Children's Tumour Foundation
CONQUERING NF

living with NEUROFIBROMATOSIS

Alex has Neurofibromatosis Type 1 (NF1); a genetic condition that causes tumours to form on nerves throughout the body, including the brain and spine.

It was suspected that Alex had NF1 as early as 6-months of age following the appearance of multiple cafe-au-lait spots, amongst a number of other indicators. Since then, Alex has only ever known a life of appointments, surgeries and disruption.

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

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

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

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

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

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

In between one of these visits, Alex was hospitalised for a severe respiratory infection that was not improving. So, within nine months of relocating, the family returned to Melbourne.

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

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

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

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

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

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

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

Alex has attended weekly therapy sessions with an occupational therapist and speech pathologist, as well as regular reviews with a physiotherapist since he was 18 months.

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

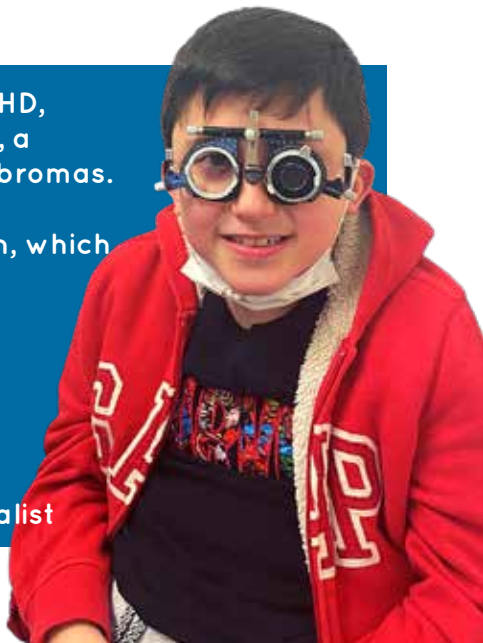
Alex was fortunate to be approved for the NDIS to assist with the costs, although they still have large gaps to cover for all of Alex's allied health and medical needs.

Whilst these diagnoses can be daunting for some, they have actually provided Alex the pathway to access funding and support that he so desperately needed and deserves," says Shelly.

In addition to being a cardiac patient with high blood pressure, ADHD, Autism and global development delays, Alex also has hip dysplasia, a cerebral cyst, tortuosity of his optic nerves and the start of neurofibromas.

There is also constant monitoring of new or existing tumour growth, which all means he has a comprehensive specialist team comprised of a:

- GP
- Paediatrician
- Cardiologist
- Endocrinologist
- Ear Nose and Throat Surgeon
- Gastroenterologist
- Nephrologist
- Neurologist (NF)
- Neurosurgeon
- Orthopaedic Surgeon
- Ophthalmologist
- Respiratory/Sleep Specialist

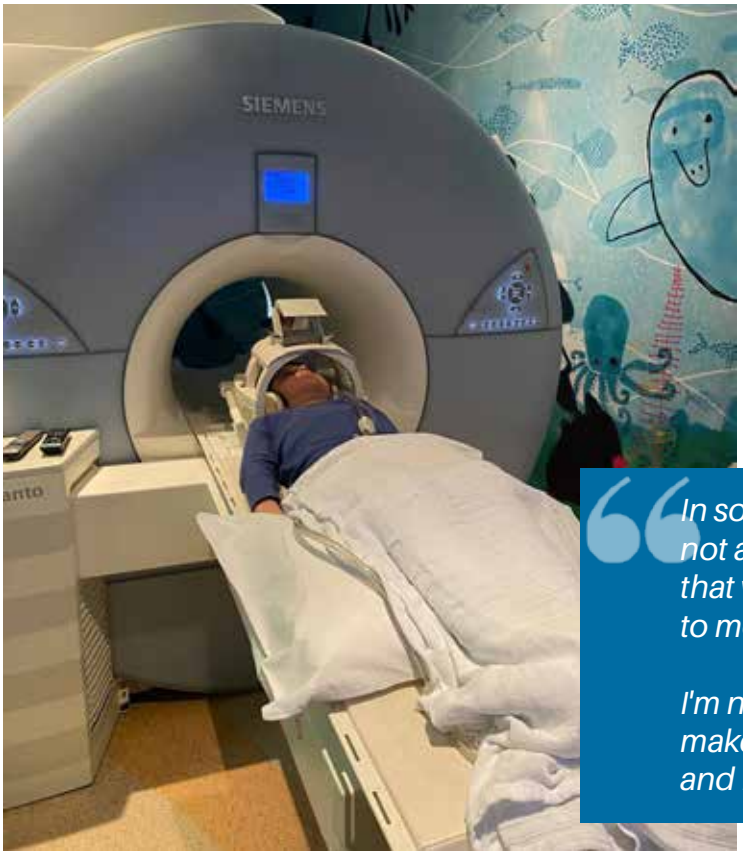


Shelly is a staunch advocate for all families with NF in Australia and is lobbying government for nationwide support. She describes her family as being "extremely lucky" as she has access to NDIS and lives in a city with a specialised NF Clinic funded by the Children's Tumour Foundation.

Not all families have this opportunity,

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

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



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

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

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

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

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

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

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

"MY NAME IS ALEXANDER JAMES NEAMONTIS, THE GREAT."

Alex IS great. Alex is a NF Hero.

NF is a lifelong condition and can cause a range of significant health issues including, deafness, blindness, paralysis, physical differences, bone abnormalities, cancer, learning difficulties and chronic pain. It can affect anyone regardless of age, ethnicity, gender or family history, so it is time more people sat up and took notice.