Children's Tumour Foundation
CONQUERING NF

Children's Tumour Foundation of Australia

Annual Report

2016

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What is Neurofibromatosis?

Neurofibromatosis (NF) is a genetic disorder that covers three conditions: NF1, NF2 and Schwannomatosis. NF1 was first described by a German doctor, Frederich von Recklinghausen in 1882. It is sometimes referred to as von Recklinghausen's disease or syndrome.

NF1 is one of the most common genetic conditions, affecting up to 1 in 3,000 individuals. It is at least as common as Cystic Fibrosis, Muscular Dystrophy and Huntington's disease.

NF2 and Schwannomatosis are rarer, affecting 1 in 30,000 people.

NF causes neurofibromas (tumours) to grow on nerves throughout the body. Essentially, every nerve cell in the body has the potential to become a tumour. This can lead to a range of significant health issues across a lifetime, including: blindness, bone abnormalities, cancer, deafness, disfigurement, learning disabilities and chronic disabling pain. It can also affect the brain; more than half of those diagnosed also have specific learning difficulties. NF2 can lead to premature death.

As a condition that often causes multiple features simultaneously, NF is known as a syndrome.

No two cases are the same. People with NF can develop multiple features at the same time; which ones, when and how severe cannot be predicted.

It is estimated that around 8,000 Australians are currently living with NF. It is most commonly diagnosed in children and young adults. It can be harder for adults to identify potential symptoms of NF as they can mistakenly attribute chronic pain, for example, to other causes for many years. NF1 can be mild, allowing patients to live active and productive lives; it can also be debilitating and life-threatening.

As a genetic disorder, NF is inherited from a parent around 50% of the time. The other 50% is caused by new mutations in NF genes around the time of conception. We do not know why these spontaneous changes occur. There is much that we still have to learn about NF.

People with NF can be susceptible to discrimination and poor treatment in the community, which can lead to feelings of isolation and loneliness. An NF diagnosis can leave an individual or family feeling afraid and uncertain for years, especially not knowing how and when it will manifest itself next.

The fight against NF is an international one. We have developed strong links with NF organisations and researchers in: the US, Great Britain, Ireland, Canada and Europe. In Australia, we are fortunate to have some of the world's leading NF clinicians and researchers. They collaborate with their international peers and act as advisors to our organisation.

Through these concerted efforts, we aim to make significant progress in our collective aims of better treating NF and ultimately finding a cure.

> "Despite the discovery of the genes for NF1, NF2 and Schwannomatosis, currently there is no known cure and few treatment options are available."

About CTF

Our enduring aims

CTF exists to deliver on three major objectives:

1 **Improving medical services to ensure that people living with NF receive adequate, multidisciplinary care throughout their lives.**

2 **Funding critical research to find effective treatments as well as a potential cure for NF.**

3 **Providing support to children and adults living with NF, their families and carers.**

SNAPSHOT OF ACTIVITIES IN 2016

Last year we celebrated 30 years as an organisation dedicated to supporting families living with NF and the ultimate cause of finding a cure.

That year began with the reopening of a dedicated NF Clinic at the Royal Children's Hospital in Melbourne; a significant and special milestone for us. Continuing that substantial forward momentum in 2016, we continued funding to the NF Clinic at the Royal North Shore Hospital in Sydney. Our significant community fundraising event, Cupid's Undie Run, produced a massive result; over $240,000 was raised thanks to the efforts of our enthusiastic runners, supporters and volunteers in Sydney, Melbourne and the Gold Coast. Next year we aim to take this event nationwide!

New initiatives in 2016 included: a photographic competition known as Being YOUnique and the Walk of Hope fundraising events in Sydney and Melbourne. Continuing events included: the Black & Gold Gala Dinner at the Ivy Ballroom in Sydney as well as several NF Family Camps (in Sydney, Melbourne and Brisbane) and Information Seminars (in Sydney, Melbourne, Hobart and Perth).

We are building an active, truly nationwide support network for NF families.

None of this would be possible without the dedication of our early members and the foundations they laid for the organisation we have today; here's a quick look back at our story so far…

Our journey from 1985

The Neurofibromatosis Association of Australia was launched in NSW by George Armstrong and a small but committed group of families affected by NF. Its main purpose was to become a support group. Social get-togethers and events were organised, including the first NF Family Camps that continue to this day. The organisation remained small and heavily reliant on the efforts of its members for the first 20 years of its existence. Groups in Queensland and Victoria eventually disbanded and then, upon the death of Professor David Danks (a leader in genetic research and NF), the NF Clinic at the Murdoch Children's Research Institute in Melbourne was closed. Things were not looking good.

What remained however was the clear need, shared by NF families, to connect with one another on a regular basis and access up to date information.

In addition, funds were needed to support research efforts and raise awareness of NF in the broader community. It was obvious that a nationwide body committed to NF was in demand.

What emerged in 2010 was a company limited by guarantee, able to operate across Australia. There was a name change to NF Australia Limited and a further decision to use the Children's Tumour Foundation of Australia as the trading name. The change of name led to broader interest from the community and aligned us with colleagues in the US, who had been highly successful, trading under a similar name.

Then came a remarkably generous bequest that we are unlikely to ever forget, from the estate of the late Lisa Palmer; $900,000 was placed into a trust known as the Lisa Palmer Foundation, with the specific aim of funding NF research. We began to pursue corporate partners and in 2011 became the main charity for the Thorn Group and their Radio Rentals business in particular. Since 2011, Thorn has contributed around $500,000 through sponsorship and fundraising events.

Our expansion in terms of initiatives, reach and impact continued to grow. In 2013, we set a new benchmark with the launch of Cupid's Undie Run (now a significant community fundraising event) and Gala Dinners in Sydney and Melbourne. NF Family Camps continued, as did a range of fundraising and social activities within our network. In 2014, we launched the NF Support Network with the creation of a new role – National Support Coordinator. We also commenced funding for the NF Clinic at the Royal North Shore Hospital in Sydney.

The NF Support Network grew in 2015, with an additional role created in Melbourne. Support Groups continued to develop around the country, from Townsville to Perth. Family Camps were held in Queensland and Victoria for the first time.

We have come a long way since 1985 and there is a long road ahead…

Our story is one of tenacity and commitment to the cause. The community that sustained our organisation in the early days has flourished into a nationwide network of NF families and supporters, all optimistic about the future.

