

**OARA AGM Presentation**  
**18<sup>th</sup> April 2007**  
**Royal Children's Hospital – Melbourne**  
**Luis Garotti**

Hello my name is Luis Garotti. I am 16 years old and I have been invited to talk about my life as an OA patient. I was born 20 November 1990, 6 weeks premature with a long gap oesophageal atresia and no fistula, as illustrated.

**Slide 2 DIAGRAM OF OESOPHAGUS**



A gastrostomy feeding tube was inserted by Alex Auldish the day after I was born. This was the first of many operations that were to follow. My parents were told that the repair would take place at 3 months of age as it would take this long for both ends of the oesophagus to grow to enable joining. However there were many complications that prevented this, which I will now talk about.

**SLIDE 3**



In the first 3 months of my life Mr Auldish had performed around 9 major operations, mostly relating to my stomach. The main one was when I had peritonitis at 2 weeks old. This was caused by a blockage in the intestine – the pylorus (which was not picked up by xrays and scans at the time). Milk could not pass through and was leaking out around the tube. After many days it blew a hole in my stomach causing severe infection. Mum told me that adults can die from this so I was very lucky being only a small baby.

#### SLIDE 4



The problems continued with the leaking so I was fed intravenously so that my stomach could heal. It was frustrating for Mr. Auldism because the scans showed very little as my stomach was so small. It was even more frustrating for mum and dad. I had many drips – basically wherever they could find a vein, even in my head, and also central IV lines which would get infected and need replacing under a general anaesthetic. I had countless xrays and scans, blood tests, morphine, antibiotics and oxygen. Apparently Mr. Auldism thought there may be a fistula after all because of aspirating and a collapsed lung, but one was not found.

#### SLIDE 5



Mum says that she was scared to hold me because of all the tubes and because I had been handled so much.

Other surgeries in this time included a new gastrostomy, insertion of a jejunostomy feeding tube directly into the bowel, dilatation to unblock the pylorus – this had been the problem all along and it was finally picked up after several weeks; and also an oesophagostomy which meant attaching my upper gullet to an opening in my neck so that saliva could drain out instead of being suctioned every 10 minutes. Mr Auldism did this operation because it was decided that the repair to my oesophagus would not happen until I was at least 1 and strong enough and so that I could go home. I was now considered a long-term patient and a primary nursing team was set up.

#### SLIDE 6



You can't see much of me for all the tubes.

In my 4<sup>th</sup> month I had infections, namely candida and ecoli due to the continued leaking problems around the gastrostomy site, and the fact that I was too weak to fight off any germs (and there are a lot of those in a hospital). This prolonged my recovery even further and of course I had not been home yet. My parents were now told that the major operation to repair my oesophagus would be done when I was into my 2<sup>nd</sup> year. I slowly got better and was able to have day trips home.

## SLIDE 7



Then on the 18<sup>th</sup> April 1991 (exactly 16 years ago), 5 and half months after I was born I was allowed to go home. Mum and dad were excited but also scared. Mum apparently asked which of my primary nurses would be moving in with us. I weighed only 7 and half pounds as all the problems had delayed my growth.

I had a gastrostomy and a hole in my neck but at least I could go home. I did very well. I pulled my tube out a few times which meant visits to the emergency ward but then I got a new and improved version with a balloon. That was harder to pull out although I did manage to a couple of times but mum was able to re-insert it.

## SLIDE 8



Meal times were interesting. I could eat mushy food only it would come out of the hole in my neck. This is called sham feeding. It was important that I learned to chew and taste food. The real feed would be put through my gastrostomy.

Mr Auldish had been overseas with me in mind looking at a new operation for my future repair.

My first Christmas at home was pretty eventful. I was 13 months old by now. The day went well until my tube fell out (and all the food with it). The gastrostomy site was red and swollen and mum was not able to reinsert the tube. So off we went to the hospital emergency, leaving all our family back at our house. Apparently I missed Santa giving out the presents. Just my luck.

Some 3 hours later I was fitted with an old style smaller tube because the hole had closed up a bit.

In the next few months I became stronger.

## POSTER

The photo on this poster was taken by my mum when I was 16 months old. The poster was displayed all around the children's and I believe other hospitals as well. It is special because it was designed and printed by my dad. This is me now at the OARA AGM, aged 16.



## SLIDE 9



In May of 1992 when I was 18 months Mr Auldish said that I was now strong enough to have the repair. Stretching the two ends of the oesophagus was not possible so Mr. Auldish decided to pull up the lower oesophagus and stomach so that my stomach was in my chest. The hole in my neck was closed and I had a new gastrostomy.

I went home and was ok for a couple of months. Then I started to have breathing problems and was vomiting and tests showed that my stomach was not emptying quick enough which meant that my pylorus was again blocked.

