

Written 25/8/2022 (updated 24/1/2023) *Not been updated since April 2023*

Re: Barker Moore

To whom it may concern,

Thank you for taking the time to see our son Barker who has had sinus problems ongoing from a young age, which has been affecting his sleep drastically, as well as his learning at school and his home life.

Barker has been a mouth breather for quite some time which was first noticed when he was somewhere between eight months and one years old, though we were not aware at the time that this could be a sign of an underlying health issue.

When Barker was almost two years old, we became concerned about his noticeably enlarged turbinates, mouth breathing and snoring and were referred by Dr Hay at Peel Maternity and Family Practice to an Ear Nose and Throat specialist in Rockingham - Dr John Harlock. When we saw Dr Harlock, he had said that it was not the turbinates that were an issue, but the adenoids and he referred us to have Barker's adenoids removed. As we were told that Barker could outgrow the adenoids being a problem by four or five years old, we went home and did our research and chose to hold off on the surgery.

At almost 4 years old Barker's problems were becoming more prominent and he was noticeably speaking more nasally. We were referred by Dr Hay to see the same Ear Nose and Throat specialist and Dr Hay prescribed Barker a nasal spray to help relieve his symptoms. This time when seeing Dr Harlock, he had said that Barker's inflamed turbinates were indeed the problem and that we should have Barker allergy tested. We were told that Barker most likely had allergies and that it was also noted that Barker had signs of scarring on one of his ear drums, although Barker had never shown signs of distress with his ears and had never had an ear infection that had been detected. The Allergy blood tests checked for allergies to dust, pollen, grass clippings and pet hair and the results showed that Barker was highly allergic to dust. We cleaned and decluttered Barkers room and kept on top of the dust from this point onwards to the best of our ability.

At almost five years old we saw Dr Hay yet again as Barker had been getting worse with his symptoms and his quality of sleep had declined, which started to affect him daily. Barker would wake 6 times or more in the night crying as he could not stop coughing and sneezing or he couldn't breathe properly, and sometimes he would wake in the night and struggle to get back to sleep. He had been prescribed a nasal spray, an inhaler, and an antihistamine medicine for a three-week trial, which somewhat relieved his symptoms. Dr Hay requested that Barker have a current set of allergy blood tests done to see if there were any changes since the last blood test. Barker had the new blood tests done in November of 2022 and was found to still be highly allergic to dust and his ferritin levels were found to be low, being 18 instead of around 30, as I had been informed by our family GP's nurse.

Dr hay had also referred us to a new ENT Specialist, Dr George Simm at Saint John of God Murdoch. Dr Simm agreed that Barkers Adenoids were extremely enlarged and needed to be removed and also suggested that the turbinates in the nose should be reduced slightly at the same time. At this point in time the Tonsils were to be left intact as they did not appear to be an issue. Barker had the adenoidectomy and Turbinate's reduction in November of 2022.

After the hospital procedure Barker somehow contracted Roseola, which is very similar to measles, and we believe that it came from the hospital due to the timing and how he was affected and given the fact that Barker had been home from school the week before the procedure and had not left the home before or after the surgery, other than going to hospital. Barker got quite sick and lost a kilo and we were struggling to get him to eat or drink anything. Barker was already a fussy eater and though we had been making great progress in the few months prior to the surgery, with Barker getting sick it set us back greatly with the hard work and mealtime improvements and now we are back to where we started with struggling to get Barker to eat.

Prior to the surgical procedure Barker's health symptoms have consisted of mouth breathing, frequent dark brown ear wax, coughing, sneezing, runny nose, blocked nose, sniffing, itchy/swollen/watery eyes, sounding nasally when speaking, pale in the face, left tonsil frequently enlarged (not the right), sleepless nights, waking multiple times in the night crying, dark under eyes in the mornings after a rough night. Also has fussy eating with gagging and texture problems and takes a long time to chew and swallow. Under 1 years of age Barker was never fussy with foods like he has been after that turning point.

Earlier this year in May of 2022 Barker had a steroid inhaler prescribed by Dr Hay, due to having a case of covid which caused shallow breathing and a chest Xray showed signs of a lung infection, though this had no relation to Barkers already existing troubled breathing and poor sleep.

Barker had a kindy health check this year and it was noted that his hearing was fine, though some learning concerns were mentioned, and were referred to the child development services through the school. A few of the school concerns were in relation to communication, fine motor skills, focus, attention and understanding. Although the learning concerns at school may or may not be related to the nasal and sleep problems, I have included a brief copy of Barkers teachers concerns which she has provided to us. I am aware that underlying health problems causing mouth breathing can lead to a sleep disorder in a child which in turn can have a negative impact on their learning and development, due to sleep deprivation, lowered oxygen saturation to the brain and lack of restorative sleep. I am also aware that Sleep deprivation can cause cognitive/fine motor skill delay and behavioural problems which may be mistaken for ADHD. Sleep is very important for anyone but especially so for a young developing child and as parents of a child with ADHD (one of Barkers siblings) we do not believe this to be the case with Barker and we are determined to get to the bottom of his health issues and get him the help he needs before his schooling is severely impacted and ultimately his life.