About CTF

TIMELINE

1985-2005

- Founded by George Armstrong and a handful of NF families in NSW
- First NF Family Camps and social get-togethers organised
- First part-time employee managing memberships and information
- Closing of Melbourne NF Clinic upon death of Professor David Danks

2010

- Reorganisation as company limited by guarantee with nationwide focus
- Change of name to NF Australia and trading name to CTF
- Bequest of $900,000 from the late Lisa Palmer for NF research
- Commencement of relationship with Thorn Group and Radio Rentals

2011

- CTF selected as main charity for Thorn Group and Radio Rentals
- Board appoints first CEO of CTF
- CTF moves from Ku-ring-gai Senior Citizens Centre to office facility in Drummoyne

2012

- Founder George Armstrong passes away
- Expansion focus on Victoria and the Murdoch Children's Research Institute
- First Victorian board director appointed

2013

- Cupid's Undie Run launched in Sydney on Sunday 10 February
- Inaugural Gala Dinners in Sydney and Melbourne

2014

- Launch of NF Support Network with hire of National Support Coordinator
- Commenced funding for NF Clinic at the Royal North Shore Hospital in Sydney
- Annual fundraising crosses $1 million

2015

- Reopening of NF Clinic at the Royal Children's Hospital in Melbourne
- Expansion of NF Support Network with hire of Support Coordinator in Melbourne
- CTF moves to current offices in Five Dock

2016

- Continued funding to NF Clinic at the Royal North Shore Hospital in Sydney
- Launch of Being YOUnique international photo competition and Walk of Hope events in Sydney and Melbourne
- Annual fundraising reached $1.36 million

CEO and Chair Update

This last year has been a momentous one for the Children's Tumour Foundation and we are extremely proud due to key achievements in a number of areas.

Throughout our 2015/16 year, there was a strong focus on strengthening our position and reputation as well as introducing new initiatives, galvanising our community and delivering outcomes for the thousands of people affected by NF.

> Our passion for and commitment to improving the quality of life for people living with NF has never been greater.

From a community engagement perspective, who can go past our Cupid's Undie Run both in terms of fundraising dollars and awareness-raising? With Bonds back on board as our Major Undie Sponsor, along with the enthusiasm and support of some 350 runners, we raised over $240,000! Our runners, including the inaugural outing of our Yellow Penguin Army, wore their undies with pride, at: Bondi in Sydney, The St Kilda Festival in Melbourne and the beautiful Burleigh Heads in Queensland. It was fantastic to receive national media coverage too!

In May we saw a couple of new events: Being YOUnique and Walk of Hope.

Being YOUnique was a photographic competition that attracted several hundred entries with the incentive of having the work shown in landmark commercial buildings in Sydney and Melbourne for an entire month. This was a wonderful initiative to achieve our objective of gaining attention in NF Awareness Month. It introduced a large number of new people to the condition, with many asking questions and wanting to know more.

The Walk of Hope brought our families together for a sunny Sunday stroll and (in its first year) contributed over $30,000! We received wonderful feedback from all of those involved and look forward to it being even bigger and better in 2017.

> “When we looked back at 2016, we were delighted to have strengthened our role in the community thanks to a record year in fundraising. Year-on-year growth in fundraising and donations was up 19% to $1.36m!”

Our annual Gala Dinner in Sydney delivered an outstanding evening at the Ivy Ballroom with Peking Duk headlining the entertainment and 350 people filling the room. Special thanks goes to the Doves Nest Foundation as well as Eddie and Melanie Listorti, without whom this evening could not be the success it continues to be.

We have many people to thank for their support, which goes far beyond financial effort, and have recognised them in this report. These hundreds of people share our vision, our values and trust us in what we do – we feel very humbled by that.

We also offer special thanks to our Corporate Partners for their continuing support. Especially Thorn Group and all of the work done through the Radio Rentals network. As our Founding Partner, we owe Thorn Group a great deal of gratitude for helping us to provide essential support services and get to where we are today.

We are delighted to now welcome Acer as a new Corporate Partner, after many years of support through various activities, and look forward to working together with them for many more years.

We are very excited about the future with these two iconic brands and building our relationships even further.

We are proud to have contributed $530,000 towards NF Research over the last 6 years with the objectives of finding new treatment options and our ultimate ambition of finding a cure.

We have also expanded our National Support Network, through support staff based in Sydney and Melbourne; they are complemented by the 11 NF Support Groups across the nation, who provide vital community comfort to those impacted by NF. Sally Maspero, our National Support Coordinator, has had more calls this year than ever before, indicating just how much our community needs us.

CEO and Chair Update

One of our most significant achievements has been providing continued funding to the NF Clinic at the Royal North Shore Hospital in Sydney and all the wonderful work being done by Dr Mimi Berman and her colleagues. This funding enabled increased services for adults with NF, particularly as NF poses lifelong risk of developing tumours and associated medical complications. With more than 150 clinic appointments and over 400 phone and email contacts, this NF Clinic has been an outstanding success and one we intend to help grow into the future. An in-depth look is available later in this Annual Report.

Our community motivates us in everything we do. Whilst it is difficult to pick one story to feature, our cover girl, Emily Kirkpatrick (the face of our June appeal) is a young lady who has inspired us enormously.

Emily's journey of amazing courage was a wonderful story to share and it resonated strongly both within our close NF community as well as those hearing about NF for the first time.

It is one of hundreds of stories that exist in our community and we are committed to sharing as many as we can. Our sincere thanks goes to those families who have allowed us to share their NF journey.

We also held NF Family Camps in Sydney, Melbourne and Brisbane and complemented those with Information Seminars in Sydney, Melbourne, Hobart and Perth. This has really started to embed a truly national support structure. We have invested a lot of time into Facebook, noting that this is an important way for people to engage with us. It is a great way for us to have a two-way conversation with our community nationally, and sometimes internationally! This is reflected in a record number of participants in both our closed and open Facebook groups.

And lastly, we assembled a new group of volunteers, willing to give up their own time and serve on our newest committee in Queensland. Chaired by Zoe Rehbein and supported by Christine James, Rebecca Lilly, Terri Price and Andrew Maunders, we are very excited to get a local perspective on the impact we can make in Queensland. This complements the continued success of our State Committees in New South Wales and Victoria, who meet regularly and help us run events to the highest standards. We are extremely grateful for their continued loyalty, hard work and support.

Our aims and objective do not change. We will continue to serve you, our community, by: funding the best research, purchasing state of the art equipment and supporting the NF community in as many ways as we can.

We do it for you and couldn't do it without you. We are excited about the future, more than ever before, and hope you share our optimism!

Richard Hughes
CEO

John Hughes
Chairman

Patron and Ambassador Profiles

The Hon Nick Greiner AC

Patron

The Children's Tumour Foundation of Australia would like to publicly thank and recognise the continued commitment of its Patron, The Hon Nick Greiner AC.

The Hon Nick Greiner AC

Nick Greiner was Premier and Treasurer of New South Wales from 1988-1992 and, since retiring from politics, has been heavily involved in the corporate world as well as many charitable causes.

In 2014, Mr Greiner was appointed as Patron of CTF. Since then, his willingness to be involved, his availability to our community, staff and Directors as well as his passion for CTF to succeed have been extraordinary.

Mr Greiner is an ideal person with whom to discuss advocacy. He has personally provided CTF with assistance to spread awareness about NF and openly talk about the challenges that our community face with this condition. CTF continues to work closely with Mr Greiner to ensure we can deliver outcomes and look for ways to engage with local and federal government.

We would like to take this opportunity to again express our deep gratitude to Mr Greiner. We hope that he continues to be our Patron for many years to come, especially as we see many new changes that will positively impact the support we are able to show our community.

> “CTF is a very special organisation caring as it does for children and adults with Neurofibromatosis, posing particular challenges for all concerned. Both its research assistance and its support networks are invaluable.”
>
> *-The Hon Nick Greiner AC*

Jade Hatcher

Ambassador

Jade is one of several ambassadors representing CTF and we are thankful for their ongoing support.

