

# Craniofacial Australia

## Newsletter

Professor David and his team made history 30 years ago when they performed live surgery that was broadcast, in a world first at the International Workshop titled Craniofacial Trauma Adelaide, from the operating theatre at the Royal Adelaide Hospital to the Festival Theatre here in Adelaide. Over 200 experts from around the world converged on Adelaide to be part of this history making conference to share and witness the best in surgical techniques for craniofacial patients. We were fortunate enough to have Mark Jaensch, one of the four patients who were part of this historic moment, call in and see us here at the Foundation and give us his side of the story some 30 years later.

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Mark Jaensch made history 30 years ago

### Life begins at 20

Imagine walking in a room at five years old, and everyone immediately staring at you. Minutes stretch for hours as the Earth stands still. Looks of horror and curiosity painted on the face of everyone in the room. What do you do? What do you say?

My name is Mariam Mezher, I am a twenty-year-old girl from Sydney and this is my story.

Continued.....page 4

“The best way to measure how much you’ve grown isn’t by inches or the number of laps you can now run around the track, or even your grade point average - though those things are important, to be sure. It’s what you’ve done with your time, how you’ve chosen to spend your days, and whom you’ve touched this year.

That, to me, is the greatest measure of success.” Wonder the Movie

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Craniofacial Australia is a registered charity (CCP2573) supporting the Australian Craniofacial Unit through patient care, family support, education, training & research

# Professor inspires Sienna



Sienna and Professor David

Sienna Woods recently called in to see us here at the Foundation to seek some information on Professor David. Sienna is currently in the leadership group at her school and was undertaking an assignment, where they were asked to prepare an article on someone who inspires them. Of course for Sienna, that would be none other than Professor David, who Sienna has been patient of for some time.

As part of her studies, we assisted with some fun facts and photos that she could use. I am happy to report that Sienna's mum sent me an email this week stating the following:

*"Sienna is thrilled. She came home today with an A for both Part 1 and Part 2 of the Leadership assignment. She is so proud. Her work and passion for this assignment is amazing. Clearly she is inspired by Prof David for all he has done for her and his achievements."*

We think you are pretty amazing too Sienna and wish you all the best for the rest of your studies and the future ahead.



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We would love to hear from you

# Kangaroo Island Cup



Our CEO along with a small party from the mainland all headed over for the KI Cup on February 16th.

The package offered transport to Cape Jervis, ferry travel to the Island by Sealink and entry to the KI Cup Luncheon. It was a fabulous day with blue skies and lots of happy race goers. Eran Boyd Craniofacial Ambassador and professional jockey is kindly donating a percentage of her prize money from the week's racing to the Foundation.



*CEO Bob Snewin with KI Cup guests*



## From our CEO

In this edition there are several inspirational stories, not only of overcoming people's perceptions of what is normal, there is also hope that you can achieve anything if you have the desire. Mariam has shown us this not only in her story but it is on display each and every time she visits us here at the Foundation. Mark has shown us, that despite his injuries, his desire to be part of the Grand Final Team and win the flag, could, with the help of his family and team mates, become a reality.

Our focus at the Foundation is to provide hope and support for the many patients and their families who have craniofacial deformities or who have suffered facial trauma. The Foundation assists patients here in Adelaide, interstate and overseas, their care being provided by specialist clinicians who have been trained by Professor David and his team, using funds raised from our various events and donations.

Whilst there has been some press surrounding the Unit, it is important for our supporters to understand that whilst Professor David is no longer Head of Unit and has no say in its management, he continues his work as Chairman of the Foundation.

Our Board of Management, maintains a focus on its primary goal of ensuring that the Foundation will continue its endeavours to raise funds for the craniofacially deformed. It will seek to assure our supporters and donors that care provided is planned in accordance with evidence-based protocols that have been developed and adjusted over many years based on scientific research.

Hope is powerful and provides light at the end of the tunnel. Please take a moment to read these stories of hope and inspiration. I am sure they will touch you and remind us all of why your continued donations will be wisely managed and directed toward providers of care, research and education. *CEO Bob Snewin*

## Life begins at 20 - An inspirational story from Mariam Mezher

*Left: Mariam and Professor David*



I was born with Treacher Collins Syndrome and have been living with it every day of my life. It's complicated to try and explain the condition medically, so I'm just going to give you the basic rundown. I was born with facial deformities, so basically I was born without cheekbones, eye orbits, and minimal bone in my face. Also, because I have an extremely receded jaw, my airways are extremely narrow. This means that I find it very difficult to breathe, kind of like having to breathe through a straw. In other words, I suck at the most involuntary human function. I was also born without ears, so I have to wear hearing aids to hear. But I'm not deaf, I can still speak just fine (trust me ask anyone and they'll tell you I'm a chatterbox).

