



The Children's Tumour Foundation

Year in Review

July 2018 – June 2019





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Message From Our Chair

The past year has been marked by both successes and challenges but most importantly one in which we have been again able to provide a strong level of support for members of our NF community, through a range of initiatives, and continued funding of research.



An issue that has been raised more so in the last year than previously has been the suggestion that there should be more funding of research. Whilst this is certainly an objective of CTF, the current core focus of

the organisation is to maintain and expand the level of support services available on a national scale. Research requires a significant amount of funding commitment and overseas countries are currently better placed to raise such funds and undertake such research. We continue to support these research efforts by assisting in local trials as part of global research efforts.

Today, NF clinics are available in Sydney and Melbourne, and these exist because of the funding that CTF provided in initial stages of development along with our ongoing commitment.

Our hope is to have a facility launched in Brisbane in 2020 and then other major cities as funds allow. Each of these initiatives require significant development work with local health authorities and the dedication of medicos who have a passion for NF.

In addition, there is the provision of a range of community activities such as the family camps that provide a great opportunity for families to share their stories and the children to enjoy a wonderful time together in a safe environment without feeling 'different'.

Most importantly, all of our endeavours require significant amounts of funding, hence fundraising is the absolute key in enabling CTF to continue current programs, expand others and fund further research.

It is pleasing to report that Cupid's Undie Run, NF Hero Challenge, Silent Auction and Tax Appeal all contributed

strongly and continue to grow. Development of further corporate sponsorships is a major focus for the future.

The appointment of Louise Skilbeck as CEO, who has a strong background in corporate sponsorship, supported by a team with a broad range of fundraising experience, plus a dedicated group of 'hands on' directors, means the organisation is well placed to generate the essential funding required to achieve our goals.

In addition, every bit of fundraising support generated by the NF community helps enormously. Whether it be a sausage sizzle at a Bunnings, a cake stall outside the local supermarket or a raffle, every dollar makes a difference.

This is my last Annual Report as I have retired from the board after a very exciting and yes, definitely challenging 10 years in helping to develop CTF into the organisation it is today. My inspiration for involvement was my mum Shirley who suffered terribly from NF and it eventually led to her death. However, the wonderful people I've met in the NF community, especially the children, have given me constant inspiration and joy.

I'm delighted to be handing over to Kerrie Kelly as the new chair, because I know that she has the skills, heart and passion to help guide CTF to a new level of achievement.

My personal and sincere thanks to all my colleagues from over the years and countless friends in the NF community for your wonderful friendship and support.

Best wishes

John Hughes
Chair, Children's Tumour Foundation

Message From Our CEO

Since stepping into the role of CEO last November, I have felt honoured to be given the responsibility of working with a team who empathise deeply and work tirelessly supporting those impacted by Neurofibromatosis (NF).



As we know, NF lacks awareness and is often misunderstood. The word itself is not easy to say and, as those of you impacted can attest to, it's even harder to live with. I continue to feel the weight of that statement with

every MRI result shared or conversation had with an anguished parent, and know that building awareness, knowledge and understanding of this condition is how I will best serve those living with NF.

A large part of my first seven months has been spent reviewing key areas of the business, including staffing, operational efficiency, addressing the lack of awareness and critically, looking at ways to diversify our revenue. In consultation with the board, this review has resulted in a number of changes, as well as the introduction of new processes and systems.

In doing so, we were acutely aware that this would impact FY19 revenue. We accepted that the changes were necessary to build a platform that would grow the organisation and move us forward.

Despite the revenue dip, I am pleased to report that we increased our provision of services across all areas including:

- Reaching the milestone of > 1000 patients supported across NF clinics;
- Increasing our national online and phone support coverage by 20%;
- Introducing Youth Chat sessions to help young people connect;
- Hosting four educational webinars;
- Welcoming a record number of families to camps; and
- Boosting our local event calendar.

We also diversified our income streams and were successful in securing a number of grants that will see

new services and equipment added next year including six family camps (including Far Nth Qld, SA and the ACT). We appointed our first dedicated staff member to actively pursue sponsors and new partners and saw significant increases in our online fundraising potential, having rolled out a much improved and less costly donation portal.