In her own words...

I have been dancing practically my whole life. It is my passion, the love of my life and my career. The Ballroom and Latin American style is not the most common sport but I was lucky enough to leave school and build a very successful career from something I adore. However, everything was stolen from me when I sustained a life changing injury to my right hip 3 years ago while on “Dancing with the Stars”.

During this life voyage, I have publicly shared very little about my injury and rehab experience, only giving brief sporadic updates on social media. I think that was mostly because I was more than desperate to dance again and, for such a long time, it did not seem like a plausible goal.

Throughout these past 3 years, I have had: 2 hip reconstructions, cortisone injections, MRIs, X-rays and countless other tests, treatments and rehab. If a treatment was recommended, I tried it. I stopped calculating the hours spent on these appointments as it was so disconcerting to watch the months and years slip away to no avail.

The trouble with my injury was the great difficulty in finding a diagnosis. Even though my injury was very treatable, it took 12 months to finally receive a verdict on the best approach to repairing my hip.

So when I was fortunate enough to meet Richard, the CEO of the Children's Tumour Foundation of Australia, earlier this year and learn more about Neurofibromatosis, including the difficulties patients encounter with awareness and achieving a clear diagnosis, I immediately knew that I wanted to help in any way that I could. I just felt on some level that I have an understanding of this unbelievably difficult and frustrating process.

I am lucky to say that after another year of dedicated rehab, I will be returning to the dance floor. However, my traumatic diagnosis experience gives me a small insight into what NF patients go through. Being so unwell and being misdiagnosed for sometimes years is so distressing and often so frustrating if there is no view to a positive outcome – it is easy to give up. However, the beautiful individuals I have met with this condition are the most positive and strong souls, they are true fighters!

This is what encourages me to continue my involvement with this growing community. Bringing awareness to a rare disease like NF with the Children's Tumour Foundation of Australia will change the lives of so many and hopefully provide better diagnostic skills, improved treatments and a brighter future for everyone affected by NF.

Jade xo

Highlights

Financial

Year-on-year growth in fundraising and donations

up 19%

to $1.36m

New corporate sponsor – Acer joins foundation sponsor Radio Rentals

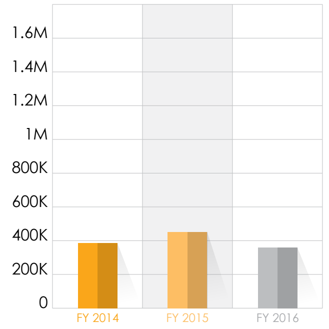
Increased regular giving program generated income

up 142%

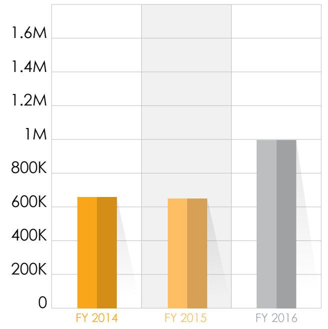
to $382k

International photographic competition: Being YOUnique

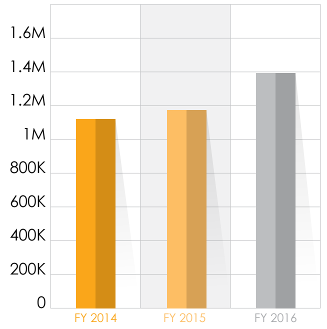
Revenue



Fundraising

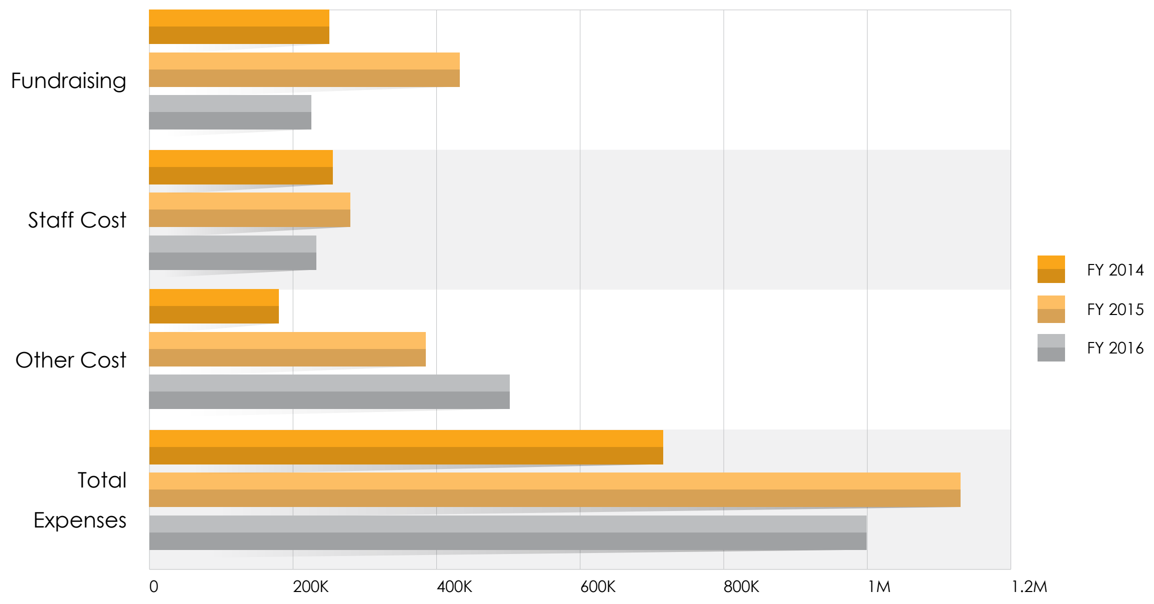


Donations



Total Revenue

Expenses



Support Services

Our National Support Network handled over 400 calls (some of which lasted 60+ minutes) and managed a private Facebook group with over 600 members

Sally Maspero and Natalie McLean assisted with 79 NF Clinics, providing broad support to NF families in Sydney and Melbourne Although their focus is on Australia, they were also able to assist with enquiries from families in New Zealand, Malaysia and Singapore

CTF Support Workers organised successful Information Seminars in Sydney, Melbourne, Hobart and Perth for over 200 participants

This year 4 new support groups were established, bringing the national total to 11; we collaborated with a further 4 support groups independent from CTF

NF Research

Contributed over 6 years cumulatively

$530k

Committed towards further NF Research conducted by Royal North Shore Hospital

$171k

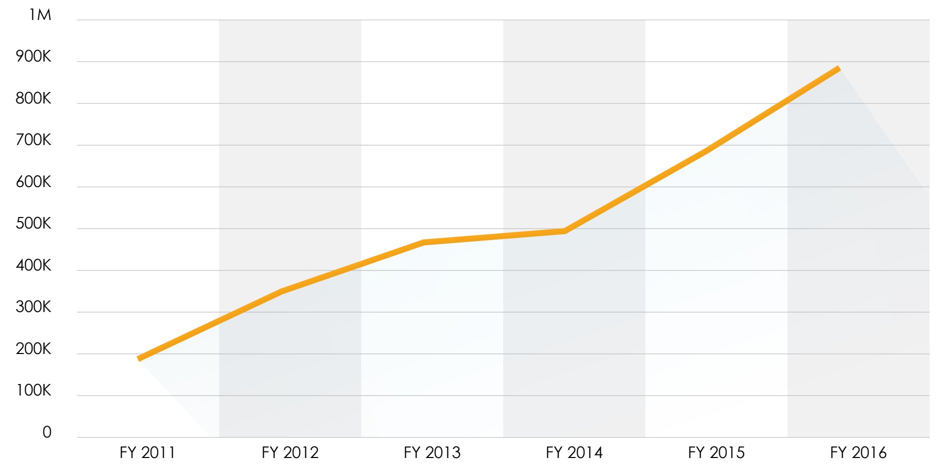
$350K+

Support

$530K+

Research

Cumulative Grants



Financial Report

The statutory accounts for the year ending 30 June 2016 have been audited and the full copy of the accounts can be found on our website www.ctf.org.au.

