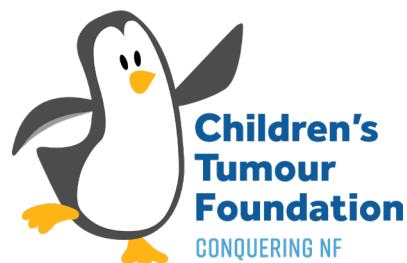


THE CHILDREN'S TUMOUR FOUNDATION OF AUSTRALIA

NF QUARTERLY

A NATIONAL CONVERSATION TO CONQUER NF

APRIL-JUNE 2020



FEATURE STORY: IN HER WORDS

A heartbreaking account of life in the shadow of NF from a Mum who has two children facing an uncertain future. Read more on pg 7



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@CTFAUSTRALIA

WHAT'S INSIDE:

WE CHANGED OUR COLOURS!

NF Awareness Month felt like the perfect opportunity to reveal our new branding and align ourselves with the international NF community.

AUSTRALIAN GOVERNMENT FUND NF RESEARCH

In June, we announced that the TiNT MEK Inhibitor clinical trial received Federal funding. This is the first ever Neurofibromatosis research partially funded by the Australian Government and is huge news for the NF community.

NF-CONNECT VIRTUAL CALLS LAUNCHED

Staying connected even though we're apart. This is what NF Connect is all about, bringing our NF Community together during a time where feelings of isolation and loneliness may be exacerbated.

FIRST EVER PEER LEADER TRAINING KICKS OFF

In June we launched the first phase of our pilot Peer Leader Program. This exciting initiative is designed to ensure those impacted by NF can connect with peer leaders who have a lived experience of the condition.

BRAND NEW WEBSITE LAUNCHED

You'll find a heap of new information about NF, useful information for every stage of life, and resources for everybody from families to school and health care professionals.

Q&A WITH THE AUTHOR OF THE NF HERO BOOK

We sat down with Lana Melbourne to understand how this book has changed not only her son Fraser's life, but the lives of NF Heroes across Australia.

THE NF HERO CHALLENGE IS COMING UP IN SEPTEMBER! LET'S SHOW 2020 WHO'S BOSS!



NF Quarterly is the official publication of the Children's Tumour Foundation of Australia (CTF).

All issues will be released at the beginning of every quarter and reflect on all that we have achieved in the previous three months at the CTF.

From upcoming events to NF research news, each issue is designed to keep you iNFormed on all NF-related news.

NF Quarterly will highlight the progress being made with respect to patient support, awareness and the accomplishments of a dedicated and deserving NF community.

We welcome your feedback and hope you find the information relevant, engaging and inspiring.

WE CHANGED OUR COLOURS!

WHY BLUE AND GREEN...AND WHAT HAPPENED TO YELLOW?

WNF has the power to change the way people look and potentially see themselves. But beneath the surface we know you are still you - capable, strong and determined to live your best life. As an organisation, we see ourselves the same way - this time we are now dressed in blue and green, the international colours of NF.

IT'S COMPLICATED

NF is a complicated condition, so of course it is not going to be represented by one single colour. The unofficial, but now very accepted colours for Neurofibromatosis are blue and green, so by aligning with our international counterparts, we help ensure greater consistency and therefore recognition the world over.

IT'S CONSIDERED

We exist to support the NF community. That means understanding their challenges and responding appropriately to address them. Many people with NF experience problems with their vision. Yellow, whilst bright and hopeful, is also a difficult colour to read and presented challenges for this audience.

IT'S NOT REALLY GONE

It's important that we evolve as a brand to remain relevant and fresh, but that does not mean doing away with everything that has made us, us - including that iconic yellow. The colour will still remain part of our palette as an accent colour to be used as required and of course, on the feet and beak of our Penguin!

IT'S COMMUNITY IN ACTION

We did not act alone. Members of the NF community were consulted during the review process to ensure that the views of those we serve were also represented and we are very grateful for their input and advice.

WHAT DO OUR NEW COLOURS SAY ABOUT US?

Blue is a stabilising colour that creates a sense of calm. It is the dominant colour in our palette with both a dark and light variation to represent our strength and reliability, while also giving us a friendly, open feel.

Green has always represented new beginnings and growth - something we want to use to move the organisation forward in a positive and uplifting way.

Yellow is associated with happiness, sunshine and hope - certainly something we aspire to achieve for our wonderful community.



*A huge thank you must be given to the wonderful team at **Elevencom** who gave their time and talents freely to ensure that our brand maintains a strong, professional edge whilst being sensitive to the heritage of the organisation.*

MUCH AWAITED BOOST TO NF RESEARCH ANNOUNCED IN JUNE

It is often said that in the middle of chaos lies opportunity. We would like to think that is true. In the chaos of a global pandemic, the Morrison Government announced the first ever funding of NF Research in Australia.

On June 7, 2020 the Federal Government granted \$13.6 million to support ten clinical trials as part of the Medical Research Future Fund (MRFF) to find innovative cancer treatments for melanoma, reproductive and gynaecological cancers and childhood brain cancer.

The TiNT Mek Inhibitor Clinical Trial was one of these initiatives, receiving just over \$760,000.

Along with our own supporting contribution of funds generated as part of the 2019 tax appeal, as well as those provided by Flicker of Hope, the MRFF grant ensures full funding of the trial is now within reach!

The trial will involve 60 patients from Australia and New Zealand and will investigate the effectiveness of Trametinib for the treatment of plexiform neurofibromas and optic pathway gliomas.

In addition to monitoring the expected reduction in tumour size, it will also monitor the improvement in pain, function and quality of life as well as brain function and social development.

The trial will take place over five years with an expanded age range of children/young adults between the ages of 3 months and 25 years. It will also consider the impact of the drug on learning and behaviour over time.

The trial has been approved by the ethics committee and major hospitals across Australia are now undertaking site approvals to meet governance standards.

We will continue to keep the community updated on developments about recruitment to the trial.

We would like to sincerely thank the 300+ individuals and companies who contributed to the funding of this trial over the past 12 months.

IMPACT OF US RESEARCH, EVERYWHERE

There have been some positive developments in the NF research space in recent months, led by the Children's Tumor Foundation in the US.

