

Audrey's Proton Experience

To summarise the journey that we have taken to finding a solution for Audrey's treatment I have provided a simple order of how we first learned about Proton Beam Therapy and how we found a facility that would support us to present her case for the appropriate support from the Australian Government.

Our daughter Audrey was a 5 year old healthy little girl, but after months of vomiting at the sound of rain on the roof and a week of headaches we could no longer take 'wait and see' for an answer. In March 2011 Audrey woke in the middle of the night again holding her head and crying – but this time she begged 'please can you take me to the hospital?' Nearly every day that week we had been to our GP searching for an answer that after a number of hours at the hospital we discovered was a rare brain tumour located in the centre of her brain called a Craniopharyngioma.

On discovering Audrey's tumour we were very unaware of what the treatment options were aside of the sound recommendation to conservatively remove the mass and then post operatively attempt to reduce its size with radiation. After undergoing immediate surgery to de bulk the tumour, Audrey then had a shunt inserted to further drain her cranial fluid and reduce the pressure. Shortly after it was time to understand the next steps in this process.

At our very first meeting with our Endocrinologist he was curious about the treatment options that had been suggested and enquired of our knowledge. When mentioning the concept of radiation he gave us a stern look and clearly suggested that 'radiating a 5 year olds brain was not a smart thing to do'.... no other information or conversation offered to clarify this point. This came as some shock to us as we had naturally given ourselves comfort that we just follow the path that others have set for us – he was asking us to make our own informed decision.

To seek clarity we discussed this with our Neurosurgeon who had already provided such good guidance. We asked him for a balanced medical perspective and he provided a clearer overview of what he understood to be options on how to treat a Craniopharyngioma. Indicating that there were additional options beyond the boundaries of Australia but cautioning us that this was not his area of expertise he suggested further clarification would be needed from a local Oncologist. This was not an immediate referral but a suggested future step.

So the search began to understand what the concern was all about – no real clarity and a challenge to balance each medical practitioner points of view with our own gut feel on why this cryptic statement had been made to start with. The clarity soon came as we started to search the web to seek some understanding. Clearly in medical journal after medical journal that were painstakingly searched for by my sister and I we had a clearer picture of the options that existed and the sound reasons why the technology had progressed by some 30 years in the USA compared with that available in Australia. The indicators of impact on her full life potential were very alarming.

With some information now on board we then set about building a plan – narrowing down the 5 facilities in the US that offered Proton Therapy for paediatric patients and asking for the foundational information. Learning about the necessity for daily anaesthetics due to her age we then went asking the big question about price. With varied indicators presented we were

already realising the enormity of the situation. As the Federal Minister for Health, Nicola Roxon was my local member in the electorate that I live in I thought some clarity from her on the support that could be offered would be important. Keeping my communication casual but informative on an email I was so heartened to receive a response that suggested there was an avenue where Audrey's case could be considered. Not easy to find by the lay Australian family but hidden away in the layers of our political system was a department called MTOP – Medical Treatment Overseas Program. Now with a link to the application form the mission began – seeking funding was my focus, however acutely aware that this was not going to be straight forward and we needed alternative options, so remortgaging our properties was the next answer.

Late night calls to the USA and further searching became the norm for a number of weeks. At one of those 3 AM moments I had reason to seek out a contact that had been given to me some 6 weeks before by my sister in law, just a name on an email of a friend of her sisters who had recently been to the USA to treat their child for brain tumour. This would prove to be a very helpful contact – even though we knew the circumstances would have to be different as this was a one in a million tumour that Audrey had.... On sending a quick email to introduce myself I was overwhelmed when half a day later the most comprehensive and supportive email returned to inform me that the circumstances for them were exactly the same; same tumour and same age. What were the chances....

This journey had just become so much easier for us with the path that they had charted before us and the quick tips that they could provide – we are forever grateful to this very considered and delightful family.

The next incredible person that we were to meet on our journey was Dr Danny Indelicato from the University of Florida Proton Therapy Institute. Another late night call allowed me to stumble on this giving and highly informative medical professional who with no hesitation provided such insight into the reasons why Proton Therapy could be a sound option for our daughter, later confirmed on receipt of our scans. Comfort came from knowing that they had treated over 20 paediatric craniopharyngiomas in the last 2 years. Danny indicated that a high number of these children had come from the NHS in the UK. This seemed alarming to me as how could it be possible that this support seemed naturally available to children in the UK but so challenging in Australia. Danny kindly put me in contact with the Senior Commissioning Manager from the NHS to gain more understanding. Without hesitation she replied with very useful information and an outstanding endorsement of UFPTI.