The following information is an abbreviated version of the Audited Annual Accounts for NF Australia Limited for the past 5 years.

CONSOLIDATED FINANCIALS SUMMARY

5 YEAR HISTORY

	FY 12 $ 000s	FY 13 $ 000s	FY 14 $ 000s	FY 15 $ 000s	FY 16 $ 000s
Revenue	300	501	1,105	1,172	1,398
Expenses	228	394	712	1,123	1,003
Operating Surplus	**72**	**107**	**393**	**49**	**395**
Grants - Research	150	102	26	88	48
Support Services	11	11	12	91	165
Grants & S/Services	161	113	38	179	213
Net Surplus (Deficit)	**(89)**	**(6)**	**355**	**(130)**	**182**
Cash	790	759	1,113	974	1,182
Other Assets	43	55	88	92	63
Total Current Assets	833	814	1,201	1,066	1,245
Fixed Assets			5	5	6
Total Assets	833	814	1,206	1,071	1,251
Current Liabilities	31	18	54	49	47
Net Assets	**802**	**796**	**1,152**	**1,022**	**1,204**

Years of Strength in Adversity:

EMILY KIRKPATRICK'S STORY

Peter and Sharon were so excited by the birth of their first child, Emily. She was born the day after Mother's Day in 2007. What better gift could there be?

However, as Emily grew, her development did not blossom. She was diagnosed with NF at 10 months old after X-rays revealed a tumour in her right tibia. The bone was becoming brittle and beginning to curve. This was a complication of NF and it was affecting Emily's ability to walk.

"We were told our new baby girl had a tumour on her tibia in her lower right leg. Initially, of course, we thought the worst… Like so many others, we had not heard of Neurofibromatosis…" says Peter.

"Our world came crashing down around us…" says Sharon.

By the time she was 2, Emily had undergone more surgeries and endured more pain than most children her age. In the first surgery, Emily had some of her own bone scraped from her hip and implanted into her lower right leg. In the second, just 6 weeks later, a Ilizarov frame was fitted (a supporting frame on the outside of the leg) designed to hold the bone meshing in place.

The excruciating pain of the procedure and subsequent disfigurement of her limb was enough to traumatise little Emily. For a while she could not even bear to look at her own leg.

Emily's Ilizarov frame was in place for 15 long months. Once it was removed, she was fitted into a full leg cast for 10 weeks, but tragically, just 1 month after having the cast removed, Emily broke her fragile bone again whilst on vacation.

She had also begun having mild seizures. She was sent for an MRI and PET scan which revealed brain tumours deep in her frontal lobe. The tumours are benign but inoperable. The seizures were later diagnosed as "petit mal" or absence seizures. Emily had developed a mild epilepsy that was unrelated to the brain tumours.

Emily had just turned 5 years old. She had never walked independently and was now facing further medical complications as well as pending surgeries.

Faced with unexpected developments in Emily's NF, and the looming prospect of future surgery to place her leg again into a Ilizarov frame, Emily's parents made the difficult decision to have her lower leg amputated.

"Can you imagine trying to explain an amputation to your young daughter?" says Sharon.

But Emily was brave beyond her years.

"You would not know that she was in severe pain every single day, living with her leg severely broken to almost 90 degrees for about 2 years. She knew more than anyone what the amputation would provide her; welcome relief. The burden of making such a decision and carrying that burden through the months that followed was, as a parent, challenging."

The procedure would remove the weight bearing from the badly deteriorated bone and provide Emily with a prosthetic limb to support her weight from the knee down. It would provide her the independence and mobility that most children her age take for granted.

"It is very difficult at times for us, and there is still such a long road ahead, but we all try to remain positive. The Children's Tumour Foundation of Australia and the NF Camps provide a lifeline for NF community support and research that is priceless to those families living with NF. They provide a place where NF children and their families can come together, to have fun, share their experiences, help each other learn and understand that they are not alone. It provides hope. It has helped our family find a way out of the uncertainty and the isolation."

Emily is now in Year 5 at primary school and, although facing some learning challenges (another symptom of NF), she has a great deal of determination to overcome this adversity.

"She is an inspiring young girl, with a beautiful heart and a determination that gives out but never gives up. We don't know what lies ahead for our family. NF is an incurable condition that Emily will have for the rest of her life, however long or short that may be, but her life is for living."

We are motivated by stories like Emily's to bring answers, joy and strength back to children and families who desperately need it. Emily turned 9 in May this year and has come such a long way since her challenging diagnosis. We wish Emily and her family all the best on their journey ahead – we'll be here for you!

With gratitude to the Kirkpatrick family for sharing Emily's story.

NF1 Won't Slow Me Down:

HANNAH MOFFATT'S STORY

Hannah was first diagnosed with NF at age 16 while preparing for one of the biggest days of her life until then, her Debutante Ball. She found the perfect dress to wear but noticed two growths on her back and shoulder. Her trip to the doctor ultimately revealed the life-changing diagnosis of NF1. She has lived with it for over 10 years now.

Having no family history of NF, the diagnosis came as a shock to Hannah.

"I was 16 and did not know what this condition entailed. I was unsure what was ahead for me and wondering whether I would still be able to do all the things I wanted to. It was hard to cope, not knowing; trying to understand the condition was also hard. Trying to understand why this was happening to me. I cannot imagine what it was like for my parents."

"When I was first diagnosed, I didn't really want anyone to know about my condition. I didn't want to be treated differently or as if I had something wrong with me. It is hard telling people that you have a condition and not knowing how they will take it. Will they still want to know me? Will they run in the other direction? Will I be able to get a job?"

With time, maturity and the support of her parents, Garry and Leanne, came a change in attitude for Hannah. Although it remains daunting not knowing how and when her condition may progress, Hannah is determined to move forward with a positive and proactive take on life.

"I have now learnt how to speak openly about my condition. I want to be there to help others with NF, help raise funds for research and support programs, provide information to families and friends, educators and health professionals, and assist those impacted to find help and friendship within the NF community. No one should have to go through this, especially alone."

"I have participated in three Cupid's Undie Runs in Melbourne to help raise funds and awareness for NF and will continue to be a part of as many events as I can to help do more. My mission is to help conquer NF."