In April, the US Food and Drug Administration (FDA) announced the first ever approved treatment for NF1 (MEK inhibitor called Selumetinib) in patients with inoperable plexiform neurofibromas.

In May, the US CTF also announced a promising potential drug therapy for treatment of NF2; a clinical trial that has been approved as part of the Synodos NF2 Accelerator program - INTUITT-NF2. The trial will allow for the simultaneous study of the various tumour types, rather than waiting for studies on one tumour type alone, thereby accelerating the information gathering and results analysis processes.

Dr Plotkin from Massachusetts General Hospital, a well-known researcher in the NF2 space will be leading the study taking place across six medical centres in the US.

Recruitment for the study has already commenced but is only available to US citizens.

Despite the impact of a global health pandemic, the US Department of Defence is considering increasing their investment in the NF Research Program from \$15m to \$20m. While government approval is still needed, it is comforting to know that such an important program is still receiving attention during these uncertain times.

Around the world further advancement of NF knowledge is going on everyday through basic science and animal modelling which can lead to clinical trials and research.

The NF Research Program has been instrumental in assisting researchers globally (including Australia) to fund more effective treatments for Neurofibromatosis.

NF Ambassador Janu Dhayanathan, raised over \$16,000 for the TiNT MEK Inhibitor Trial in June 2019. Since then, she has been using her story to continue the fight by helping to raise awareness of the condition.

She has become a regular speaker at events run by the CTF and is now mentoring other young adults by giving a voice to the social isolation and anxiety of living with NF.

FEATURE STORY: IN HER WORDS

This beautiful, yet heart-breaking letter has been written by an incredibly strong woman whose adult life has been at the mercy of this devastating genetic condition. Kirsty is a Mum to four gorgeous children, two of whom are battling life-threatening symptoms of NF.

Kirsty has chosen to share a different side to NF - the impact it can have on the entire family, not just those living with the condition. It speaks to the importance of self-care, of recognising when you may need help and a reminder that what you are doing right now, as a parent, is changing the life of the people most precious to you, your children.

Written by Kirsty Whitehead,
NF Mum



“How could I bring these helpless children into a world where hospitals, chemo and surgery are their normal?”

Part of advocating for your children means sharing their experiences to help others understand the sheer terror and trauma of a condition like Neurofibromatosis (NF), but knowing the reality is nothing you can prepare for.

My eldest daughter, Shelby is 16 and her brother, Jackson is 12. They both have NF1. I have been advocating for them for a long time, lending my strength and keeping my own emotional battles hidden – to relieve their anxiety and give them hope.

Lately I have been feeling the deep emotional

effects of their health challenges as years of bad news start to really weigh on me; too much for anyone to bear in silence.

Our journey has been a roller coaster. Sometimes I close my eyes and hold on terrified, waiting for the moment I can raise my arms again and simply enjoy the ride.

But after 16 years of tumours, surgeries, and a relentless stream of new health problems being diagnosed – each more terrifying than the last – you start to wonder how long you have left with your children. You start to reflect on what they will no doubt miss out on in life.

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 heart sinks every time I watch Jackson push around a trolley while we shop, pretending he is driving a car.

Each time I remember that his vision impairment, intellectual disabilities, and other health issues will probably prevent him from ever getting behind the wheel.

There is so much joy in raising these beautiful children, but there is also so much heartache.

I’m actually a proud Mumma to four beautiful children. Joseph is 4 and Anna is 2, and they have lots of fun keeping me on my toes. Joseph and Anna do not have NF. Raising them has been an interesting journey and a great learning experience, but also quite painful.



Whilst I have loved watching my babies reach all their milestones, it has put into stark perspective the differences between them and their older siblings.

It is clear just how much Shelby and Jackson have struggled. Watching your four-year-old teach their 12-year-old brother how to do a puzzle is difficult to comprehend when you know it should be the other way around.

NF has affected every member of the family. Whilst my experience as a mum has been highlighted as a result of my campaigning, people often forget how it affects my husband, Shelby and Jackson’s Dad and every child in the family.

The hospital has become the entire family’s second home. Our two youngest children have never experienced a life where their siblings are not sick and don’t require continual medical attention.

Inevitably, a day will come when they start asking questions. They will no longer accept this as their normal and want to know why their siblings have been dealt such an unlucky hand in life. They too will have to live with constant worry and anxiety.

Will another tumour grow? Will this be the tumour that takes their life? **These are questions that no child should have to grow up wondering.**

Not all cases are as severe as Jackson and Shelby’s. In fact, doctors have said that many of their health problems only arise in 0.002% of NF patients.

We have been forced to face the uncertainty and mortality of our children, and this is when the guilt kicks in.

As a Mum you are fiercely protective and do everything in your power to fix things for your children. But what do you do when that is physically impossible?

I cannot take their pain away. I cannot cast a magic wand and make everything better. Instead, I hold my daughter as she sobs asking if this is the day she will die.

I watch my son curl up in a ball crying because he is unable to handle the pain. I have to answer them when they ask what they did so wrong to deserve this life, and listen to them talk about what colour they want their coffin to be.

Each time I must swallow the lump that is building in my throat. Because it is up to me to be strong.



If Mum is okay, it must mean everything will be okay. I have been pushing these emotions down so deep to avoid facing them, for so long that when they finally reappear, it is when you least expect it.

During these times, my husband becomes our emotional rock.

Our family faced one of the hardest moments of our lives just a few weeks ago.

Shelby required brain surgery to debulk a plexiform neurofibroma that had wrapped itself around the main drainage vein in her brain.

The surgery was life threatening. One small touch to this vein and Shelby would have a stroke or die on the table.

If we did nothing and let it grow, we would have the same outcome.

The sheer weight of the tumour was causing immense pain for Shelby and it became clear the surgery was necessary.



We were not prepared for how quickly the surgery would happen. We had only days to enjoy what could have been our last moments with Shelby.

I made it my mission to do things she loved every day; however, COVID-19 made it impossible to do everything we wanted. Instead, we enjoyed the small moments.

Going to the beach at night and dipping our toes in the cold wintery water under the stars.