Our major fundraiser, the Cupid's Undie Run, enjoyed increased participation and a record audience reach of > 4 million. We made in-roads into schools as part of our annual Mates Day initiative and rolled out a very successful, "A Mother's Love" Campaign during May Awareness month. This led to a record tax appeal that raised \$100,000 to support the upcoming TiNT (MEK Inhibitor) trial for Australian kids and young people.

Without doubt it has been a busy start to my tenure as CEO. The new team I have assembled is capable and passionate, and I am excited by the positive trend lines in our social media and marketing campaigns in building awareness.

I would like to acknowledge John Hughes whose planned retirement as Chair has recently been announced. John and his wife Robyn have given a decade of their time, skills and personal generosity to the NF Community. I do hope they feel a sense of pride seeing the organisation as it stands today and am pleased that they have been acknowledged by the Board, who have appointed him as a Life Patron.

May I also express my sincere appreciation to all of our partners, sponsors and donors. Without your support, the CTF could not provide the services to our NF Community. I look forward to deepening our partnerships and growing new ones, as it is only by working together that we can #conquerNF.

Louise Skilbeck

CEO, Children's Tumour Foundation

About Us

Our Purpose

The Children's Tumour Foundation of Australia (CTF) is the leading national charity supporting individuals and families impacted by Neurofibromatosis (NF) in Australia.

While some people with NF will never suffer major complications, for others the condition can be severe, debilitating and even life-threatening.

Unfortunately, it is impossible to predict how mildly or severely someone with NF will be affected, so we exist to help those impacted by NF navigate a pathway from fear to hope.

We believe that tumours should never be a person's normal and we are on a mission to create hope while we work passionately to #conquerNF.

WE EXIST TO HELP THOSE IMPACTED
BY NF NAVIGATE A PATHWAY FROM
FEAR TO HOPE.

Who We Are

We are the link that connects people with NF to services. We are dedicated to raising money to fund vital research, awareness and practical support for people with all types of NF.

We are focused. We work in pursuit of an important mission and understand that many people are counting on us.

We are a united and collaborative team. Teamwork comes naturally to us because of our passion and dedication to do the absolute best we can to fight the one common enemy.

We are not afraid to work hard and know that trust must be earned. We accept responsibility for our actions, hold ourselves accountable for our results, and take ownership of our mistakes.

We are continually evolving. We encourage feedback and are always striving to do things better. We are confident enough to know that just because we do things a certain way now, doesn't mean we can't find a better way.





What We Do

We empower individuals and their families impacted by NF with the knowledge, connections and support needed at every stage of their journey, working to improve life outcomes in three ways:

- Support Services
- Research
- Advocacy

By providing access to critical support services:

Beyond the need to treat the physical symptoms of NF, living with this condition can also take an emotional toll. To help reduce feelings of isolation and anxiety, the CTF creates opportunities for people to come together in safe, supportive spaces; encouraging them to connect, learn and share stories. Some of the ways we do this include:

- National phone and online support network
- Family camps and community days
- Information Seminars
- Online chat sessions
- Parenting support groups
- NF Sipper Clubs

WE EMPOWER INDIVIDUALS AND THEIR FAMILIES IMPACTED BY NF WITH THE KNOWLEDGE, CONNECTIONS AND SUPPORT NEEDED AT EVERY STAGE OF THEIR JOURNEY.

By investing in effective treatments:

We invest in better treatment solutions and health outcomes in two ways:

- Multi-disciplinary NF clinics that give patients access to support coordinators and specialist clinical nurses who help patients and their families navigate the complex hospital system and provide information on diagnosis and treatment options for the ongoing care and monitoring of NF symptoms.
- Research into effective treatment solutions that deliver better understanding of the impact of NF on social and developmental issues like autism, ADHD, anxiety, auditory processing and other learning and behavioural issues, as well as bringing advanced clinical trials of drug treatments that have been successful internationally into Australia.

By raising awareness and advocating for the NF community:

NF is more common than Cystic Fibrosis, Muscular Dystrophy and Huntington's Disease, but awareness is lacking - even among some healthcare professionals.