Hannah has had several operations to remove neurofibromas, with two major operations for the removal of plexiform neurofibromas from her mouth and part removal of one in her finger. Hannah also has a tumour on the base of her spine, situated near her kidney and an optic glioma behind her right eye. She has a host of other NF symptoms such as cafe-au-lait spots, Lisch nodules and needs to be monitored for scoliosis. She also battles vasovagal syncope which causes low blood pressure leading to blackouts and loss of consciousness.

"I know I will probably always have ongoing issues arising from my NF, but I try not to let them stop me from achieving what I want out of life. The scariest part is the unknown; NF is so unpredictable, not knowing if or when things will take a turn for the worse, that I may suddenly not be able to complete the things I am doing, is really difficult."

Amid her battles, Hannah's drive and tenacity have paved the way for milestone achievements and a promising future. Hannah has completed a combined Bachelor's Degree in Law and Business (Accounting) at Victoria University and completed her Graduate Diploma in Practical Legal Training. She was admitted to the Supreme Court of Victoria in July 2015 and is now practicing as a Solicitor. Hannah is the Secretary of the Victorian Committee for the Children's Tumour Foundation of Australia.

"It does feel good to see my specialist or doctor shocked or proud after telling them what I've accomplished, since NF typically comes with learning difficulties. It is hard, but I try my hardest not to give up, even though I sometimes want to. The support of my parents, family and friends helps me get through anything – they believe in me and know I can achieve what I want no matter what condition I have."

"I count myself as one of the lucky ones. I might have NF, but I don't let that stop me from aiming high and making the most out of every day. I know the best is yet to come."

With gratitude to Hannah Moffatt for sharing her story.

What We Do

BUILDING A NATIONAL COMMUNITY THAT UNDERSTANDS AND SUPPORTS ONE ANOTHER:

The National NF Support Service

Sally Maspero and Natalie McLean have worked hard this year in providing a broad range of support to NF families around Australia and occasionally in New Zealand, Malaysia and Singapore. The support is varied and very well-received by families.

They attend NF Clinics at the Royal North Shore Hospital in Sydney, the Children's Hospital at Westmead and the Royal Children's Hospital in Melbourne; working alongside clinicians assisting individuals and families through their NF journeys. This is achieved in a number of ways, including: helping people to understand new terminology, providing ongoing information, assisting with appointments and much more. Sally and Natalie have assisted with 79 NF clinics in the past year.

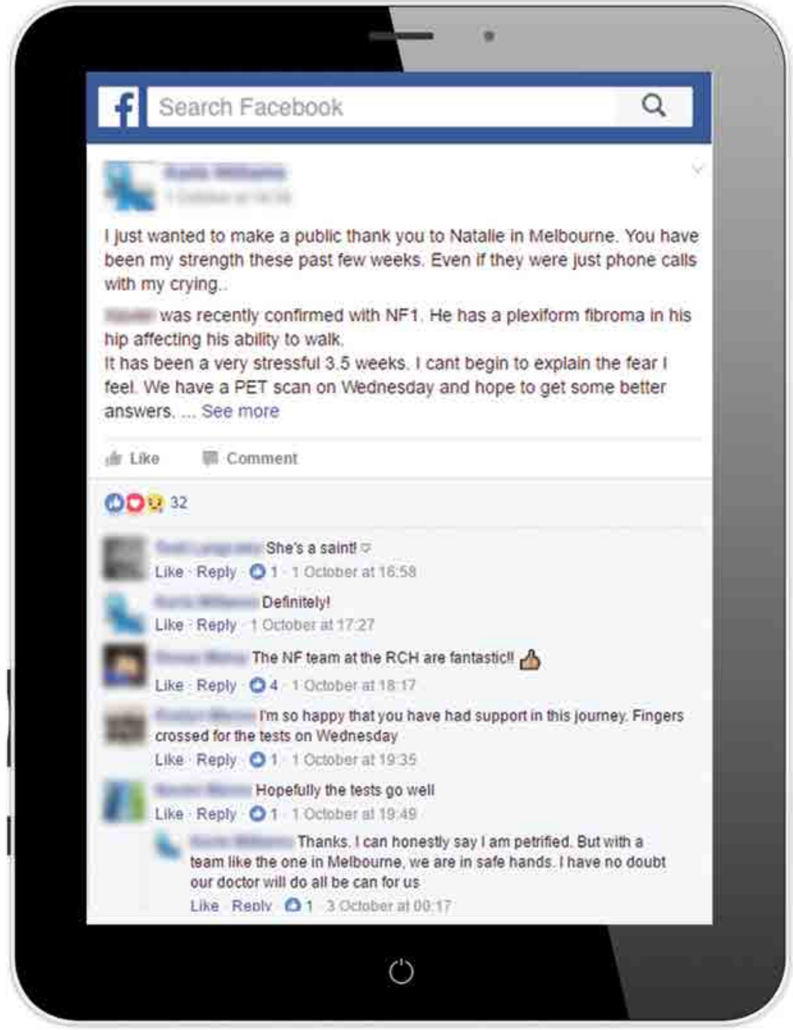
Family weekends away were held during this financial year in Portsea, Brisbane and the Mid North Coast of NSW, with many families participating. Children enjoyed meeting others (with and without NF) and being able to play in a protected environment where they felt safe and "just like the other kids". Adults also benefited from meeting others, many of whom told us that they had never met another person with NF and thoroughly enjoyed the experience. Many have gone on to form friendships and plan more weekends away. We couldn't be more pleased with an outcome like that.

Support is provided by telephone as well as the occasional email or Facebook message to families around Australia. We have had well over 400 such contacts over the last year. A phone call can last more than 60 minutes; recipients always express their gratitude at being able to speak to someone without having to explain NF and having things explained that help them better understand the condition. We also host a very popular closed Facebook group with over 600 members, mostly from within Australia. Members use the group to network, raise issues, ask questions and find information. They also enjoy the camaraderie they are able to generate in this way.

People who have NF often describe themselves as feeling isolated. With our national network of NF Support Groups, we are able to help them make contact with others in their local area. This year a further 4 support groups were established, bringing the number of CTF-supported groups to 11 nationwide. There are an additional 4 NF support groups around Australia that are independent from CTF but work with us in providing information and much needed local support.

CTF support workers organised successful Information Seminars in Sydney, Melbourne, Hobart and Perth during the 2015-16 financial year that attracted over 200 participants. Local NF clinicians gave interesting and informative presentations at each seminar and attendees were able to mingle with the presenters as well as each other during breaks, providing even more valuable networking opportunities for our families. In February this year, we commenced a monthly e-Bulletin communique which has attracted many positive reviews and feedback. The bulletin carries interesting information, news of local events and links to items that people find useful.

We have new initiatives lined up for the coming year and, as ever, aim to increase the support delivered by CTF to our community.



[redacted]

I just wanted to make a public thank you to Natalie in Melbourne. You have been my strength these past few weeks. Even if they were just phone calls with my crying..