I would take in her laugh, her voice and at times record it... just in case. She would ask how I was so sure she wouldn't die. I would fumble through the words and somehow bring a small amount of reassurance to her.

Shelby and I also talked about the experiences of other NF Heroes who were living with this devastating and unpredictable condition.

We talked about the impact that research could have on the lives of so many children with NF and knew the Children's Tumour Foundation (CTF) were seeking funding for an Australia-based MEK Inhibitor clinical trial.

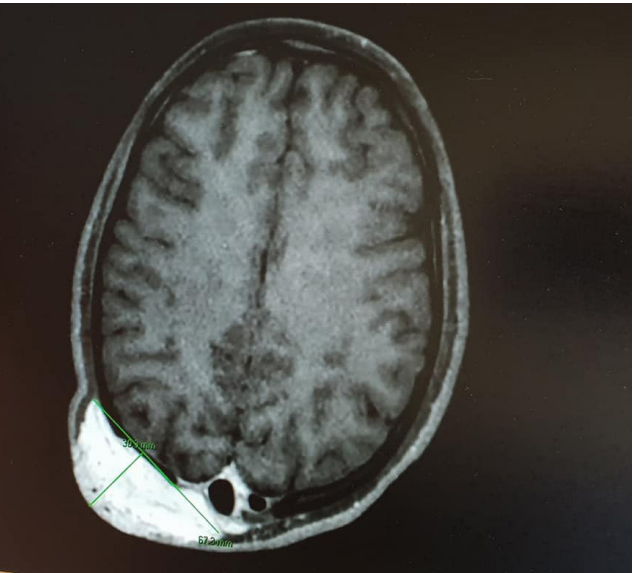
A drug with proven success in shrinking and stabilising the size of plexiform neurofibromas and optic pathway gliomas.

Together Shelby and I decided that it was our responsibility to help and by doing so, we could turn something negative into a positive. If the worst was to happen, the funds raised would be part of Shelby's legacy.

This became our family's focus in the lead up to her surgery and on Mother's Day I shaved my head. A small action in support of something so much bigger than me.

It became our focus to bring hope to other families and to ensure no child will have to face life threatening surgery simply to "buy them more time".

Thankfully, the surgery was a huge success. It went better than we could have hoped for. The debulking of the tumour went smoothly and they managed to do something we were told was impossible. They placed a titanium plate over the 5cm hole in Shelby's skull.



When you've been told nothing but bad news for over a decade, it is almost impossible to remain positive and hopeful.

Waiting for the news, I contemplated which 10 people we would have at Shelby's funeral. I wondered how I would break the news to her siblings, and how I would possibly cope with the loss of my eldest daughter.

I remember the moment the surgeon came and told me the good news. It has been years since we have received anything positive, so this was a lot to take in. It took me a little while to process just how amazing the news was. It felt like a little miracle.



While Shelby recovered at home, I finally had the opportunity to stop and reflect on who I am as an individual, the impact that NF has had on my life and how these experiences have shaped me. I have been a NF mum for over a decade, and this has consumed my identity. I have thrown myself into raising my children and making memories, knowing just how short and unpredictable life is.

“Through this process I have discovered a deep sense of grief - something I think I will always carry with me.

You see, I never imagined my life this way. I had goals, I had dreams. I wanted a career and, honestly, I wanted to change the world. That sounds kind of corny, but I always thought I was meant for something big.

I have struggled to figure out how to continue my goals as an individual, not just as a mother. These are feelings I have been unable to process on my own. So, I reached out to the Children's Tumour Foundation and made a connection with people who genuinely care. They have time to listen and it feels like they “get it” in a way most cannot.

During our most recent experience with Shelby's surgery, Ruth has been there through the tears, through my fears and through the subsequent grief I am now experiencing.

It was Ruth who really listened and helped me see that it is not that I'm not accomplishing my life's goals, it's simply that a world with Neurofibromatosis means my goals simply look different. That it is ok to feel, to be scared, but to also be hopeful.

I always thought the CTF was simply there to raise awareness for NF, fund research and find a cure. But, recently I learnt they are so much more.

There is a network to help families through the challenges this condition throws at us, and there is someone who will listen without judgement.

I wish I had realised this sooner.

All this time I have felt alone, exhausted and drained. Advocating for my children's needs would have been easier had I spoken to people with the resources and experience to help.

Children's Tumour Foundation
CONQUERING NF

LET'S SHOW 2020 WHO'S BOSS

**JOIN THE
NF HERO CHALLENGE
FOR FREE THIS SEPTEMBER**

**AND HELP THE CHILDREN'S
TUMOUR FOUNDATION CONQUER NF**

www.ctf.org.au/events/nfhc

Harvey Norman

every 3 days A child is born WITH NF in Australia.

Neurofibromatosis or NF is a genetic condition that leads to a lifetime of uncertainty and tumours. It is painful, progressive and there is no cure. But there is hope.

September is NF HERO MONTH.

That gives you 30 days to complete a challenge that tests you physically, mentally or emotionally.

You could choose a single day to complete it or challenge yourself every day for a month.

What you choose to do is up to YOU!

TAKE THE PLUNGE



DARE TO SHAVE



WHY? BECAUSE NO TWO CASES OF NF ARE THE SAME.

So WHY SHOULD THE NF CHALLENGE be ANY DIFFERENT?



TUMOURS should never be A PERSON'S NORMAL

Register as an individual, with friends or as a team at work and help us raise \$100,000 to continue our support of individuals and families living with NF in Australia!

WWW.CTF.ORG.AU/EVENTS/NFHC

We take our responsibility to those living with Neurofibromatosis (NF) in Australia very seriously. We are acutely aware that awareness of this devastating condition is far too low and that many struggle to receive the information and care they need at critical moments in their journey. We want to make sure that the CTF continues uninterrupted now and in the future, which is why event like this are so important.



Registrations are now open and we are asking everyday Australians to help show 2020 who's boss by registering for the NF Hero Challenge.