In addition to raising awareness through campaigns and fundraising initiatives, like the Cupid's Undie Run, we also collaborate with hospitals and help our members navigate health systems, as well as their government entitlements. Additionally, we provide contact details for medical and allied health professionals who have experience treating NF patients.

Working with state and federal governments, we advocate for improvements in availability and cost of diagnostic scans, medications and improved treatment options.

We create opportunities for schools, corporate and community groups to engage and fundraise to help improve the life outcomes of people with this genetic disorder.

What is NF?



EVERY 3 DAYS A CHILD IS BORN WITH NF IN AUSTRALIA

NF IS A LIFE-LONG CONDITION THAT IS PAINFUL, UNPREDICTABLE AND PROGRESSIVE.



NF AFFECTS ALL POPULATIONS, GENDERS & ETHNICITIES EQUALLY

Neurofibromatosis (NF) is a set of complex genetic disorders (NF1, NF2, and Schwannomatosis) that can affect almost every organ system, causing tumours to grow on nerves in the brain, spine and throughout the body.



NF AFFECTS 1 IN 2,500 PEOPLE IN AUSTRALIA

A PARENT WITH NF HAS A 50% CHANCE OF PASSING IT ONTO THEIR CHILD



NF can lead to a range of significant health issues including deafness, blindness, paralysis, physical difference, bone abnormalities, cancer, learning difficulties and chronic pain.

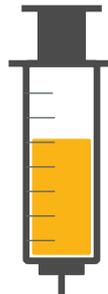
NF can affect anyone regardless of ethnicity or gender. It is impossible to predict how mildly or severely someone with NF will be affected and roughly half of all cases arise in families with no history of NF.



BETWEEN 60-80% OF CHILDREN WITH NF WILL EXPERIENCE LEARNING DIFFICULTIES



APPROX 15% OF CHILDREN WITH NF1 WILL DEVELOP AN OPTIC NERVE GLIOMA



THERE IS CURRENTLY NO CURE FOR NF AND TREATMENT OPTIONS ARE LIMITED

Strategic Focus

The Children's Tumour Foundation works to improve life outcomes of those living with NF by empowering individuals and their families with the knowledge, connections and support needed at every stage of their journey.

Our key areas of focus for the next 12 months are:

Support



1. Expand the current footprint of multidisciplinary clinics (Sydney and Melbourne) to another state.
2. Improve diagnosis capability of front-line medical personnel.
3. Expand the services focused on Youth Services.
4. Expand our Peer Support Program to cover the larger regional centres of Australia.
5. Provide programs to help parents and adults deal with the unique challenges of NF.

Research



1. Provide funding for the MEK Inhibitor Trial.
2. Support local studies around the social and developmental challenges faced by children with NF.
3. Seek increased funding from all levels of government and other philanthropic sources for NF related research in Australia.
4. Form stronger relationships with overseas organisations who concentrate on NF research.

Advocacy



1. Advocate for increased funding for the CTF as the national patient representative group.
2. Establish a Medical Advisory Committee.



Operational



1. Continue to diversify and grow revenue streams.
2. Attract, engage, develop and retain effective staff.



Key Outcomes

This report provides the key outcomes for services and projects completed during the period 1 Jul 2018 – 30 June 2019.

Support Services



2,776

hours of online and phone support provided by CTF and NF Clinic Support Staff.



4

webinars hosted.



3,150

support-related interactions by phone and email.



3

NF Family Camps hosted across three states and attended by 269 people and 116 families:

- 95 people in NSW
- 90 people in QLD
- 84 people in VIC.



1,008

patients assessed in four NF Clinics across two states (NSW and VIC)

The Children's Hospital Westmead

- 388 patients seen at the clinic
- 60 newly diagnosed children referred

Royal Children's Hospital Melbourne

- 339 patients seen at the clinic
- 77 newly diagnosed children referred

Royal Melbourne Hospital

- 32 patients seen at the clinic
- 20 new patients referred

Royal North Shore Hospital

- 249 people treated at adult skin clinic at Royal North Shore Hospital, a 93% increase on previous year.



9

Community days: Melbourne (4), Sydney (3), Hobart (1) and Townsville (1).



27

NF Sippers Meet Ups across Melbourne, Kiama, Western Sydney and other locations.