[redacted] was recently confirmed with NF1. He has a plexiform fibroma in his hip affecting his ability to walk.
It has been a very stressful 3.5 weeks. I cant begin to explain the fear I feel. We have a PET scan on Wednesday and hope to get some better answers. ... See more

32

[redacted] She's a saint! ♡
Like · Reply · 1 · 1 October at 16:58

[redacted] Definitely!
Like · Reply · 1 October at 17:27

[redacted] The NF team at the RCH are fantastic!! 👍
Like · Reply · 4 · 1 October at 18:17

[redacted] I'm so happy that you have had support in this journey. Fingers crossed for the tests on Wednesday
Like · Reply · 1 · 1 October at 19:35

[redacted] Hopefully the tests go well
Like · Reply · 1 · 1 October at 19:49

[redacted] Thanks. I can honestly say I am petrified. But with a team like the one in Melbourne, we are in safe hands. I have no doubt our doctor will do all be can for us
Like · Reply · 1 · 3 October at 00:17

Meet the Team

This year we wanted to provide an insight into some of our team members, all working towards our shared goals of: building a supportive NF community nationwide, improving clinical treatments and access to them as well as raising awareness about NF. Meet three members of our dedicated team below:

Sally Maspero

National Support Coordinator, Sydney based

What is your main role at CTF and what is the most rewarding part for you?

My role at CTF is to be there when people want information, or just to talk. They may be the parents of a child with a new diagnosis or an adult who grew up with NF now seeking advice on where to go, who to see and meeting others. Having NF can be quite isolating so my work always feels very worthwhile.

What was a highlight for you in 2016 and what are you looking forward to most in 2017?

I have enjoyed reaching out to people with NF around Australia and building our national network of support. In June, we facilitated the first ever NF1 Information Seminar held in Perth and attracted over 40 participants. I was lucky to also meet with some wonderful families with NF2, one of whom travelled over 800 km to attend. I'm building a network of NF families across the NT and northern WA and am looking forward to meeting them and others around Australia in 2017.

What's your message to the people you serve?

NF is often difficult to explain and its impact is quite variable. The support coordinators at CTF can help with your questions, direct you to a welcoming NF Support Group near you, tell you about upcoming family weekends and invite you to Information Seminars held around the country. There is no cure for NF yet but there's an increasing amount of quality support and community!

Natalie McLean

Support Coordinator for Victoria and Tasmania, Melbourne based

What is your main role at CTF and what is the most rewarding part for you?

My role involves organising support-related events such as Family Camps and Information Seminars, coordinating aspects of the NF Clinic at the Royal Children's Hospital in Melbourne as well as connecting with NF families. The most rewarding part is seeing the families I work with develop and grow, taking the challenges they face in their stride and knowing that they have somewhere to reach out when they need it.

What was a highlight for you in 2016 and what are you looking forward to most in 2017?

My favourite part of 2015-16 was seeing everyone enjoying the Family Camp run last November in Portsea. We had 34 attendees who enjoyed the opportunity to connect with others in their community and have some fun. I'm looking forward to seeing how CTF grows and changes, as well as beginning an informative webinar series, which I am currently working on. We are running a competition soon to give the community a say in the topics that will be covered first.

What's your message to the people you serve?

NF may be a diagnosis that presents challenges throughout life, but every single one of you affected by these conditions deserves to be treated in a way that provides you with as much stability and support as possible, so that you can focus on being you. For most people with NF, there are no restrictions on what they can and cannot do. Whether you are feeling limited or isolated, we are here to support you and your family in any way that we can.

Kaitlyn Zhang

Marketing Coordinator, Sydney based

What is your main role at CTF and what is the most rewarding part for you?

I help communicate quality information to our families, the public and promote NF awareness through the effective management of our website, social media and other marketing initiatives. I also help run our office, including IT support and database maintenance. The most rewarding part is that I know I'm always directly or indirectly helping people in need, and I'm doing something that improves our society and world.

What was a highlight for you in 2016 and what are you looking forward to most in 2017?

The Black & Gold Gala Dinner was one of the best parts of 2016 for me. Thanks to so many generous and kind-hearted donors, we raised over half a million dollars! These funds are invaluable to our cause of raising NF awareness, support and eventually finding a cure. I'm looking forward to my first Cupid's Undie Run in 2017 and seeing it go national for the first time – it will be exciting to work with people around Australia with a common cause.

What's your message to the public about NF and the people you serve?

I would let people know that NF is a genetic disorder with no cure at the moment. It can be debilitating and life-threatening, but the hardest part is never knowing if, how and when the condition is going to worsen. One thing we do know is that people with NF deserve our understanding, respect and support. They should be treated just like everyone else. To people with NF, I would say never lose hope, have faith in yourself and technology, and we are here to help.

Update on the NF Clinic

AT ROYAL NORTH SHORE HOSPITAL

One of our key aims as an organisation has been to increase the level of support as well as treatment options available to NF families. As a result, we have endeavoured to provide funding for clinical research and services at nationally renowned institutions, including: Murdoch Children's Research Institute & the Royal Children's Hospital in Melbourne as well as the Children's Hospital at Westmead & Royal North Shore Hospital in Sydney (RNSH).

In 2014, we were proud to commence funding of the NF Clinic at RNSH with the aim of increasing service provision for adults living with NF. A research study, performed in collaboration between the NF Clinics at RNSH and the Children's Hospital at Westmead, found that there is a lack of appropriate and accessible health services for adults living with NF1. The funding was intended to help address these findings and deliver outcomes for adults at risk of poor care.

The Clinical Genetics Department at RNSH is often the first point of contact for adults and children with NF1 across the state. The NF Clinic assists in coordination of care, especially for those with complex disease and ongoing health needs. They assist patients in accessing local specialists or by providing an appointment at RNSH.

Prior to funding, waiting times for NF patients could be as long as 12 months. After funding, they reduced to 1-3 months with an average of 8 weeks.

Over **150** clinic appointments have since been held and over **400** phone or email contacts made.

In order to achieve these and other positive outcomes, the team at the RNSH NF Clinic has utilised our increased funding in several ways, such as:

- Employment of a Genetic Counsellor to assist in coordination of care
- Extension of Clinical Geneticist staff specialist hours, providing increased access to diagnostic assessments and medical management
- Employment of Neurologist for specialist consultations
- Training of junior medical staff to increase the number of clinicians with specialist skills in the diagnosis and treatment of NF
- With extra staff hours becoming available, the establishment of a NF Skin Clinic with RNSH Dermatologists to address cosmetic concerns

The NF Skin Clinic was developed in response to evidence that the cosmetic impacts of NF are of high importance to young adults with NF1. Patients are now able to access excisions and radiofrequency ablation to remove neurofibromas (tumours) at no cost to them. A laser has been purchased as an additional treatment option for patients. Research continues into possible future treatments.

A regular NF Radiology meeting has been established at RNSH with multidisciplinary attendance, including: Clinical Genetics, Radiology, Neurology, Oncology and Neurosurgery. The Head of Department of Clinical Genetics at RNSH, Dr Mimi Berman, has also engaged with the Agency for Clinical Innovation; contributing the completion of a Diagnostic Report and continuing to support the implementation of certain prioritised action areas. Additionally, the RNSH NF Skin Clinic design and outcomes were presented at the Clinical Excellence Commission to Clinical Managers of varying specialties around NSW.