IT'S FREE

IT'S VIRTUAL

LEAVING THE HOUSE IS OPTIONAL

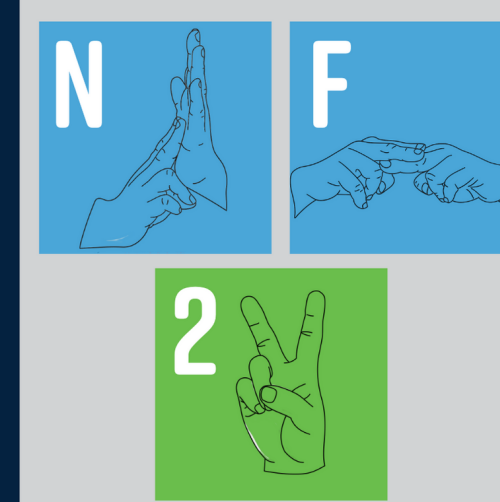
Last year Hilda Maroun and her family participated in the event in support of her daughter, Bianca (left) who has undergone numerous rounds of chemotherapy for her NF related tumours.

The Maroun family jumped into the freezing cold waters of Brighton Bay in Melbourne and raised over \$17,000 for the CTF!

What is within your power to help raise \$100,000 and #CONQUERNF?

WWW.CTF.ORG.AU/EVENTS/NFHC

LOOK OUT FOR...



INTRODUCING NF2 TUESDAY

NF2 Tuesday is all about putting our NF2 Heroes in the spotlight. Every Tuesday we will be sharing various resources, stories and facts about our amazingly strong NF2 community, highlighting the strength and courage they show in the face of adversity.

Follow us @ctfaustralia to access these amazing stories and resources.

If you've got an NF2 story or resource to share, get in touch on fundraising@ctf.org.au

#nf2tuesday



PROUDLY SUPPORTED BY
 QBE | Foundation

Anxiety, depression, and social isolation is something many members of our community experience on a daily basis. We recognised that these feelings would likely be exacerbated during the pandemic as people were forced to distance themselves from family, friends, and other members of the community.

With all NF community events on hold, we considered how best to continue supporting the mental health and wellbeing of individuals and families during this time.

NF Connect is a new virtual destination to check in, catch up and exchange information from the comfort of your own home, from anywhere in the country.

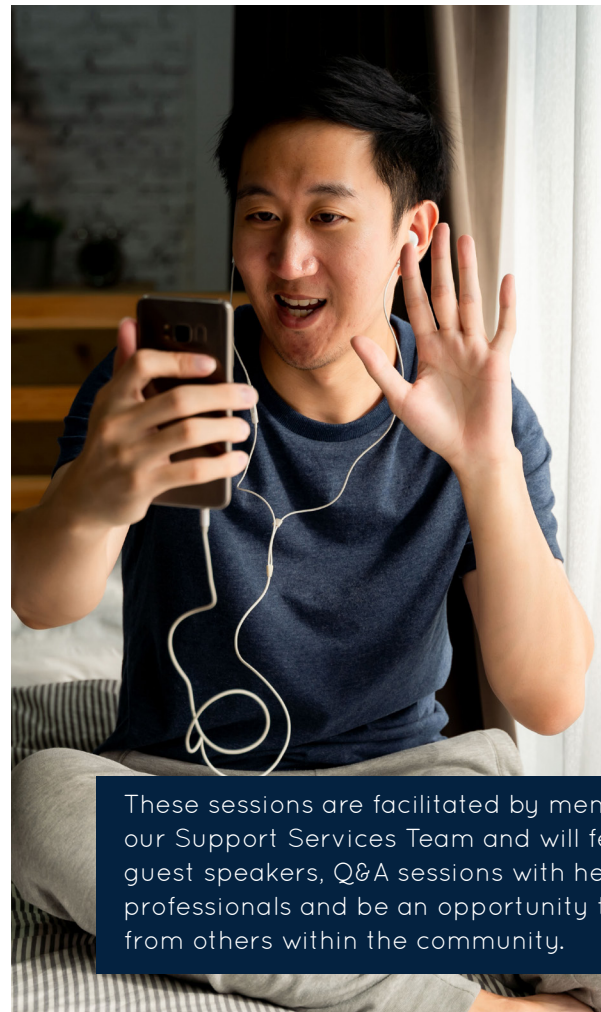
It is designed to help alleviate some of the stresses, fears and anxieties community members may be experiencing right now, while also providing access to engaging guest speakers and each other.

Who can join?

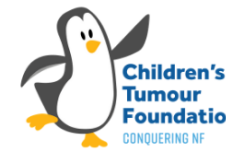
There will be four sessions per month, each targeting a different life-stage.

- NF Connect for Teens
- NF Connect for Young Adults
- NF Connect for Parents
- NF Connect for Adults

In August we will be running our third session. Dates and registration details are available on the website at www.ctf.org.au/nf-connect



These sessions are facilitated by members of our Support Services Team and will feature guest speakers, Q&A sessions with health professionals and be an opportunity to learn from others within the community.



WHAT'S HAPPENING
THIS AUGUST ON



TEENS & YOUNG ADULTS

GUEST SPEAKER: HEATHER REHTLANE ON LEARNING TO LOVE YOURSELF



MON 10 AUGUST
8pm AEST

Heather was diagnosed with NF1 at birth, a condition she has inherited from her mother. In addition to various complications related to her NF, Heather has struggled with depression and anxiety, eating disorders & body dysmorphia.

Heather will join NF Connect for Teens & Young Adults as a guest speaker for a combined session. She will share the journey she went on to learn to love herself and her body, as well as how she created a platform that has allowed her to talk freely about NF.

ADULTS WITH NF

Managing your NF can be quite an isolating journey. NF Connect is all about facilitating friendships through shared experiences.

This session will be facilitated by our Support Coordinator, Ruth and will be a chance to connect and catch up with other adults living with NF from around the country.

This is the perfect opportunity to share your story, learn from others, and connect with peers who are navigating a similar path.



WED 12 AUGUST
1130am AEST

PARENTS & CARERS

GUEST SPEAKER: JOIN SALLY MASPERO FOR AN IN DEPTH Q&A SESSION



THU 13 AUGUST
1130am AEST

Sally works as the NF Nurse Specialist at the Sydney Children's Hospital of Westmead NF Clinic. Her role involves coordinating specialist diagnostic scans and appointments, providing family support and helping to link families with the Children's Tumour Foundation.