1

NF Conference hosted approx. 32 Health Professionals.



200

hours of facilitated online support groups provided.



87

attendees at the Community Information Seminar.



12

facilitated online youth chats.



NF2 Tertiary referral service established at RNSH for adult patients seeking advice about chemotherapy.

SINCE 2010, THE CTF HAS INVESTED OVER \$1 MILLION INTO RESEARCH AND CLINICAL TRIALS TO SUPPORT MEN, WOMEN AND CHILDREN AFFECTED BY NF.

Research



TiNT MEK Study: \$100,000 raised to support an Australian-based MEK Inhibitor Research Trial. This will support a five-year program to study the impact of Trametinib on young people aged 3 months to 25 years with NF1.



28 women recruited for NF1 Breast Screening Study at Royal North Shore Hospital. Early success has led to changes in the eviQ treatment guidelines.



Efficacy studies conducted of topical rapamycin for reducing cutaneous manifestations.



NF1 Severity Scale research led to the development of an overall scale designed to enable clinicians to communicate effectively with each other and to ensure optimal clinical care is provided.



Research into the link between children with NF1 and auditory processing deficits with associated speech perception problems.



Documenting and characterising MRI brain changes seen in children with NF1 at the RCH clinic.



Predictors of Autism in NF1 Development to Adolescence discovered using functional MRIs.



Research into the genomic causes of malignant peripheral sheath tumours in patients with Schwannomatosis.

Advocacy



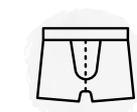
33%

uplift YOY in accumulative reach on the CTF Facebook page in the last quarter.



475

people attended NF Hero Event Days in 2018.

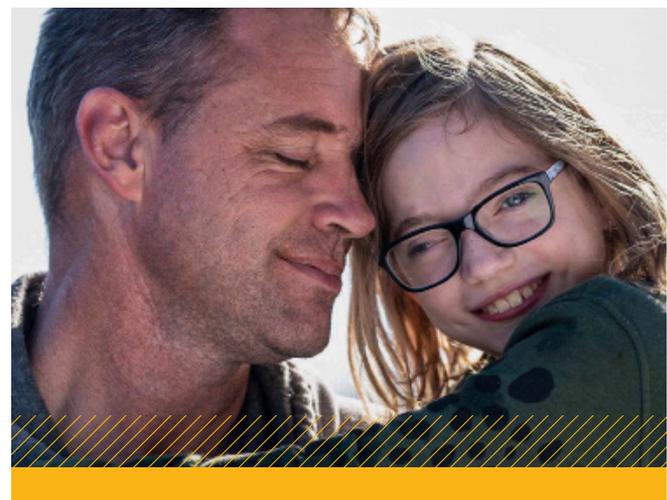


1,500

runners participated in the 2019 Cupid's Undie Run across 15 locations. Cupid's had a reach of over 4 million impressions, including five prime-time TV segments.



Advocacy efforts resulted in a new Breast Screening protocol being developed, which will offer women with NF1 aged 30-50 years access to a free breast cancer screening program (including MRI, mammogram +/- ultrasound) under Medicare, resulting in less out of pocket costs for patients.



Financial Report

The statutory accounts for the year ending 30 June 2019 have been audited and the full copy of the accounts can be found on our website: www.ctf.org.au

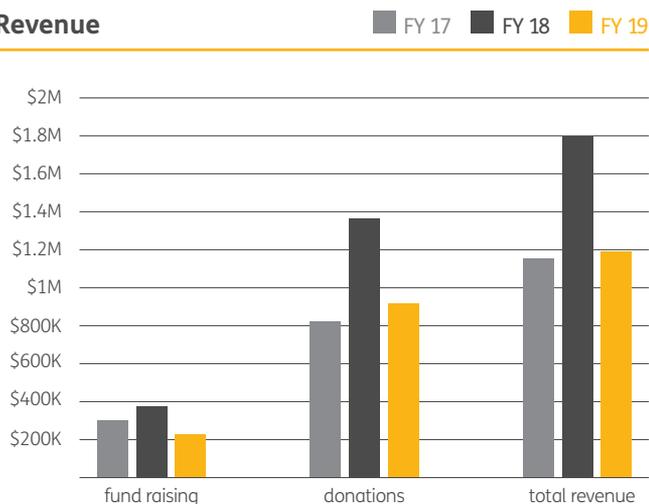
The following information is an abbreviated version of the Audited Annual Accounts for the Children's Tumour Foundation of Australia for the past 5 years.