So that's the run down on my condition. Now, having to grow up was kind of tough (yes that's an understatement). Every time I'd walk into a room everyone, and I mean everyone would stare at me. Some kids would cry, others would run, and some would point. And then there were those kids that would ask "what happened to your face" and "where are your ears". Now, when you're a young kid and someone asks you questions, you don't really have an answer. I mean, how would you even answer a question like that, let alone try and explain it to another child? I knew I was born like this, but how do I explain it to others? So I guess it's pretty obvious that I was bullied a lot. I remember coming home from school crying. Always asking, why am I like this? Why me? What did I do to deserve this? It's not fair.

With this condition came a lot of surgeries. I have had too many surgeries to count, but they all had one purpose; to keep me alive (no I'm not being dramatic). Now there is nothing I hate more than surgery, more specifically anaesthetic. When you're only a few years old and that ridiculous mask gets put on your face while literally everyone tries to tie you down, that trauma kind of sticks with you.

My health really started to decline during my last few years of high school. I remember the surgeons telling me that I was ready for surgery, but I wanted nothing more than to finish my HSC with my friends. I mean, what kind of teenager wants to be held back a year? So, I had to try and get through my senior years with very tight airways. Now, I'm the kind of person that stresses over literally everything when it comes to my education. To me, education is the most powerful tool a person can have. I valued my education so much, which is why sometimes I would foolishly prioritise that over my health (I know, stupid right). Anyway, so I finally graduated (thank God), and got early acceptance into university (yay!).

So, I was ready for my surgeries now. I had finished my HSC and was ready for the next stage in my life. However, this time the hospital wasn't ready. So I was waiting. And waiting. And waiting. I would get a call like twice a year saying, "Surgery will happen soon". So obviously I wasn't able to start Uni. I didn't want to start, and then have to stop. And I didn't want to be in the middle of my studies when I got the call. But the main reason was that my health was so bad, and my airways so tight, that any stress, anxiety or panic attack, would mean that I'd stop breathing. So in other words, it wasn't really safe for me to be at Uni.

This meant that I was doing nothing. For a year and a half, I was doing absolutely nothing but waiting and hoping. Basically I got into a really bad mental state. I would go to sleep every night, terrified that I wasn't going to wake up in the morning. In other words, things were really bad. It was July 2018, when I finally spoke to my new surgeon (the great Dr Flapper) and revealed my struggles and fears. I was so scared to be that vulnerable and reveal my inner emotions, but I had to. Next thing I knew, I was having my final major surgeries a few weeks later.

Now, these were my final major surgeries. That meant bringing out my jaw and midface with mandibular distractors, then using bone grafts from my hip and ribs to create cheekbones and eye orbits. The main purpose of this surgery was to bring out the jaw, so I had more room to breathe. Sounds simple right? **WRONG!!** Because I had literally barely any bone in my face (specifically my midface), they had to take a different approach. Instead of four major surgeries lasting over the course of a year, it was two major surgeries instead, lasting over the course of just under four months. However, the catch was that I would have to wear a giant frame around my head (like in Mean Girls) with bars coming out of my mouth and jaw, and screws in my head (yikes!). I also had to have a tracheostomy to secure my airway. I had the death frame on for just over three months and every single minute was absolute hell. I had to sleep on my back the whole time, couldn't shower or eat properly, and couldn't leave the house because I was a walking hazard and couldn't afford any accidents like falling or bumping into someone. I couldn't even speak, and I love to talk.

Long story short, it was a long few months. And I spent my time binge watching TV shows, reading, and studying (I'm not kidding ask the doctors they thought I was insane). Although when it was finally over, I never felt happier. I could finally breathe properly and unassisted and it is the best feeling in the world.

So now I'm back home in Sydney and loving my life. Having to go back looking completely different to what I looked like before was extremely confronting. I had a new face and had a hard time adjusting at first. For a while it felt like my old self had died, and in a way it did (I even wanted to hold a wake).