Mr Auldish consulted colleagues in the US and decided that I would need another operation to lower the stomach because it would continue to cause problems if it stayed in my chest. This would be the 2<sup>nd</sup> repair and the plan was to open the chest bone and cut into the stomach to make the oesophagus longer and lower the stomach below the diaphragm. This was a very new surgical technique. The operation took place on 8<sup>th</sup> September, I was 22 months old.

## SLIDE 10

This photo was taken 4 days after the surgery, it shows the long cut on my chest and stomach.



## SLIDE 11



It was another long stay on ward 4 west. I'm told I was a bit of a favourite with the nurses. Pity I don't remember any of them. The good thing was that now I could have small amounts of oral feeds – but only liquid - and it would not come out of my neck, although it would drain out into a bag connected to my gastrostomy tube as my stomach was not ready to cope with food. My favourites were vegemite, broth and ice cream.

## SLIDE 12

Apparently whenever I saw the kitchen lady I would yell out 'yum-yum' and she would bring me vegemite and ice cream.



The problems started again because my stomach was still not emptying and so another operation was needed to stretch the pylorus as it was blocked yet again. There was so much scar tissue around the stomach area that Mr Auldish almost gave up, but he didn't. I now had 2 tubes - a jejunostomy to feed directly into the bowel and a gastrostomy to drain the stomach. The healing process took a few months, again many drips, central lines, x-rays, dilatations of the oesophagus, etc.

## SLIDE 13



I turned 2 on the 20<sup>th</sup> November and I was allowed to go home for the day. I was having continuous feeding through the tube into the bowel. The tube was connected to a portable battery-operated feeding unit which I carried in a back pack so I could move around.

## SLIDE 14.



I was home again for Christmas.

The blockage in my pylorus continued to be a problem and in July 93, when I was 2 and half Mr Auldish operated again. Dilatations were not working so this time he totally reconstructed the pylorus so that it would be impossible to get blocked. Mr Auldish recut an existing scar so that I wouldn't have another one.

#### SLIDE 15



My stomach slowly started to work better and I was able to begin eating solid food when I was about 3 years old. I still had a gastrostomy which would be drained if my stomach became too full. Life became considerably better even though I had regular gastroscopies and dilatations.

Just after my 4<sup>th</sup> birthday in November 94 the gastrostomy tube was finally removed. This was a happy day.

#### SLIDE 16



My stomach took a long time to adjust to solid food and now there was no tube to drain so I would often need to vomit. I know that a lot of OA patients have a fundoplication done to stop reflux and vomiting but that was not possible in my case. Nothing could put me off food though. I was told that some of the other patients were difficult eaters. Not me – there was no stopping me.

From then until now I've had many trips to the childrens. I now go in once a year for a gastroscopy and dilatation if needed. Biopsies of my oesophagus and stomach are also taken for testing. I take Nexium to control the acid as my stomach produces too much, so I will probably need to take this forever.

My parents lost count of how many general anaesthetics I've had since birth but it's around 50.

I am very grateful to Mr. Auldish for literally saving my life when I was a baby, and all the other doctors and nurses in neonatal and 4 West. Mr. Auldish is still looking after me along with my other doctors - Lionel Lubitz, my pediatrician, Tony Catto-Smith, gastroenterologist who does the gastroscopies with Mr. Auldish; and Margaret Zaccharin who checks my growth.

**Currently the problems I have are:**

Food getting stuck – when I eat chunky or hard food it usually gets stuck where the join is, these foods are usually meat. I can usually clear it but sometimes I throw it up which is easy for me because the join is in my neck. I drink a lot of water when eating to help with swallowing.

Stomach pains – I get stomach pains when I eat too much food or I eat the wrong thing because it takes a long time for my stomach to digest food. It gets full and becomes very hard and I can't eat any more. When I have a growth spurt my scars stretch and it feels like a bad stitch and a very sharp pain.

Coughing during the night – Some nights I wake up because the reflux makes me cough up mucus, this usually happens when I eat late at night.

Burning throat – When I get reflux, most of the time it makes my throat burn, this is a sharp pain that feels like my oesophagus is on fire. The gastroscopies show that I have some inflammation & redness of the oesophagus – this is called oesophagitis.

Blood tests – Every 6 months I go in for a blood test so that Dr. Lubitz can check my iron and hemoglobin levels. After years of this I still get a little nervous when I go in there because the nurses always have trouble finding a good vein.

I have had growth hormone injections which gave me a boost but they are bit painful. I hope I don't need anymore of those.

I have lots of scars on my torso and each one has a story. When my friends see them they ask lots of questions. I sometimes get annoyed with all the questions but I suppose people are just curious.

It doesn't worry me that I am smaller than most of my friends but I do feel different because of my body shape. But as the saying goes, good things come in small packages!

I am looking forward to getting my learner's permit this year. My hobbies are listening to music, playing computer games and working on my computer to make it better and faster, going out with my friends, cars and dancing. I hope to study graphics and video editing when I leave school.

That's all I have for you. Thank you for listening and thank you to the OARA committee for inviting me to speak tonight.

Just to finish off, here is an image time line of my earlier years.