	FY 15	FY 16	FY 17	FY 18	FY 19
	\$ 000s				
Revenue	1,172	1,398	1,163	1,813	1,185
Expenses	1123	1,003	777	1288	862
Operating Surplus	49	395	386	525	323
Grants - Research	88	48	178	191	133
Support Services	91	165	137	201	412
Grants & S/Services	179	213	315	392	545
Net Surplus/(Deficit)	(130)	182	71	133	(222)
Cash	974	1182	1,297	1,296	1,234
Other Assets	92	63	62	244	129
Total Current Assets	1,066	1,245	1,359	1,540	1,363
Fixed Assets	5	6	4	5	15
Other Assets				35	7
Total Assets	1,071	1,251	1,363	1,580	1,385
Current Liabilities	49	47	88	172	200
Net Assets	1,022	1,204	1,275	1,408	1,185

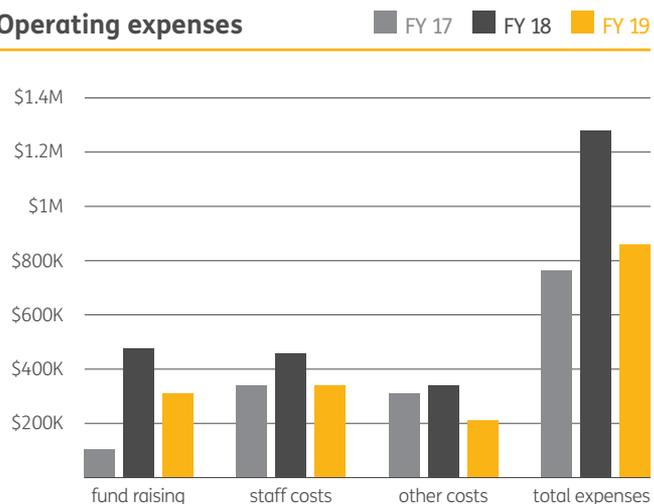
Financial Report (Cont'd)

GENERAL

Revenue



Operating expenses



SUPPORT SERVICES

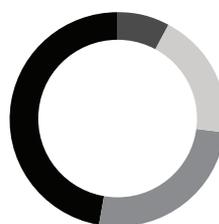


Increase in Support Services over the last year of 105%.

FY2018 – \$201,000

FY2019 - \$412,000

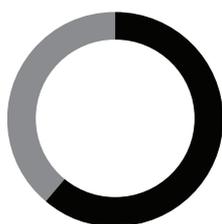
In FY 2019, the breakup of our Support Services was:



NF clinics	47%
National support	26%
General support	19%
Family camps	8%

CUMULATIVE RESEARCH

Money invested into research to date



Children	61.3%
Adults	38.7%



As at June 30 2019, the CTF has invested over **\$1 million** in NF research to date.

Breakdown of research investment



General NF Symptom Research	52.2%
Clinical Testing of Improved Treatments	38.8%
Social & Learning Development in NF Children	9.0%

Board of Directors

Our board has extensive professional knowledge and are all well-respected in their areas of expertise. Each member of the board plays an important role in strategic planning at the Children's Tumour Foundation and gives their time and skills on a voluntary basis.

John Hughes, Chair

Member of the Lisa Palmer Foundation Committee

John was previously Deputy Chair of Fantastic Holdings Ltd, CEO and Managing Director of Thorn Group Ltd. He was also Managing Director of Ruralco Holdings Ltd. He has more than 40 years' experience as a director and senior executive experience in a number of leading Australian and International companies including Thorn EMI, Dominos Pizza, Sharp Corporation, Competitive Foods and Grace Bros. He is also Director of Infonet Australia Pty Ltd and Co-Founder of Doves Nest Foundation.

Hugo Dudley-Smith, Director

Member of Audit & Risk Committee

Hugo is a Managing Director of the independent investment firm Gresham Advisory Partners. He has extensive experience in providing advice in relation to corporate strategy, M&A transactions and capital raising and previously worked with Goldman Sachs in London and Sydney.