As the school have raised their concerns and we have our own concerns for Barkers health, we saw our family GP, Dr karine hay, and requested a referral to a speech therapy clinic called Smart Talk Therapy for Kids, they specialise in speech and language but also other areas such as eating and swallowing problems and orofacial myology - which is to do with incorrect development of the tongue and facial muscles and resting posture, which in turn may cause problems with eating and sleeping. As Barker is a picky eater and at times gags with some foods and has a problem with chewing certain foods, I thought that it would be a good idea to have Barker assessed. He also would not give up his dummy until three and we had considered whether this may have caused a problem somewhere along the way.

Continued...

We saw Melissa-Sue Wat in November of 2022, who is a senior speech pathologist at smart talk therapy. She specialises in myofunctional therapy and picky/troublesome eating also. Upon seeing melissa-Sue we discovered that my hunch was right about Barker and his eating struggles were due to a posterior tongue tie and weak jaw and tongue muscles as well as weak core muscles and a weakness with his chew and his bite. Barker is unable to chew and bite certain foods and doesn't seem to be able to clear his mouth and swallow his food entirely like he should be able to. Melissa-Sue has made recommendations in her report provided to us and as Barker is going to likely require an OT, a speech pathologist, and a physio, as well as a physio specialising in respiratory strengthening, she advised that we may be able to apply for funding to help us with barkers needs. We have opted to seek private specialist assistance sooner as we were told that it could be up to a two year wait to have Barker seen through the Child development services. At this time, we will be seeing Melissa-Sue ongoing to assist with Barkers eating troubles and help him with better habits in eating and breathing through his nose.

In November of 2022 we also managed to get in with Dr Shereen Lim, who is a dental airway specialist at Sparkle Dental in Joondalup. She also assessed Barker's airways and oral health, prior to the adenoid's removal surgery, and we will have a follow up appointment with her in February of 2023. Shereen discovered that Barker does indeed have narrow airways and does not seem to breath through his nose like he should. Shereen also found that Barker's pallet is too high and narrow, and his smile is too gummy. Barker will require therapy tools to assist with training Barker to position his tongue in the correct resting posture, to help promote the nose breathing rather than mouth breathing and will also require a pallet widening plate. Shereen felt that Barker was not mentally ready or calm enough for these interventions and suggested the review after he had recovered from his surgery and nasal obstruction and was hopefully getting a better night rest. This follow up would be in February of 2023.

On December the 6th 2022 we saw the ENT Doctor George Simm for a post op appointment, to follow up how Barker was going with recovery after his Adenoidectomy and Turbinates reduction. At this time Barker was still not sleeping well and his allergy symptoms had not reduced, it was also found that Barkers Tonsils were inflamed. Dr Simm suggested a follow again in 6 months' time (about June 2023), to assess whether Barker may also require his tonsils removed. He did however also mention that Barker may still take another 6-8 weeks to fully recover. As of January 2023, we noticed a drastic improvement in Barker's quality of sleep, and we also noticed that Barker was surprisingly no longer sneezing, coughing, or having breathing troubles and he wasn't triggered by his high dust allergies. We were able to stop giving Barker all medications entirely (which was our goal). These medications included an inhaler, nasal spray, and antihistamine medicine. We hope that in time with the quality of sleep returning, Barkers cognitive ability will improve, and his understanding and concentration with daily tasks and with his learning at school will also improve.

18th January 2023 – We have been seeing Melissa-Sue Watt for frequent appointments at Smart Talk Therapy in Wembley, she is a myofunctional therapist and picky eating children's therapist. The focus had been on gradually assisting Barker with oral physio to help train and strengthen his jaw, bite and chew and to correct his tongue use, in order to teach him to properly chew and swallow his food. The goal will be to continue to improve and move forward with this therapy and then move on to the picky eating and detecting possible food sensory issues. In getting to know Barker, Mel has detected that Barker would benefit from sensory profile testing when he has his OT assessment. Barker seems to be stimulating and regulating during sessions with fidgeting and making noises and has Mel explained that this is all sensory input.

Continued...