Sally will be joining NF Connect for Parents & Carers to answer any questions you may have about your child's NF diagnosis.

HOW TO REGISTER

To register for NF Connect, head to

[WWW.CTF.ORG.AU/NF-CONNECT](http://www.ctf.org.au/nf-connect)

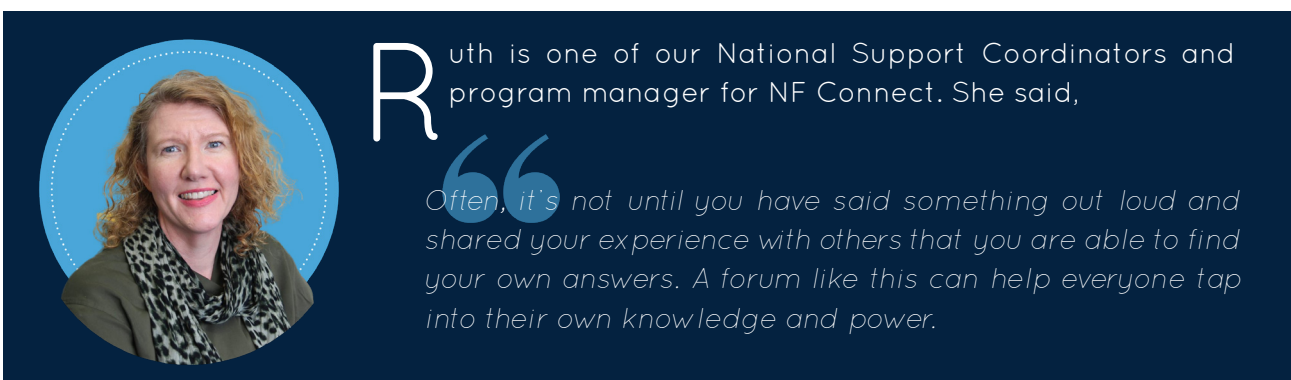
Please note: If you have already registered for a previous session, you will not need to register again. A member of our Support Team will send out a link to join the conversation prior to your NF Connect session.

CONTACT US

- (02) 9713 6111
- support@ctf.org.au
- @ctfaustralia

SUPPORTED BY

QBE | Foundation



Ruth is one of our National Support Coordinators and program manager for NF Connect. She said,

“Often, it's not until you have said something out loud and shared your experience with others that you are able to find your own answers. A forum like this can help everyone tap into their own knowledge and power.”



PEERS SUPPORTING PEERS

NEW PEER LEADER TRAINING PROGRAM LAUNCHED

A diagnosis of NF can be both overwhelming and distressing regardless of whether it is expected or not. So it is very important to know that you are not alone on your journey.

Being able to talk to someone else who has walked in your shoes can greatly lessen the experience of isolation and distress, improving a person's overall mental health and ability to cope with what comes next.

In June, we launched the first phase of a new pilot Peer Leader Program. This exciting initiative was originally designed to establish local Community Support Groups (CSGs) that would ensure anyone impacted by NF could connect with trained peer leaders with a lived experience of the condition.

However, given the current environment, the Support Services Team modified the program to become a national telephone-based service. A group of volunteers have been carefully selected and comprises individuals with a lived experience of NF1, NF2 and Schwannomatosis.

They are working alongside Meredith

to complete a "Peers Supporting Peers" training package and will be available to connect with community members by September.

The training consists of online modules and video teleconferencing encompassing listening skills, empathy, conflict resolution, confidentiality, self-care and mental health awareness, as well as dealing with people in crisis.

Peer support enables people to share helpful resources and strategies around how to manage the condition and empower those diagnosed and their families. It also offers a forum for forming new friendships and networks.

The program was developed in conjunction with Amanda Spillare Social Work Services, the CTF staff and community members.

If you would like to speak with one of our Peer Leaders, please contact the CTF Support Services Team by phone or email.

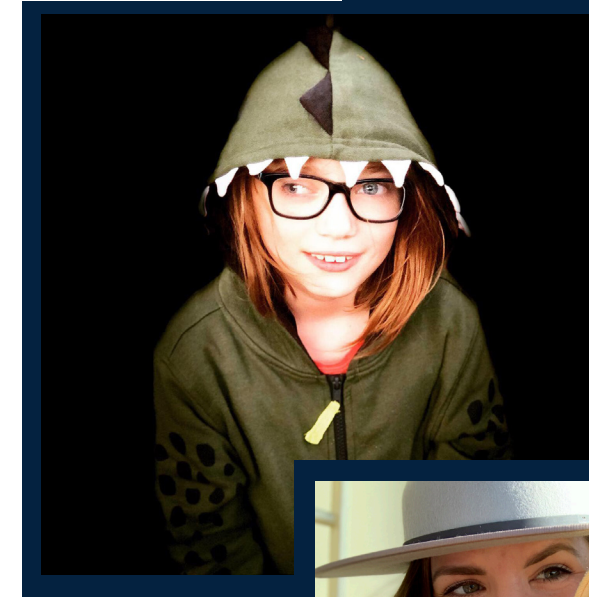
If you would like to volunteer or nominate someone for the next round of training, you can register your interest with us today!

PROUDLY
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NF HERO STORIES

WE WANT TO HEAR FROM YOU!



Sharing your NF story can be an empowering experience.

It may help you to cope with a diagnosis, remind yourself of challenges overcome and validate how you have been feeling. Through their telling, it also helps create a greater sense of community.

It is important to feel like you are not alone and that your experiences may help others too.

**WANT TO SHARE
YOUR STORY?**
Email us at
fundraising@ctf.org.au
to find out more

WE LAUNCHED OUR NEW WEBSITE!

We are so incredibly proud of our new website and we are thrilled that you love it too!

As a small team with big dreams and humble budgets, we aimed to deliver top quality without the expense. So to achieve the result you see now, we engaged talented young interns, relied on the support of our amazing probono partners and invested enormous amounts of our own time and energy into producing an end product that is worthy of our community.

By choosing to roll up our sleeves and get stuck in, the time it took to complete the project took longer than expected, but we think it was worth the wait!

So get stuck in and tell us what you think!

What other information, sections and news are available on our new website?

