

Flicker of Hope Foundation



Newsletter September 2019, Issue No 2

Welcome to our second newsletter!

It's hard to believe it has been almost a year since we launched the Flicker of Hope Foundation and what a roller-coaster ride it has been.

Our social media campaign is ramping up; we currently have 551 followers on our Facebook page and our posts have reached over 30,000 people. If you haven't already 'LIKED' our Facebook page you do so by clicking on the link below <https://www.facebook.com/flickerofhopefoundation/> and then clicking on the LIKE button underneath our main photo. Feel free to share any of our posts to help spread the word.

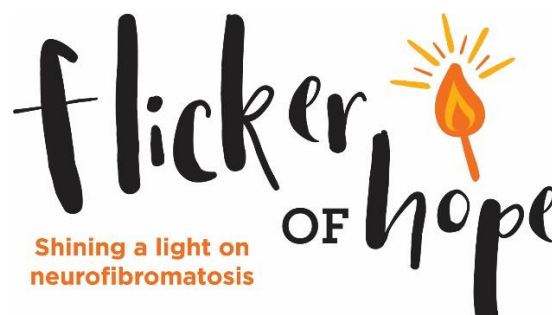
Our Instagram page was launched at the end of July by Zoe and already has 232 followers @Flickerofhopefoundation

We are proud to announce that with the support of our donors and the wider community we have almost reached our target of funding the Melbourne section of a drug trial to treat Neurofibromas.

One thing I have learned is that setting up a charity is much more involved than I could ever have imagined. A big thank you goes to Sarah from Minter Ellison who has helped us negotiate all the legal loopholes. Another thank you to all the individuals and businesses who have continued to support us. Without your help it would not be possible to achieve all that we have.

Thank you to all those who have helped shine a light on Neurofibromatosis; the future for many sufferers is now much brighter.

Anne Petropoulos



Eddie's Story

My NF journey began I suppose in 1949 when I was born, but it wasn't until I was about five years old that I was diagnosed with NF. My Grandmother who had been a nurse in the 1920's & 30's noticed I wasn't walking properly and suggested my Mum got it checked out. Subsequently, I ended up at the Royal Children's Hospital in Melbourne where the specialist (who was a leader in childhood paediatrics) told my parents that she had only seen one other similar case and that person was in a wheelchair. My diagnosis was therefore the same although I only discovered this years later when I participated in a bike race. My mother remarked that Dad was so proud of me, considering he had not expected me to walk, let alone ride a bike!

My co-ordination had always been poor, catching or kicking a ball ruled me out of ball games, hand eye mastery left me out of the cricket and softball games. Walking in a straight line and balance issues saw me leave the building trade the day after I finished my apprenticeship.

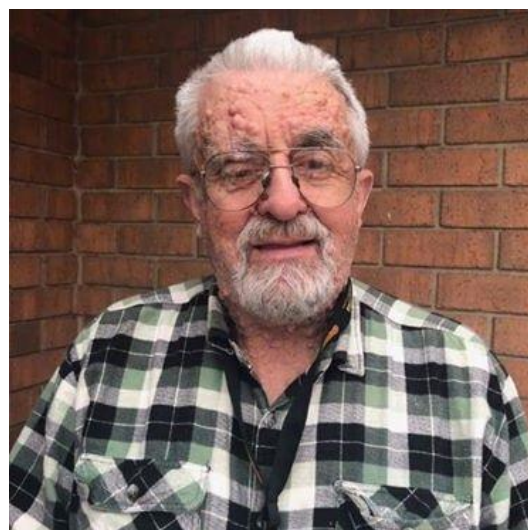
My speech issues, which I had treatment for when I was forty, successfully I might add, saw me face years of insults and assaults, including being left for dead on the side of the road by fellow work colleagues, who were pushing for me to get me dismissed from my job, in which I had risen to the equivalent of foreman because they considered me disabled and deserved a pension. My job became redundant when I was fifty-five and I never worked again.