Nirmal Hansra, Director

*Chair of Audit & Risk Committee
Member of the Lisa Palmer Foundation Committee*

Nirmal is Chair of Campbell Page Ltd, Non-Executive Director of Eureka Group Holdings Ltd, Link Housing Ltd, Kuringai Financial Services Ltd, Have A Voice Pty Ltd and Council of the Aging NSW. He has more than 12 years' corporate advisory and board experience and 35 years' senior executive experience as Finance Director/ Chief Financial Officer of leading Australian and International companies, including Industrea Ltd, Australian Pharmaceutical Industries Ltd, Ruralco Holdings Ltd, Rentworks Ltd, NetComm Australia Pty Ltd, Fujitsu Australia Ltd and Texas Instruments Australia Ltd.

Geoff Bottom, Director

Chair of NSW State Committee

Geoff has more than 35 years of retail experience. He is currently Store Manager of Bernardi's Supa IGA in Bathurst NSW. Geoff is actively involved with the Rotary Club of Australia and has received the Paul Harrison Award and the Blue Sapphire Award for fundraisings.

Stephen Kulmar, Director

Chair of the Marketing Committee

Stephen is Chair of Edge & Co Pty Ltd, Non-Executive Director of Thorn Group Limited and RCG Corporation and Founder of Retail Oasis, a boutique retail marketing service company. He was previously Chairman and CEO of IdeaWorks and has more than 30 years' experience in retail and brand strategy, channel to market strategy and business development.

"I BECAME INVOLVED WITH THE CTF QUITE SIMPLY BECAUSE I WANTED TO HELP WITH THE TREMENDOUS WORK THE ORGANISATION DOES IN RAISING FUNDS AND SUPPORTING THE NF NETWORK."

Hugo Dudley-Smith

Laurence Dell, Director

Chair of Victorian State Committee

Laurence is a Partner at PwC in Melbourne, leading the enterprise performance improvement practice. He specialises in delivering productivity programs that result in significantly improved and sustainable business performance. With over 15 years consulting experience, Laurence has led complex performance improvement projects across a range of industries. He is an expert in the telecommunications industry.

Peter Krideras, Director

Member of the Marketing Committee

Peter has more than 20 years' retail experience and is the former co-founder and director of Global Market Place, which owned Australia's leading online events platform Click Frenzy and number one online publication *Power Retail*.

Anthony Robson, Director

Member of Audit & Risk Committee

Anthony is currently CEO and Managing Director of Yieldbroker Pty Ltd. He was previously Managing Director and Head of Markets at Barclays Australia and Managing Director at UBS (London and Sydney). He's a Member of AFMA Governance Committee, previously Board Member of iSwap Australia, Club Captain and Board Member of Avondale Golf Club. Anthony has over 25 years in Financial Markets living and building businesses in Sydney, London and New York.

Lisa Barclay Shand, Director

Member of Audit & Risk Committee

Lisa has more than 30 years' experience as institutional account executive in the Australian equity market working for global investment banks such as ABN Amro, RBS Equities Australia Ltd and Nomura Australia Ltd. She is currently Director of Sydney, Morgans Financial.

Alissa Hildebrand, Director

Member of the Marketing Committee

Alissa is Managing Partner of VIP Sydney and the former Chief Operating Officer of Beluga Capital and former CEO of Valet Private – Australia's leading Concierge and Travel business catering to high net worth individuals and families. She has more than 20 years' experience in a variety of executive roles both in Australia and the United States. Her industry experience covers media, banking, healthcare, technology, childcare and travel.

Adon Tse, Director

Adon is Founder and Managing Director of Royale Group of Companies and has more than 10 years corporate experience in advisory, funds management and financial and property markets. He's a securities trader and investor in Australia, Hong Kong, Macau and Singapore.

A True NF Hero

Cupid's 2019 was dedicated to NF Hero Belinda Weihen, who sadly lost her battle with cancer in October 2018. She was a huge fan of the Cupid's Undie Run event and could always be found at the top of the fundraising leaderboard.