LIVING WITH NF	LATEST NEWS
RESOURCES	STORE
GET INVOLVED	STORIES
ABOUT US	

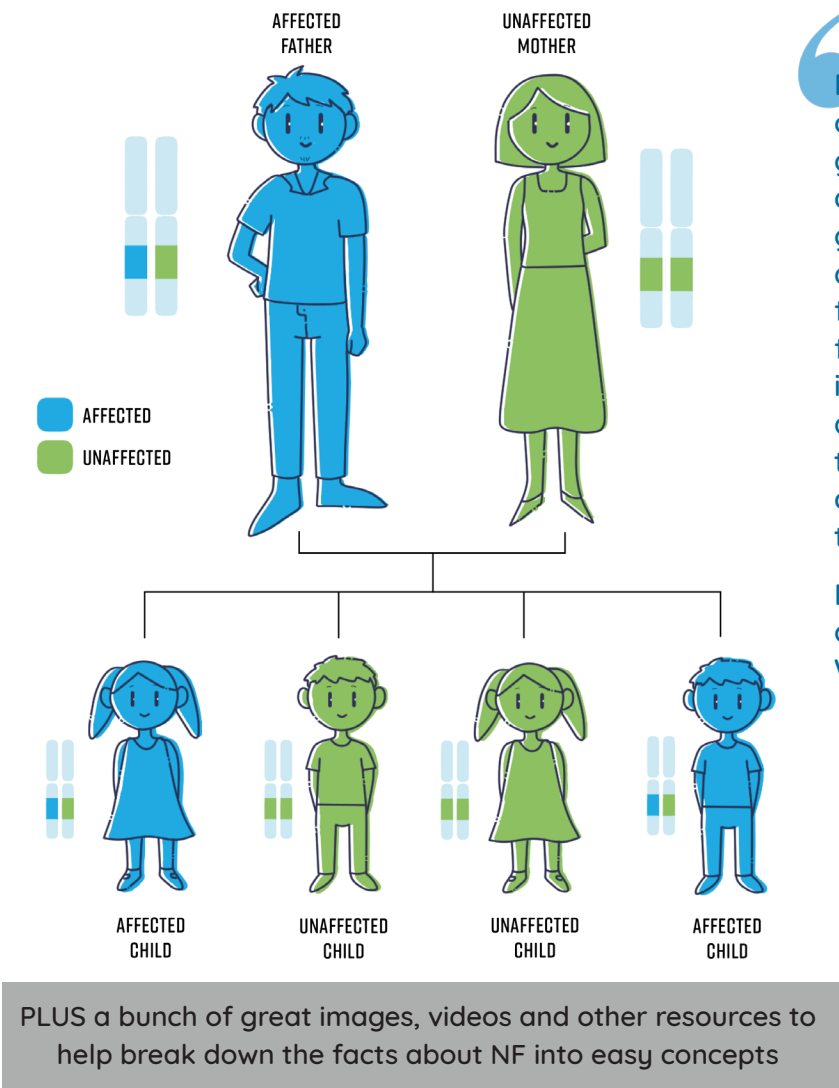
UNDERSTANDING NF

Diagnostic criteria for each type of NF and health implications broken down by location on or in the body

Delving into the causes of NF and the genetics of the condition

FAQs and a glossary of terms

CHECK IT OUT
WWW.CTF.ORG.AU



“Love it. The breadth of information is great - so informative and helpful. Not only great for the newly diagnosed, but also for those looking for accurate and informed information about a change in their condition, or the condition of someone they care about.

I also love the new colours and design. Well Done!

ARE YOU ADDICTED TO FACEBOOK AND WANT TO USE YOUR LOVE OF SOCIALS FOR GOOD?

With the click of a button you can set up a Facebook Fundraiser and start raising money for the Children's Tumour Foundation.

You can set up campaigns for birthdays, events, in honour of loved ones, or just because you want to be an advocate for the CTF.

START A FACEBOOK FUNDRAISER

DOWNLOAD THE GUIDE HERE



“THE ONLY THING WORTH SPREADING THIS MAY IS AWARENESS OF NF”.

It's safe to say things looked a little different this year. We revamped our website and changed our brand colours, not to mention social isolation! But the fight to conquer NF could not be dampened by COVID!

With a little creative thinking and the help of technology, we saw our community come together to raise awareness of neurofibromatosis from the comfort of their own homes and that is certainly something to celebrate!

We form one part of a global community working to improve awareness and deepen understanding of Neurofibromatosis, while raising much needed funds to support better treatment options and enable access to critical support services.

Through our owned channels we reached over 250,000 people and saw engagement increase by more than 350%!

With the support of national media outlets like Take 5 Magazine and Kids Spot, as well as state and local media outlets like ABC Radio, WIN News and Nova 969 digital channels, we had the potential to reach an additional 1 million people!

We partnered with Nova 969 in Sydney to produce and run an on-air and digital campaign for three weeks which reached over 1 million people alone!

So, what did you say about the new brand colours and logo?

I feel more connected to NF fighters around the globe just knowing we share those colours now.



Take 5 Magazine, May 21 Issue



WIN News Gippsland, 27 May 2020

The new website launched in stages across the month of May and we could not be more thrilled with the result.

Across the month, we saw significant growth in users visiting the site and remaining engaged for long periods of time.

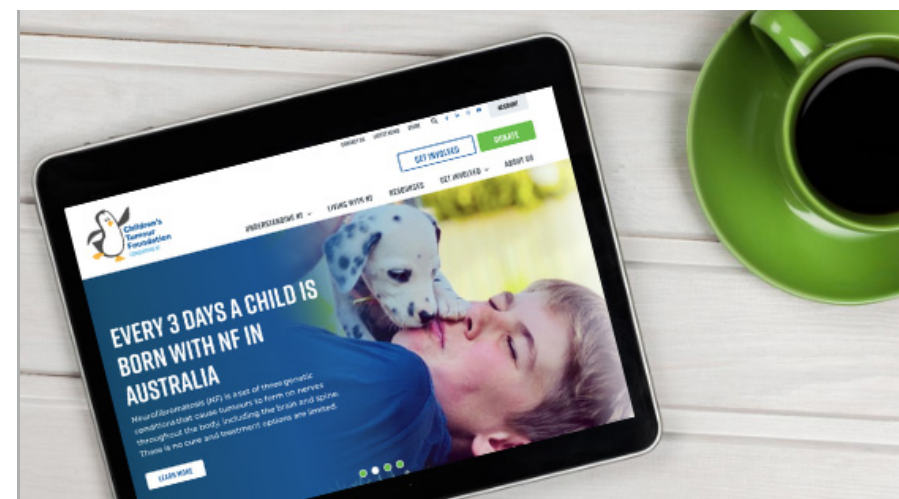
It is a resource that will serve the NF community at any stage of life. We hope it becomes a useful companion and safe space to access balanced and up to date information throughout your NF journey.