> “Collaborations such as these assist in developing clinical consensus, optimising patient care as well as raising the profile of NF in NSW and beyond.”

A Cheeky Day of Fun and Fitness for NF

CUPID'S UNDIE RUN

Our fourth annual Cupid's Undie Run was our best yet. It ran at Bondi in Sydney, The St Kilda Festival in Melbourne and the beautiful Burleigh Heads on the Gold Coast. Once again, people took to the streets and beaches in their bedroom-best; supporting children, adults and families living with NF.

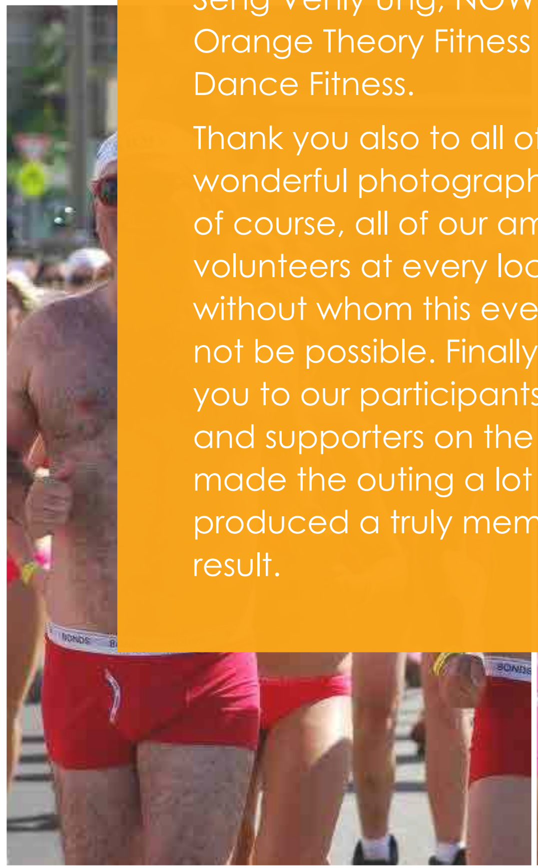
In Sydney, we were very lucky to have the support of The Bucket List at Bondi, an eatery right on the beachfront. Our ambassador, Andrew "Reidy" Reid, got everyone excited and pumped for yet another year (his involvement has been amazing from day one). He was supported by 150 of Sydney's finest fundraisers, who collectively raised over $80,000! Our highest individual fundraiser, Belinda Weihen, raised over $23,000. She was closely followed by our very own Chairman, John Hughes.

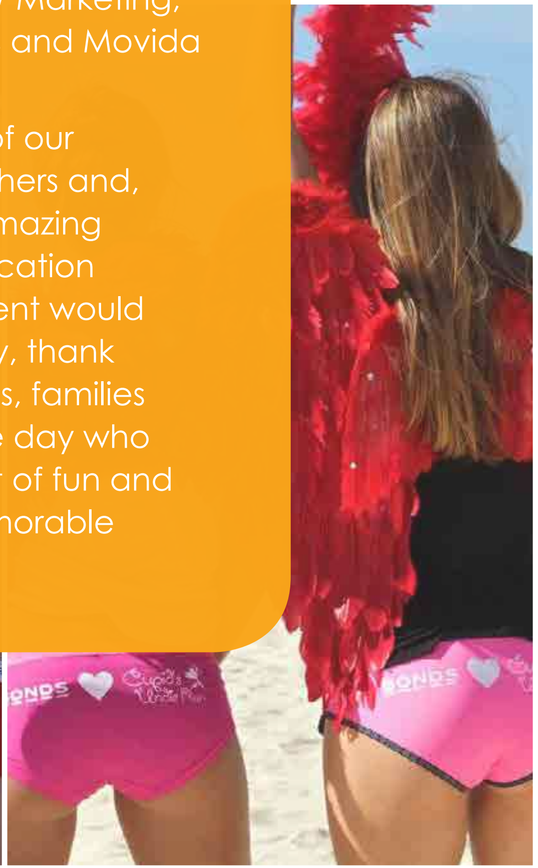
In Melbourne, down at The St Kilda Festival, we had a lot of people hanging around just to see what all the fuss was about – why 140 amazing people were in their Bonds undies, right next to Luna Park! Justin Smith got everyone running and we finished in the park with a live band; all the bodies, in their undies, were blessed with some nice Melbourne sunshine.

And for yet another year, The Barney Army came out in force, breaking all records with an outstanding fundraising effort for a team, raising over $63,000!

On the Gold Coast for a second time, we had Jade Hatcher (one of our amazing ambassadors) running the show. We had a small but enthusiastic contingent of around 60 committed fundraisers who sprinted up and around Burleigh Heads – they got some brilliant coverage on the TV networks too! In fact, across the board, 2016 was our best year yet in terms of local and national media coverage; no less than 26 articles covered what we did on the day. We are grateful for that since it is such a great way to raise awareness for NF, nationwide!

All this great work helped increase awareness of NF across the community and, importantly, resulted in an outstanding fundraising outcome. The final total came in at just under $240,000!





These funds will go a long way, towards: supporting the world-class research that we help fund at Australia's leading NF Clinics, increasing support services that we operate nationally and purchasing state of the art equipment that improves quality of life for those in our community affected by NF.

In 2017, Cupid's is going national for the very first time so watch out for a Cupid's Undie Run that will be happening near you!

Thank you to our key partners and sponsors for supporting our 2016 event: Bonds, Radio Rentals, Acer, The Bucket List, SJW PR, Andrew "Reidy" Reid, Jacqueline Alwill, Jade Hatcher, Justin Smith, Trophyland, Castel Electronics, Green Peppercorn, Burleigh Heads Life Saving Club, Jetts Fitness, Body Matrix, The St Kilda Festival, Seng Venly Ung, NOW Marketing, Orange Theory Fitness and Movida Dance Fitness.

Thank you also to all of our wonderful photographers and, of course, all of our amazing volunteers at every location without whom this event would not be possible. Finally, thank you to our participants, families and supporters on the day who made the outing a lot of fun and produced a truly memorable result.

A Luxurious Night on the Town for NF

THE BLACK & GOLD GALA DINNER IN SYDNEY

Our annual Gala Dinner is a major fundraising event, raising critical funds to sustain support services for children and adults living with NF. In 2016, it was hosted in one of Sydney's trendiest establishments, the Ivy Ballroom. It was successful in raising an astonishing amount of money and providing a memorable night for all involved.

All in all, The Black & Gold Gala Dinner contributed over $500,000!

The Gala Dinner attracted 350 people, with guests including CEOs and Executive Managers of some of Australia's leading health corporations as well as health professionals from The Children's Hospital at Westmead and Royal North Shore Hospital. Guests enjoyed a three course meal while learning about NF from special guest speakers, including: Dr Mimi Berman (Head of Department of Clinical Genetics at Royal North Shore Hospital) and Fiona, a NF Hero who is 12 years old (daughter to Geoff and Helen Bottom, members of the CTF Committee and Board), who spoke about her everyday challenges living with NF.