She said that it can be normal, and he may do this due to boredom or when feeling fatigued and it may not just be related to sensory issues. Physical Physiotherapy will be required to help Barker's core strength as he seems to rely on leaning on objects when trying to chew and swallow and also moves his head around a lot when trying to chew and swallow and appears to be using a lot of cognitive thought and energy in this process. Barker uses his finger often to push the foods around in his mouth and doesn't use his molars correctly to chew and grind foods down. His tongue is not able to clear foods from his mouth and swallow properly and fully and his tongue muscles get tired during the chewing and swallowing process. Barker is a picky eater and avoids certain foods and textures but is a frequent snacker. He could be constantly wanting to snack on his safe foods throughout the day to curb boredom or to become more alert when feeling fatigued, or it could be that he is seeking sensory input. We have decided to use a chewy therapy tool to use in between significant meals to try and build more hunger at more important mealtimes. The chewy tool will be used for sensory regulation when Barker may need it and then it will also be used for oral physio to strengthen the chewing of the molars and to build on the task of the rotary grinding required to be able to break down meat, this will be a specific chewing that will require supervision and will need to be done at least 5 times a day on each side. We started with cutting down Barker's foods into tiny pieces to be placed directly on the molars and then to be chewed but have now moved forward to Barker placing these foods on his tongue and using the tongue to move the foods on to the molars, instead of him using his fingers. We are also encouraging Barker to chew on strips of biltong to work his jaws and molars.

Thursday 12th January – we saw Jessie King at smart talk therapy for a speech assessment, jessie had detected a few concerns and would send a report out as soon as possible and would inform us if she needed to do further assessment with Barker, we ran out of time to have a chat after the assessment as we were delayed in getting to the appointment due to a terrible accident on the freeway. We will wait to receive assessment results and find out whether further assessment will be required.

23rd January 2023 – We saw Rhianna at smart talk therapy for an occupational therapy assessment. She suggested a sensory profiling test be done. I was unable to make specific notes during this session, but she did notice and mention that Barker is hard to get top focus on the task required of him and she detected that runs and jumps with his feet facing outwards and seems to go up on his toes from time to time but it may not be an issue. It was detected Barker was not quite where he needed to be with some areas of fine motor skills, though two things Barker had improved with was using scissors and writing the numbers from one to ten and though not perfect, these were things that he could not do at all without assistance and constant prompting just a few months prior, perhaps his sleep improvement may have helped with the improvement with these tasks. Rhianna said that assistance with regulating may be helpful before important activities where Barker needs to really focus and pay attention, though she did say that this is quite common in little boys. She will send a final report once we have completed the sensory profile testing in a weeks time.

24th January 2023 – We saw Brianna at the Mandurah child development services for a physio assessment. Brianna completed various tasks with Barker while I filled out forms and completed a questionnaire (possible called a Harcourt questionnaire, I cannot recall now). It was found that Barker was in the orange zone for this questionnaire. The chat with Brianna was brief and she said that she would like to see Barker again for further assessment on the 20th of January. She would get her report summary to me as soon as possible but mentioned Barker would benefit from regulation through an OT - something that seems to be mentioned reoccurring by all of the therapists. Brianna said that Meeting Barkers needs for regulation
Continued...

Before significant activities will help him with the focus on the task at hand, he is easily distracted and needs regulation input. Sensory possibilities were brought up. She said that it was hard to tell if Barker was unable to participate with tasks such as throwing and catching of the ball or if he just wasn't interested and wanted to do his own thing with other equipment around the room. She also said that Barkers seems more willing to do full body movement actions rather than requested smaller movements or tasks such as throwing and catching of the ball. Brianna Will type up a summary report and send a separate one specifically for applying for NDIS funding as she is aware that we are trying to apply for some temporary funding to assist with gaining help sooner for Barker if required. The report summary will be sent out before our next assessment on the 20th of February, so we will be sent a separate summary report for the second assessment.

April 2023 – Barkers eyes had become very sore, red, dry, irritated, and inflamed and we were not sure of the cause and whether it was dust allergy related. We took Barker to see the optometrist and found that Barkers eyes were not producing the proper lubrication and the inner eyelids were rough and irritating the eyeballs (possibly from the past health history impacting and with the eye rubbing). We also found that Barker has astigmatism in both eyes and may require glasses in future. We were told to give barker lubricating eye drops and to keep Barkers eyes clean with a cool or warm damp cloth frequently and were told to come back for a review in three months' time. I decided to get Barker a referral to an Ophthalmologist to rule out any possible future eye site deterioration and to try and gain better insight on the situation and for better management of. It was noted by the GP that a similar eye condition can be linked to an autoimmune problem, so this is something that I would also like to rule out.

In this time Barker had also been breaking out around his eyes and mouth and we believe it to be low immune system and food intolerance related as Barker has had this occur before quite often as a younger child. It had been tricky to give Barker antihistamine medicine to treat though as this would cause drying to Barker's eye problems as antihistamine is drying to the eyes and could irritate his eyes further. Barkers improvement with his picky eating had also gone quite backwards with the improvement made and we have been struggling with Barker once again, with food groups as well as the duration of meals dragging out.

It may or may not be relevant, but Barker had an issue with textures touching him when a toddler, such as the grass and the sand and the issues with food texture developed around about the same time. Eventually we got him used to the sand and the grass but still the foods remained a struggle. Barker also lined up objects as a toddler but in no specific order, it was just a part of his play, and he no longer does this.

I will update information as further reports and knowledge is gained.

Kind regards
Amy