After my redundancy I did twelve months volunteer work in a special need's kindergarten, then enrolled in Deakin University to undertake Museum Studies and Cultural Heritage. About six weeks after I sent in my last assignment, in January 2008, I was diagnosed with a malignant NF Tumour. I did several volunteer stints at some other museums and galleries until travel and fatigue issues prevented me attending regularly. At this time, I was diagnosed with PTSD relating to work issues and I was put on a pension. In 2016 I was diagnosed with cancer again; another malignant tumour.

I learnt a long time ago to focus on the things I can do, or enjoy doing, not the things I can't do. I am a Shell Collector. I collect animal skulls and study them. I have been doing research for the Morwell Historical Society. I have been involved with the Gippsland NF Support Group, the Morwell Walking Group and Morwell Rostrum Club.

I have friends I catch up with for coffee and lunch. I have friends I can liaise with on all matter of subjects. I don't fret over what I can't do or haven't done, but I am looking forward to the future.

I am an NF Survivor.



School Support

Yarra Valley Grammar school has now raised over \$4,000 for Flicker of Hope in the past year. Their first event was a senior school Cross Country event and in May they had a whole school free-dress day with a gold coin donation. The students also had the opportunity to purchase our Flicker of Hope merchandise and sport their new fashion items!

Donburn Primary school hosted a question and answer session with Zoe asking about Neurofibromatosis and how it affected her. The school did a gold coin donation which was presented to Zoe at the Q&A.

A special thank you to St Kevin's Catholic School for your generous donation.

Manningham Young Citizen of the Year 2019



Congratulation to Zoe who was voted Manningham Young Citizen of the Year for her work with Flicker of Hope. She was nominated by Freya Evans, a friend who has been inspired by Zoe and her approach to life with Neurofibromatosis. Here is a little excerpt from Freya's nomination.

"A lot of people may do volunteer work or raise money for charities, but I've never met anyone like Zoe, and she's become such a huge inspiration to me in so many ways. She puts a lot of time into her charity work and is very hard working and organised, especially as she's doing year 12 this year. Zoe's

personality is so positive, caring, compassionate, non-judgemental, brave and she's a genuinely kind, good hearted person. She's inspirational for all these reasons, but at the same time, she keeps going despite operations and other challenges that she faces daily due to NF and yet she never complains.

I admire the relationship Zoe has with her supportive family, but especially her Mum who is a tower of strength [despite her own serious health problems]. They seem to inspire and motivate each other to work hard, to go out of their comfort zones, to be optimistic and proactive for the future and to always help others. There is a lot of love and compassion in her family which is why I think Zoe is the person she is. If you get to meet Zoe, you'll understand why she's so inspiring. She radiates all the qualities I've raised; her friendliness, kindness, courage, optimism and warmth always shine through. I sometimes walk away from spending time with her feeling like I wish the world was full of Zoe's. Other times, I'm inspired to give back to my community or others less fortunate, and more recently as I've got to know her again, I really feel lucky to have a friend like her."



The award ceremony took place on Wednesday 22nd May at the Manningham Function centre in Doncaster and Zoe received her award from the Manningham Mayor, Paula Piccinini. The theme this year was 'making a world of difference' and this is exactly what Zoe and Flicker of Hope Foundation aims to do for people living with NF.

Thank You Luncheon



On 29th August we took the opportunity to host a morning tea in celebration of our first birthday and to thank our major sponsors who have donated so generously towards our research project. The event was hosted at Delta Group offices in Port Melbourne. Their support and that of others has enabled us to almost reach our target of funding for the Melbourne section of the drug trial to treat Neurofibromas.



Research into early detection of cancer in NF

Flicker of Hope is proud to announce our support of a new research programme, the aim of which is to develop a blood test for early detection of aggressive soft tissue cancer in patients with NF1.

Patients with NF1 live 10 - 15 years less than the general population. The major reason for early death is aggressive soft tissue cancers known as Malignant Peripheral Nerve Sheath Tumours (MPNSTs).