Belinda was brave, hilarious, incredibly positive and embodied the Cupid's spirit. She was a constant source of support and inspiration for the NF community, and even while battling chemotherapy and recovering from her countless surgeries, she did not miss a chance to raise awareness of NF.

Last year (2018) was Belinda's fourth Cupid's Undie Run, but it was also the year she tragically lost her battle with cancer. The entire community grieved and she is missed every day.

Her memory and courage live on and it was incredible to see Belinda's friends and family carry on her legacy for Cupid's 2019 in her team 'Bee's Best Undressed'. Together, they raised \$29,241 and helped ensure that Sydney topped the country for fundraising. We miss you Bee, and promise to carry on your fight to #conquerNF through the Cupid's Undie Run.



Team Bee at Opera Bar 2019



Belinda at Cupid's Undie Run in 2018

Acknowledgements

We are constantly heartened by the generosity of the people and organisations we connect with as we work towards improving outcomes for people impacted by NF.

The Board and management of the Children's Tumour Foundation would like to express their gratitude to all donors, sponsors and partners who have helped us to achieve so much in this financial year. We are indebted to all of you. Your generosity, time and resources are all appreciated and we trust you will continue to partner with us so we can continue to support and connect our NF community to the people and resources they need to have the best life possible.

Due to the space available, we are only going to list significant partners here in alphabetical order. However, please do know that we appreciate even the smallest donor as every donation or small community fundraiser, when combined with the power of numbers, enables us to continue to move closer to our mission of Conquering NF.

Corporate

Acer Computer Australia
Gresham Partners
Insitu Group
Jaxam Industries
Jufan Investments
Morgans Foundation
Orion Print Management
PBK Management
Petit Barcelona
Whiteley Medical
Yieldbrokers

Major Donors

Brian Gallery
Eddie and Melanie Listorti
John and Robyn Hughes
Laura Filia
Margaret and Des Dodds
Oliver and Brooke Smith

Pro Bono Support

Brand Haven
Crowe Horwath
Elevencom
Elton Ward
Herbert Smith Freehills
Simcosec
Nine Cares
vbe Creative

Foundations

Australian Chinese Charity Foundation
Australian Stockbrokers Foundation
Doves Nest Foundation
Golden Health Personal Super Fund
Mazda Foundation
Perpetual 2019 IMPACT (Baxter Foundation)
QBE Foundation
Syd Stass Perpetuity Fund /LATMA
Australia
The Barney Research Fellowship

Community Fundraisers

Cam and Jen Elliott
Hampton Yabbie
Janu Dhayanathan
Kay Muir
Marisa Gullo
Mia Lawrence

Top 10 Cupid's Undie Run Teams

1. Emme's Cupids
2. Best Undressed
3. Libby's Lionhearts
4. Eddie's Village
5. Bella's NF Heroes
6. Xavier's Team
7. Easier Said Than Run
8. Darcy
9. The Athlete's Foot Team
10. Jasmine's Jelly Jumpers

Cupid's Undie Run Ambassadors

Amoss McKinley
Ben Keays
Cameron Merchant
Dan Conn
Davina Smith
Dolly Diamond
Felicity Egginton
Glen Buttriss
Jai Arrow
Jai Whitbread
Jake Spence (Apollo)
Josh Horner
Josh Langley
Josh Schache
Jules Robinson
Justyna Kalka
Meghan Jarvis
Melissa Wu
Mike Gunner
Nick Robertson
Sam Reid

Cupid's Undie Run Venue Sponsors

West Beach Bathers Pavilion
The Opera Bar
Envy Hotel
Mary Mae's Bar and Kitchen
The Ball and Chain
Nobbys SLSC Newcastle
The Crossing Cafe
The Carrington
Waters Edge Cafe
Panorama Hotel



NF CAN AFFECT ANYONE REGARDLESS OF ETHNICITY OR GENDER. IT IS IMPOSSIBLE TO PREDICT AND ROUGHLY HALF OF ALL CASES ARISE IN FAMILIES WITH NO HISTORY OF NF.



We would like to thank Elton Ward for giving their time freely to design the 2018-2019 Year in Review and to Harvey Norman for printing it on our behalf.

eltonwardcreative

Harvey Norman



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