We used it's launch as a way to reengage our existing community and invite new interest. But this is just the beginning.

The website will serve as a tool to continue bringing greater understanding of NF to everyday Australians, media and educators.

You can check it out here

WWW.CTF.ORG.AU



So, what did people have to say about the new website?

Loving the way the information is easy to navigate to find information specific to each type of NF.

I found the roadmap to be great, as in a highly emotional time, it sets a clear guideline of things to think about leading up to and following a diagnosis.”



ISOLATION BIN OUTINGS SEND NF MESSAGE TO THE WORLD

Who would have thought that by taking your bins out you could reach tens of thousands of people all around the world! But that's exactly what these amazing NF Heroes and their families did to raise awareness of NF in May!

Decked out in their NF Hero Capes, they posted their photos and stories to the Isolation Bin Outing Facebook Group, that started in Australia, but grew to inspire a following of well over 1 million people worldwide.

We crunched the numbers and worked out that together their posts received more than 40,000 likes and comments from people all over the world.

This was a chance to share a reality that few could imagine, but inspired an outpouring of sympathy and warmth that was beyond measure.

That is a truly amazing feat!

Q&A WITH THE AUTHOR OF THE NF HERO BOOK

Explaining to your child what Neurofibromatosis is and how to answer the questions is an enormously difficult task for parents of NF Heroes. This is what inspired Lana Melbourne (Hanssens) to write her book “The NF Hero”

We took advantage of the opportunity to ask her what she hopes to achieve from writing this book for both her family and the wider NF community and shared it across social media on Mother’s Day in May.

WHAT INSPIRED YOU TO WRITE “THE NF HERO”?

Initially I was inspired to write this book to help my eldest daughter Jayla understand what her brother was going through. She had started to ask questions about why Fraser visited the doctor so often and what the doctors were doing to him.

Like many parents of a child with NF, I spent countless hours on Google trying to search for “the answers” to give her. I couldn’t find a resource that helped me explain this to her, so I decided I would make one!

Once I had written the book, I then teamed up with my talented friend and illustrator Luke Harrap who really bought my words to life with his amazing artwork – including making the main character look just like my little NF Hero - even his spots are in the same place!

HOW HAS IT BENEFITED YOU AND YOUR FAMILY?

Fraser is about to turn 8 and is becoming more and more inquisitive about his NF as he grows.

When he is feeling uncertain, he will curl up on my lap and ask me to read him the

book. I know this is his little way of asking for reassurance.

This book says everything that I struggle to say at times. Every parent of a child with NF carries their own pain, particularly on days when the future seems uncertain or scary. Sometimes I struggle to talk to him about the future without a lump in my throat and tears in my eyes.

“For my family, this book always gives us a sense of hope and positivity, even on the worst of days. It reminds us to adjust our capes, and switch superhero power mode on!”

HAVE YOU BEEN SURPRISED BY HOW MUCH THE BOOK HAS HELPED OTHERS?

I am absolutely amazed by how many families this book has helped.

When I wrote it, I actually only ever wanted one copy – for my own family. I wanted both of my children to know that Mum did everything she could to help them understand.

I never imagined that so many families around the country would be reading this story to their kids. It’s very surreal for me. I will be forever thankful to the incredible team at The Children’s Tumour Foundation for sharing my dream and ensuring that families have access to this resource.

HAVE THERE BEEN ANY HIGHLIGHTS?

Absolutely – last year during Book Week!

My Facebook newsfeed was full of little NF Heroes all around the country dressing up in their favourite superhero costume and taking ‘The NF Hero’ book to school or daycare!! Those proud, cheeky, smiling little faces made this book one of my greatest achievements.

I also saw a YouTube clip of a gorgeous little NF Hero called Bella. She conducted a “review” of the book, critiquing the story. Luckily for me it was a positive review and she decided she loved the book! To hear her mum asking her questions, and seeing little Bella cradle my book and talking about being an NF Hero was an unbelievably rewarding feeling.

WHAT IS YOUR HOPE FOR THE BOOK?

My hope for ‘The NF Hero’ is that it continues to create conversations in homes and schools all around the country that removes the stigma of this condition.

I want our children to be able to talk about their NF with confidence, pride, and optimism. I want them to embrace their superhero powers!!

New print run of books are available for purchase or [download](#) on our website for \$10 + postage thanks to Mazda Foundation.

BUY A BOOK

To celebrate NF Awareness Day on Sunday 17th May, we asked renowned children’s book author and CTF Ambassador, Josh Langley read The NF Hero Book as part of a live-streamed storytime event on Facebook.

If you missed it, you can find the video on our Facebook page, YouTube Channel or by clicking [HERE](#).





DO YOU NEED A HEALTH MANAGEMENT KIT?

The Health Management Kit is jam packed with a bunch of great information about Neurofibromatosis, as well as resources that will support you on your NF journey.

The kit contains tools to help keep track of your health information and history, upcoming medical appointments, scans and reports, as well as general information on NF Specialists and services in your state.

Depending on your child's age and family circumstances, the Health Kit will contain resources on learning difficulties, information for schools, FAQs, Talking to Children about NF, Transitioning to Adult Care Checklists and a range of other info.