Currently, the only way to know if a patient with NF1 has cancer is if they present with a growing, hard and painful mass. The patients often present too late for a curative operation.

This multi-year project is an innovative collaboration between The Royal Children's Hospital, MCRI, The Royal Melbourne Hospital, Peter McCallum Cancer Institute, and Royal North Shore Hospital, Sydney. The project, funded by Flicker of Hope, leverages existing relationships and infrastructure to create a registry of patients and their samples to collect circulating tumour DNA for future genomic analysis.

This project will build a registry of patient samples which will be the first step in harnessing cutting edge technology in trying to develop an early detection method for cancer in patients with NF1.

Donvale Footy Club Ladies Luncheon

On Saturday 24th July the Donvale Football Club held its annual Ladies Luncheon. This year, the club decided to combine the luncheon with a fundraiser event for Flicker of Hope. A great deal of thought and organisation went into the event and a sincere thank you goes to John Giles, the Club President and Kellie Smith and her team for all their hard work.

Zoe made a speech explaining how Neurofibromatosis can impact the lives of so many people and what Flicker of Hope is trying to achieve.

Other activities included raffles and auctions. These, along with the sale of cupcakes and hoodies helped raise approximately \$4.2k.

The lunch was enjoyed by eighty women who were all interested and supportive, and our message of hope was spread that much further. Thankyou Donvale for your involvement.



Trucks on the road



Two more Delta trucks are now on their way up the Hume Highway to Canberra. This brings our total to 10 trucks and bins promoting our message. If you spot one on the road, let us know on Facebook!

Ambassadors



We are delighted to welcome Moira Kelly to the Flicker of Hope team as our newest Ambassador.

Moira's belief in the power to change the world for the better, her insight, determination and her positive attitude have made her an extraordinary role model.

Her innovative thinking and leadership have supported some of the world's most disadvantaged children from an early age in countries including Australia, India, Romania, Bosnia, Botswana, Albania, South Africa and the USA. Her own home is like stepping into a mini United

Nations, there are children from Bangladesh, Pakistan, Sri Lanka and Nairobi. They are all equally loved and equally valued; it is the happiest home one could imagine.

Moira's interest is also compounded by the fact that one of her children, Angel, aged 7, also has a congenital disorder that results in the growth of tumours through her body. It is not NF but a very rare condition called Cloves Syndrome.

Like us, Moira is full of hope for the future. She understands that without research into conditions like NF meaningful treatment will not be found and is therefore enthusiastic about helping us further our cause.

We look forward to the positivity and ideas that Moira can bring to the table, helping us move forward in our second year.



From the Board's Perspective

The Flicker of Hope Foundation is incredibly important to our family. Our daughter has NF.

In the early years following of our daughter's diagnosis, we learnt about NF and put our effort into supporting our daughter but it was evident that although this disease impacts one in every 2500 people, very little is truly known about NF and how to treat the condition.

We were living overseas in Asia when our daughter was diagnosed with NF. We came to Australia for monitoring and treatment, as Australia is one of the few places in the world with experts in this field. When we moved back to Australia, we wanted to do more to help research NF so that better treatments and management could benefit our daughter and the millions around the world like her.

As a Director, with the rest of the Board of Flicker of Hope Foundation, I can help to personally drive forward to improve the community awareness of this condition and fund the best research possible to help NF people lead the best lives possible.

Thank you for your support to the Flicker of Hope Foundation.

Let's continue to shine a light on those with NF.

Mark Nicholls (Board Director)

Big Birthday Raffle for Research

Every birthday should be celebrated, and Flicker of Hope is no different. To help us celebrate our first birthday we are launching a monster raffle for research on 9th September. Two caged trailers have been generously donated along with an abundance of spectacular prizes.



First Prize 7 x 4ft caged trailer donated by Roylance.

