans, X-RAYS, MRI's and doctors notes from my time in the children's hospital.

This little stick and DVD were something that helped me know my new specialist would have all the information my paediatrician knew from all my years in his care.

"Jasmine," my name was called.

I glanced at my Mum and she nodded her head with a smile. She walked beside me into the doctor's office; coming to sit in on my first adult care appointment for my NF.

This is something I recommend. It made me feel safe knowing that someone was with me, listening, absorbing the information I was hearing.

I handed my digital files over, spoke about my history and felt comfort in the process. I left the appointment feeling like a weight had been lifted off my shoulders.

Looking back at the Jasmine who walked into that hospital earlier that day, compared to the Jasmine who walked out, made me giggle at her nerves.

Little did she know it was all going to be fine.

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If I could have made my transition different, I would have visited the hospital before my first appointment to get a sense of the environment; giving myself a little more time to adjust to what my new normal would be.

Sometimes the scariest thing is the unknown, so if you can tick one thing off that list, then it can help reduce some of those nerves.

As a young adult who is three years into the adult care health system, my other piece of advice would be **to never be afraid to ask questions.**

No question is ever a silly question and don't hesitate to speak up.

Something that my new NF Specialist, Professor Kate Drummond reiterated when I approached her with a handful of questions about her experience supporting other young adults' transition into her care.

She recognises that the process may feel "confusing and frightening" and wanted to offer some of her own advice.

- Young people should exercise both their rights and responsibilities when moving to adult care
- Prepare themselves in ways that may make them feel more comfortable.

This might be physical tasks like chasing up MRI's, sourcing strong communication between you and your teams, and use your right to the information and care you need.

“Keeping educated about your condition and health is always a good idea, as is keeping everything in one spot. It not only benefits you, but your team too,” Prof. Drummond explained.

“Those who are struggling a bit, there is a care coordinator, neuropsychologist and a psychiatrist who can help out, as well as a social worker, the genetic clinic and more. There is always support,” she said.

**There is always support.**



**GET YOUR CAR STICKER  
FOR JUST \$5!!**

Thanks to our friends at Assta Label House, new car decals for your back window are now available for purchase through our store.

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 to help raise the profile of NF to a much broader audience is by placing a sticker on the back window of your car.

The decals are an easy, yet effective way to create awareness and they are only \$5 per sticker.

**Dimensions:** 13.5cm high x 9cm wide

[CLICK HERE TO ORDER](#)

The affable Josh Langely joined us on Christmas morning for a very special reading of *"There is a Monstor Under My Christmas Tree Who Farts"*.

Josh is a much loved Ambassador for the Children's Tumour Foundation and an acclaimed children's book author in his own right.

He brings such joy to everything he does and is as committed as we are to ensuring young people feel connected, understood and loved.

His message - "YOU ARE IMPORTANT TO THE WORLD!"



**BECOME A  
REGULAR GIVER TODAY**

[SIGN UP HERE](#)

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

With a regular donation, you can help create better outcomes for children and adults with life-threatening tumours. You will be helping to fund ground-breaking trials and studies, create support programs and providing opportunities to build connection.





## 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

### **Cupid's Undie Run 2021 Challenge**

**Location:** Virtual Event

**Date:** 14-28 February

### **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

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**NF Quarterly** is the official publication of the Children's Tumour Foundation. All issues are available on our website at [www.ctf.org.au](http://www.ctf.org.au)

Please direct any questions or feedback to [info@ctf.org.au](mailto: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](http://www.ctf.org.au) for more information or follow us on social media (@ctfaustralia)



# GRAB YOUR FRIENDS, GRAB YOUR UNDIES

## CUPID'S UNDIE RUN IS GETTING A MAKEOVER, BUT STILL THE MOST FUN YOU CAN HAVE WITH YOUR UNDIES ON

DETAILS COMING SOON





**#CONQUERNF**

**WWW.CTF.ORG.AU**