



# Parley

Parents And Relatives  
Listening and Empathising  
with You

## Oliver's Story

Oesophageal Atresia (OA) and Renal Impairments.

My name is Catherine Cobden and I am married with 4 gorgeous children. I have a son of 7, a son of 5, a daughter of 3 and a baby boy called Oliver who has just turned a year old. He was born on 14<sup>th</sup> July 2009 at 38 weeks weighing in at a healthy 7lb 9 ounces.

He was born with Oesophageal Atresia (OA) and Renal Impairments.

At my 20 week scan when pregnant with Oliver I was asked if there were any family history of kidney problems and to my knowledge there isn't. We were told that it was suspected that Oliver had a Multi-cystic Dysplastic Kidney on the right side which is basically a mass of cysts and as a result the kidney would have no function. Oliver's stomach was also not visible at this stage so we were sent up to St George's hospital in Tooting the very next day.

At St Georges it was confirmed that Oliver had a Multi-cystic kidney and we were also told that the stomach was there but not filling up! This meant that there was either a narrowing or blockage in his Oesophagus or that he had a condition called a TOF which is no Oesophagus.

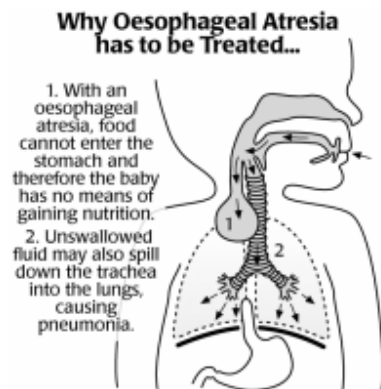
We were kept under close observation by Worthing and St Georges hospitals.

It was decided that Oliver be born at the Royal Sussex County Hospital in Brighton by c-section at 38 weeks and a diagnosis would be made after birth. On 14<sup>th</sup> July 2009 Oliver was born and it was confirmed that as well as his kidney defects he had Oesophageal Atresia. He had no Oesophagus and the gap between the top pouch and his stomach was 6 vertebrae long. This is classed as a long-gap Oesophageal Atresia.

### **Oesophageal Atresia (OA) Taken from TOFS website:**

In Oesophageal Atresia (OA), the baby is born with a pouch at the top of its oesophagus (food pipe) which prevents food from reaching the stomach.

Prior to surgery, this pouch can fill up with food and saliva, which can eventually overflow into the baby's trachea (windpipe), entering the lungs and causing choking.



Immediately after birth Oliver was taken to the Trevor Mann baby unit intensive care nursery to be cared for. He had a replogle tube up his nose and into his throat to suction any saliva he swallowed straight out to prevent it from entering his lungs.

The next morning at less than 18 hours old he had a general anaesthetic to insert a gastrostomy feeding tube into his stomach. He remained in Trevor Mann for 4 days where the care and support were superb.

At 4 days old he was transferred just next door to the Royal Alexandra Children's Hospital where he spent 10 weeks getting bigger and strong enough for major surgery to join the two ends of his oesophagus together. On 30<sup>th</sup> September 2009 Oliver endured a 6 hour operation to join the two ends of his Oesophagus together in an operation called a Primary Repair. There are different surgery's available for this condition and each child may require different techniques. We were hoping for the Primary repair which is where the two ends of the oesophagus are pulled together.

Oliver was kept sedated for 3 days after surgery to enable his Oesophagus to heal. He made a remarkable recovery and on 16<sup>th</sup> October 2009 he was allowed to leave hospital for the first time and come home with his family. Feeding a baby that has never had a bottle of milk is a very daunting experience. Oliver had no idea what to do with his bottle and it took until Feb 2010 to get him to successfully drink from a bottle. Up until this time he had received all his feeds through the gastrostomy tube in his stomach.

In Feb 2010 Oliver aspirated some fluid which means fluid entered his lungs causing a chest infection. During surgery to dilate his Oesophagus it was found he had severe Oesophagitis which is where the acid in the reflux causes inflammation in the stomach and Oesophagus and presents a risk of the anastomosis (repair site) becoming brittle, meaning there is a risk of perforation.

On 24<sup>th</sup> Feb 2010 Oliver had another 5 hour operation called a Fundoplication. This was to tighten the neck of the stomach and reduce the ability to reflux meaning the Oesophagitis would heal. Again he made a remarkable recovery and the operation was a great success.

During his time in hospital tests on Oliver's kidneys have confirmed that his right kidney is multi-cystic and has no function at all. It was also discovered that his left kidney has a condition called Hydronephrosis.

Hydronephrosis is a condition in which one or both of your kidneys become stretched and swollen. This is usually because:

- there is a blockage somewhere in your urinary system (along the urine flow path), which is the usual cause, or
- urine is flowing from the bladder back to the kidneys

Oliver is still under investigation regarding his kidneys but it is unfortunately inevitable that surgery will be needed at some stage. He takes medication every day to prevent urine & kidney infections.

Despite surgery every 3 weeks to dilate his oesophagus Oliver is a cheeky happy boy who is crawling around and getting into mischief!