Your kit will be tailored to your individual needs and is available by contacting our Support Services Team by phone (02) 9713 6111 or by email at support@ctf.org.au

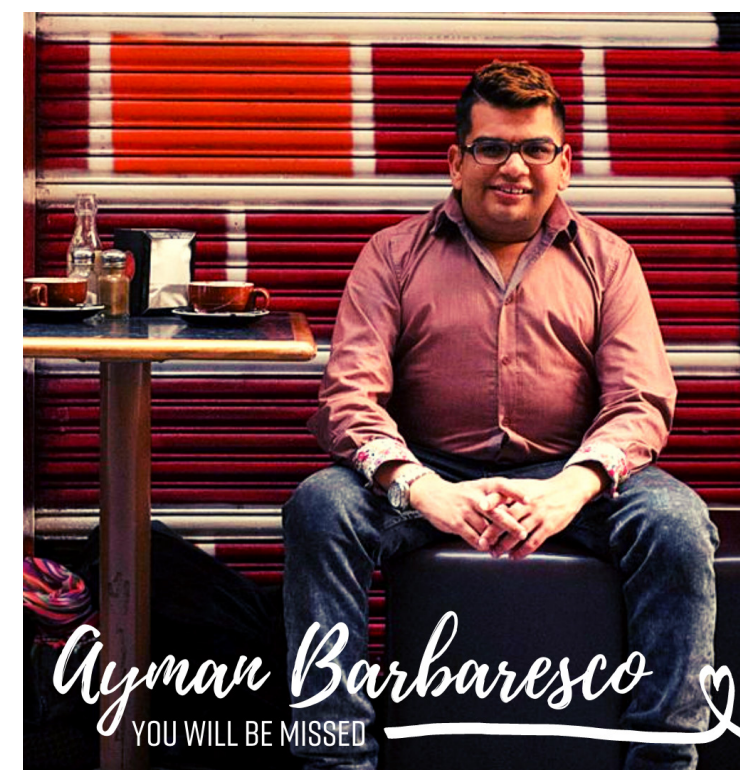
In late June we lost a friend, a volunteer, an advocate, and an inspiration for the NF community. Ayman Barbaresco passed away due to health complications of his NF.

Since first meeting Ayman in 2015, he aspired and succeeded whole-heartedly in becoming an advocate for disability and LGBTQIA+ issues.

Ayman's NF journey was a long and complex one, but despite all that he faced, Ayman continually showed a caring, happy and resilient outlook on life.

In his own words, Ayman shared his experience of NF with the Genetic Support Network of Victoria (GSNV) in November last year; a legacy that will live on and give greater understanding to this devastating condition. Something he was deeply passionate about.

Our deepest sympathies are with his family and friends during this incredibly difficult time. Ayman will be missed by so many in the community, but we are determined to continue his legacy and keep on fighting to conquer NF.



Ayman Barbaresco
YOU WILL BE MISSED

With Our
Deepest Sympathies

The passing of a loved one is devastating for those they leave behind. We would like to help honour those NF Heroes who have lost their battle by providing a space for family to commemorate and celebrate their lives within the NF Quarterly or through our social media channels. How you would like to do this is up to you.

For those who would like to create a space for people to give in memory, there is also the option to create an in-memory page on our website where donations can be accepted.

To discuss either of these options, please contact us on 02 9713 6111 or email us info@ctf.org.au

A LESSON IN GRATITUDE

AN UPDATE ON OUR RECENT APPEAL FOR FUNDS

This article was supposed to be an update on the tax appeal and how the generosity of our community has stretched in such uncertain times. We all know 2020 has not been kind. But as I was looking for inspiration as to how to begin, this note appeared in my inbox and it summarised perfectly the sentiment I was trying to communicate.



Sometimes I just want it to stop.

Talk of COVID, protests, bushfires, recession. I lose my way. Become convinced that this “new normal” is real life. But then I meet an 87-year-old who talks of living through polio, diphtheria, Vietnam, protests and yet is still enchanted with life.

He seemed surprised when I said that 2020 must be especially challenging for him. “No” he said slowly, looking me straight in the eyes. “I learned a long time ago to not see the world through the printed headlines. I see the world through the people that surround me. I see the world with the realisation that we love big. Therefore, I just choose to write my own headlines:

“Husband loves wife today”. “Family drops everything to come to Grandma’s bedside”. He patted my hand, “Old man makes new friend.”

His words collide with my worries, freeing them from the tether I had been holding tight. They float away. I am left with a renewed spirit. My headline now reads:

“Woman overwhelmed by the spirit of kindness and the reminder that the capacity to love is never ending”.

I don’t know who wrote it, and I took a small liberty in relating the worries of the world with Australian concerns, but the message I hope you take away from this is that everything is a matter of perspective.

At the beginning of June, we opened up to our supporters about how challenging the last 6 or more months has been for fundraising and the subsequent impact this will have on our service provision.

We called on you, seeking understanding and support – and we have been overwhelmed by your response. More than we could have hoped for and a reminder that **kindness is catching**.

I wanted to take this moment to thank you personally for your kindness and generosity. Along with your messages of support, we saw fundraisers pop up all over the place, donations of time and money were extended and a wonderful sponsor, PBK Management offered to double donations in June - helping inspire even greater generosity.

Long-time supporter Dr Greg and Michelle Whiteley and Whiteley Corporation also committed additional funds to ensure our critical support services continue to be prioritised now and in the future.

It is also a perfect moment to remind ourselves of what we have achieved while in lockdown.

- NF Connect was born out of COVID
- Our Peer Leader Training program was initiated; and
- We were able to launch our new website - a resource that will continue to serve our community for many years to come.

Not to mention everything else that you have just read about in this newsletter,

If I was to write a headline that summarised how we feel as an organisation right now, it would read:

“Sorry COVID, but kindness is also contagious”

Never under-estimate your own ability to rise to a challenge and look at the world through a different lens. Our NF Heroes and their families do it every single day.

Thank you for your ongoing support and generosity.

Together we can CONQUER NF.

Yours,

Renee Anschau

Head of Marketing and Fundraising

BECOME A REGULAR GIVER

Good things happen when we come together. Great things happen when we do it regularly. That’s the nuts and bolts of monthly giving – legends coming together to be part of something bigger. Are you in a position to give just \$25 a month?

Head to www.ctf.org.au/donations to make a year-round impact



**Children's
Tumour
Foundation**
CONQUERING NF



#CONQUERNF