The venue was beautifully styled in the "black & gold" theme by Phillip Carr, setting the scene for a night of glamour and sophistication. The event kicked off with a silent auction (that had opened 10 days prior to the event) with a wide range of items, including: luxury getaways to Hawaii, Tuscany, Queenstown, the Hunter Valley and Port Douglas; women's and men's high end designer fashion items from brands including Gucci, Jimmy Choo, Valentino, D&G and Raymond Weil; "Money Can't Buy Experiences" including a day with Bondi Rescue, a stay at Gerry Harvey's private accommodation followed by a VIP tour and wine-tasting with Bruce Tyrell. Other items included: sought after artwork, furniture, electricals, fine jewellery, luggage, collectors' items, photography sessions, sailing experiences, memorabilia, dinner at Rockpool, Beppi's restaurant and more.

Live auction items were among the main attractions of the night, with the expert assistance of auctioneer Jason Kazanis. Prizes included a Bathurst 1000 VIP Experience, especially put together for our Gala Dinner thanks to Supercheap Auto, a Gregory's black and white diamond necklace thanks to Doves Nest Foundation, one week's work experience at Channel 7's Sunrise and a limited edition Kimberley Sunset coin featuring an Argyle Pink Diamond thanks to J Farren Price. A champagne bar was set up with patrons purchasing $100 glasses of G.H. Mumm for the chance to win a Gregory's pearl and diamond necklace valued at $12,500. Two wishes were also granted on the night, which saw the purchase of a much-needed laser machine for the NF Skin Clinic and a NF Symposium.

The night concluded in high spirits with our headlining music duo Peking Duk getting all the guests up off their seats and onto the dance floor.

Thanks to the support of all these generous businesses, and everyone who attended, we were able to raise a substantial amount of money as well as raise the national profile of Neurofibromatosis.

We would also like to thank: Helping Hands for their overall contribution, MC Kent 'Smallzy' Small from Nova FM, Merivale for hosting, Regression for their design work on the auction book and other displays, Sony Foundation for providing entertainment, SJW PR for assisting with PR and events, Bendigo Bank for terminals, Elevencom for their beautiful video production of NF Hero Emily as well as beverage sponsors G.H. Mumm and CRU Wines.

The funds raised will continue to sustain and grow our National Support Network in order to better serve adults and children living with NF across Australia. Thank you to everyone who participated and we hope to see you again next year!

A New Initiative with a Promising Future

WALK OF HOPE IN SYDNEY AND MELBOURNE

We introduced a new annual event, Walk of Hope, to our communities in Sydney and Melbourne. Like other initiatives, its purpose is to raise funds and awareness for our ongoing activities in support of children and adults living with NF. We chose May for our inaugural events to coincide with NF Awareness Month.

Small but excited contingents took part in our first events, with 48 walkers joining us in Melbourne and 82 participating in Sydney. They enjoyed beautiful weather while walking along some of Australia's most scenic coastal landscapes.

Although we are aiming for more participants in 2017, our inaugural Walk of Hope events together raised more than $32,000 – a fantastic result and more than enough reason to keep this new initiative going! A big thank you to everyone who participated and contributed.

Around $10,000 was raised in Melbourne and around $22,000 came from Sydney. We see a Melbourne-Sydney fundraising rivalry developing over the coming years!

Melbourne participants walked roughly 14 km from Williamstown to St Kilda, crossing the Yarra River using the Westgate Punt Ferry. A water station and cheer squads were established along their route to keep them going. They ultimately met again at the finish line at Veludo, where refreshments were served and an award ceremony held; the highest fundraiser, Naomi Elkin-Jones, won a Thorn Tablet for raising over $1,500!

Sydney participants commenced their journey at the Arthur Byrne Reserve in Maroubra, walking past the beautiful beaches of Coogee, Clovelly, Bronte and Tamarama, until they reached the very trendy Bucket List at the iconic Bondi Beach. Walkers were welcomed with refreshments, followed by a presentation from our CEO Richard Hughes and CTF Ambassador Jacqueline Alwill from The Brown Paper Bag. They thanked all of our walkers and fundraisers, singling out Geoff Bottom- who also won a Thorn Tablet- for having raised over $9,200!

> “We look forward to growing this event in the coming years and achieving an even better result for our community next year. We hope to see you there!”

Walkers who take part in our peer-to-peer events, like the Walk of Hope, automatically become a member of our team Yellow Penguin Army (YPA). YPA was founded to unite people behind our cause and work towards raising money for our fight against NF. We do this through fundraising and also raising awareness.

We would like to thank our Melbourne event staff and volunteers, including: Slavka, Mario and Natalie; as well as our Sydney team and volunteers, including: Stana, Kaitlyn, Michael, Alexis, Francis, Hareth, Roxana, Sarah and Yiming; for making this event possible, let alone the success that it was.

An integral part of an event like Walk of Hope is for our participants to meet new people within our community. In addition to keeping active, these events are great social opportunities that are deeply valued by NF families and friends. The money raised goes towards: research projects, local support programs and funding specialised equipment.

Stories from the Community:

OUR COMMUNITY HEROES

We would like to take this opportunity to share four stories from our community. These individuals and groups have organised their own events to raise much-needed funds and awareness for NF in their local areas. We could not be more grateful to have such wonderful, caring and capable people around us. They saw a need in their community or family and then did something about it. They are, very much so, our Community Heroes!

With gratitude
to each of our
Community Heroes
for sharing their
stories.

Broken Hill Family Fun Day

Brooke Lance from Broken Hill works for Family Day Care Australia. One of the kids at her day care centre had recently been diagnosed with NF. She decided to do something to promote NF awareness in her local area. With support from family, friends, the community and local businesses, she organised the amazing Broken Hill Family Fun Day that was held in March. Through the kind generosity of her local community, she was able to raise $3,806.40 on the day! The event was a great opportunity to build NF awareness and promote understanding in the local community.

Alabar Gold Crown Carnival

In February, Marianne Donnelly and the Bathurst Harness Racing Club hosted the Alabar Gold Crown Carnival and appointed the Children's Tumour Foundation of Australia as the beneficiary charity of the event! This 10-day event included 6 race meetings and 6 social functions as well as a Miss Gold Crown Competition. The event raised over $2,147 for CTF to help us deliver much-needed NF support services. They have also helped spread the word about NF and our work in the fight against it.

A Huge Morning Tea

Kay Muir's beloved granddaughter suffers from NF1. As a result, Kay is keen to make a difference in the lives of people living with NF and to promote NF awareness in her local community. She hosted a Huge Morning Tea during May to coincide with NF Awareness Month. More than 40 local community members joined her on the day, along with our own National Support Coordinator, Sally. This event raised $1,712 on the day to support our ongoing work and mission. Kay is one of our most active and invaluable volunteers in support of multiple CTF events, like: the Being YOUnique international photography competition, the Walk of Hope and more.

Long Table of the Season Dinner in Auburn

Dianne Tilley's grandson, age 4, suffers from NF. To her, organising this event was a form of therapy; taking back a sense of control in very difficult circumstances. With the help and commitment of Daniel Moss, her family, friends and community, she organised a Long Table of the Season dinner to support NF research. It was held at Daniel's restaurant, Terroir Auburn, with produce matched to Clare Valley wines. With the generous donations of those in attendance, the dinners raised $12,400 in total!

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