Although now a few months later, I've adjusted and am so so happy. It feels amazing to be able to exercise and not be tired straight away. I love being able to wear my glasses and them not fall off because I have no cheekbones to support them (even though they aren't

shaped like Angelina Jolie's like I asked). But most of all, I love being able to sleep

soundly at night and not be afraid of not waking up. Even though I regretted going through with the surgery at the time, I am so glad I went through it. I can honestly say that I wouldn't be here without the love and unwavering support of Professor David, my team of doctors, surgeons, the nurses, the Craniofacial Foundation, my friends and most of all, my family. I am now about to start Uni in a few weeks and can honestly say without a doubt, that I cannot wait for the rest of my life to finally begin.

**Unedited story By Mariam Mezher.** *Mariam thank you for sharing your inspirational story with us and we wish you all the best for your future.*

**Right: Mariam today**



# History in the Making

There was nothing different about this September day than any other when Mark Jaensch and his girlfriend Vicki decided to go for a ride on their motorbike. That was until they hit something on the dirt road that catapulted them into the air and Mark into a concrete post. Initially Vicki thought Mark might have been seriously injured, however, upon inspection she realised that he only seemed to have a blood nose and concussion. It was decided to make sure that nothing else was wrong and that Mark would go to the



*Mark Jaensch following his accident in 1988*

Woodside Hospital for a check up. After x-rays were taken, it was discovered that Mark had fractures to his jaw, eye socket and chin which would require surgery. He was transferred to the RAH in Adelaide and remained there for 17 days waiting for surgery. Other than a face swollen like a basketball, Mark was allowed to go out for day trips and spend his time relaxing and watching TV. Why wait 17 days? Well Mark was asked to be part of a pioneering world conference, the International Workshop on Craniofacial Trauma that was to be held in Adelaide. Surgeons and associated specialists from all over the world were going to be here at the Festival Theatre watching Mark and 3 other patient's surgeries being performed live from the theatre at the Royal Adelaide Hospital and broadcast back to the Festival Theatre. This was 30 years ago, a world first and certainly not something that you would be permitted to do today. The conference was chaired by Professor David and included experts Dr Jacques van der Meulen, Dr Ian Jackson, Dr Tony Wolfe, Dr Wolf Holtje, Dr Douglas Ousterhout, Dr Joseph Gruss and a host of other esteemed experts in their field, who attended to provide valuable knowledge to all in attendance.



After this groundbreaking surgery, Mark went on to play in the local Football Grand final, which they won, married Vicki and they have two wonderful children, Nicholas and Courtney.

As you can see from the photo on the left he has no obvious deficits. Mark still works on the family farm and has no long term side effects or pain. This is despite the 5 plates that remain in his face and shaved bone in his skull that was used to help repair his facial injuries. Mark and his family have remained long term supporters of the Foundation and can't thank Professor and the team enough for making a difference to his life.

Thank you Mark for sharing your story.

*Mark Jaensch today*

# Research Update

## *Cognitive, Behavioural and Psychological Outcomes Following Unoperated Metopic Synostosis*

*Investigators: Dr Amanda Osborn, Dr Rachel Roberts and Mr Walter Flapper*

### Progress Report:

As has been reported in a previous newsletter, this project commenced in March 2016, with the aim of investigating whether unoperated (Australian Craniofacial Unit) patients diagnosed with metopic synostosis experienced any intellectual, behavioural or psychological problems.

Thus far 36 individuals have been assessed and two more have since been recruited into this study. Initial results found a trend towards unoperated patients having lower intellectual ability, however it was unknown whether there were other factors contributing to this. Ethics approval was then obtained to recruit a comparison group of children and adults without metopic synostosis. Advertisements were placed in the Messenger newspapers as part of a media campaign. 27 control cases have been recruited at the time of this report. The results to date do indeed indicate that those with unoperated metopic synostosis are functioning at significantly lower levels than their healthy peers in multiple areas of intelligence and also have slightly more behavioural problems. It is anticipated that these results will be presented at the upcoming International Society for Craniofacial Surgery Conference which will be held in Paris later this year.

Once again, the researchers wish to acknowledge the financial assistance that has been provided via Craniofacial Australia without whom such a study could not proceed. It is envisaged that future studies such as these will continue to provide invaluable insights for the ongoing management of such conditions.

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