Products packed into this trailer include a set of Cobra Golf clubs, Karcher 1800psi pressure washer, portable air conditioner, Sidchrome Toolkit with trolley, 21 litre Engel Fridge, Emily Webber Q, smart TV, Jack Hardy generator, 130 litre bar fridge and many more items valued at \$15,500



Second Prize 6 x 4ft caged trailer donated by Bulk Transport Equipment

This trailer will make Christmas exciting for one lucky winner. It includes a tent, sleeping bags, camping chairs, bike, Jack Hardy generator, outdoor drinks cooler, toy box, Osmosis cosmetic pack and lots of assorted toys and accessories valued at \$5,500.



Third Prize \$1000 voucher for international travel donated by Globetrotter Corporate Travel

A huge thank you to everyone who has donated items to make this 'Raffle for Research' possible including:

F & A Sette
K & A Curulli
E & D McSweeney
K & S Evans
M & C Smith
United Press



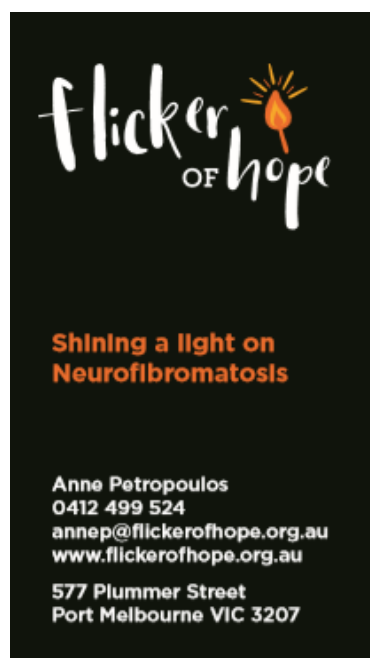
Tickets will be on sale from 9th September @ \$10 per ticket. If you wish to help sell the tickets, we have books of 10 available. Please contact Anne on annep@flickerofhope.org.au or call Anne on 0412 499 524.



Interested in making a difference?

Are you a dreamer? Can you make our Flicker of Hope grow and help brighten the lives of everyone living with Neurofibromatosis? Someday, somehow, with the help of many, we will make it happen. Our newsletter is a way of keeping you up-to-date on our progress as a charity and help raise awareness of the effects of NF. We are also striving to raise the much-needed funds to support the research programmes. If you wish to be part of our efforts, there are several ways in which you can help.

1. Complete the pledge card and return to annep@flickerofhope.org.au



I want to shine a light on Neurofibromatosis

I wish to pledge:

☐ \$50 ☐ \$100 ☐ \$250 ☐ \$1000 ☐ \$5000

☐ Other _____ ☐ Corporate partnership

Preferred payment method: ☐ Cash ☐ Direct debit ☐ Credit card

Name: _____ Phone: _____

Postal Address: _____

Email: _____

Signature: _____ Date: _____

Thank you! Your generosity will turn a flicker of hope into a flame and help fund research into new and effective treatments for NF sufferers.

2. Donate via our website

www.flickerofhope.org.au click on the donate button.

All donations are tax-deductible, and a tax receipt will be issued.

Thank you for helping us shine our light that little bit brighter and giving hope to many Australians.



Thank You

A special thank you to those who have made major financial contributions since our last newsletter. These include: -

Delta Group
Yarra Valley Grammar School
Coverforce
Karl Heinz
Delta Workforce
Nick Lacovou
Eastern Plant Hire

M. Nicholls & A. King
JR & JG Nicholls
Petrooulos family

Supporting a charity can take on many forms, the offer of someone's time, a valuable connection, the donation of a venue, raffle prizes, attaching stickers to candles or taking photos for our Facebook posts. All of these and many more are things that friends of Flicker of Hope have donated to help support us in this last year, making us grow and achieve more than we could have imagined. Our thanks and appreciation go out to all those who have been part of our journey so far.

"One of the biggest things that Neurofibromatosis can lead to is fear. The pathway for each person is both different and unpredictable. Fear of what may happen is significant."



If you would like to contribute to the next newsletter or have any questions regarding Neurofibromatosis please do not hesitate to contact annep@flickerofhope.org.au