Not only did the facility and the medical team at UFPTI seem amazing but their estimations for Audrey's treatment were nearly half of the quotes provided by other institutions. This was an important factor for us as the financial implications were large. We committed to not compromise on quality but there was no compromise with UFPTI – the quality of information, documented evidence of their performance and personable nature back up with a genuine care and interest in our case meant we could see no point in spending anymore time looking for an alternative option as the contrast was very clear. At every other facility we had never been offered the opportunity to speak to the treating specialist, just the intake nurse. At UFPTI we did not have to ask, Danny just offered to step in and provide whatever help or clarity around our options that he could.

The journey then really began to build the very strong case that there was no alternative option. A task that originally seemed insurmountable but progressively with the support of Danny providing such helpful and factual information and contacts was so much easier. Our Australian medical team was our next target to determine their level of support for our findings – one that had some pleasing results. Although always realistic that this may not be an easy win but a comforting that they agreed that this was a valid case of medical necessity was all I needed to pursue the mission of assembling all of the documents required in a comprehensive and clear way, a mission that took me some four months. However in late August we were in a position of submitting the application and playing the waiting game that we expected to be some six weeks long.

On the 7th September 2011 we spent the day at the hospital gaining an understanding of the growth of the tumour which thankfully at this point was insignificant. However this presented a suggestion from the treating team that slowing down the path to radiotherapy would be an option. I felt that in some ways this doubted the benefits of the process that I had so painstakingly gone through to make a submission. Concerned and somewhat frustrated by this I then sought understanding from Danny on the best practice approach in the USA. He confirmed that there were benefits and challenges with both options but agreed that we wait for the next scans and track the progress before slowing down any of our plans.

Having comfort in this approach we thought we would now just continue the waiting game, however not for long as that afternoon we were blessed with a personal phone call from the Deputy Secretary of the MTOP program confirming full support of Audrey's comprehensive and thorough application – a enormous relief and a credit to the amazing few who were so supportive in assembling this, without doubt Dr Danny Indelicato leads the credit roll. This was so significant for our family as the only thing we needed to focus now was Audrey and not the financial road map that we needed to follow to get through this.

At this time we recognised that I was blessed to firstly have the drive and dedication to this cause as clearly it is possible to make yourself understood if you can present a logical and factual argument, however this was not possible for an individual such as me without being able to find the information that I needed. The vast majority of the current and well informed journals and supporting evidence came from the team at UFPTI. The true point of difference in this organisation shone through in Danny's letter of medical necessity when he not only supported Protons as the only safe option but made it clear that if it was not possible for Audrey to be treated at UFPTI that he requested she be still be treated with Protons at another facility. It appears that the care of our child has always been their first priority and secondly they did not forget about us in the process – regular encouraging sign offs from Danny and the team recognising the work that we were doing to be the voice of our child and give her the best option.

This encouragement was summed up in an email from a delightful team member from UFPTI received just before we left. 'It is good to know that you have confidence in your decision to travel such great distance for Audrey's care. You will not be disappointed in your decision to have Danny treat your daughter...he is truly so gifted medically and is a wonderful person as well.'

So in taking off to Florida we had confidence that Audrey would not be treated by those who were people focused as well as professional.

Our time in the US was so important for our family to recoup and refocus. Precision planning and encouragement for Audrey resulted in her having the confidence and trust to undertake her whole treatment without anaesthetic. This was a remarkable result achieved by Kim her Child Life specialist that we would never have thought possible. Kim shared so much of herself with Aud – a special bond that will remain for life. From arts therapy programs to afternoons catching up with other families from all over the globe going through treatment with their children, it all became so easy and so rewarding. The weeks slipped by and before we could think we were faced with the reality of returning home. I had always thought this would be the happiest moment. How wrong I was, mixed emotions were had by all as we left our very valued support crew from specialists, therapists, artists, neighbours and families, a job well done to support Audrey to live a full and remarkable life.

We watch the journey of these little people with interest and see only positive results from their time at UFPTI. Audrey has been such an inspiration to us as a family and we have a strong need to give back to others and pass on the giving that we gratefully accepted. Her life is largely back to normal and we now just manage the follow on effects of the damage to her pituitary gland and hypothalamus.

We welcome any contact from families challenged by the decisions of treatment for their child and hope to offer a balanced perspective from our journey.