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Welcome back to our Spring edition

Isn't it nice to see a little sunshine for those of us who live in the cooler southern states. As many will know, winter weather can bring about its own challenges with colds, coughs and chest infections, often impacting on our OA TOF community more than the general mainstream population. Well with Spring upon us, hopefully their general health and wellbeing will be at its best and the sunshine will get everyone outdoors and playing amongst the beautiful newly sprung flowers and lush colourful gardens.

Spring also heralds a new opportunity to make some new friends, reacquaint yourself with old ones, or simply catch up with the OARA's National Catch Up Day happening across the nation. This wonderful event will take place on the 9th of November with State co ordinators working hard to make each event as successful as possible, but as you know these events depend on your involvement, so be sure to come along for the morning.

Again thank you for being apart of this special group, we love hearing your stories and sharing in your photos. Please keep sending them through and enjoy reading our Spring edition.

Take care. xx

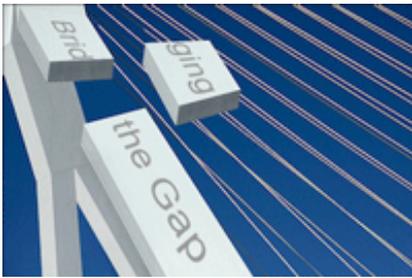
NSW Notice

The Sydney Children's Hospital OA TOF clinic is planning a parent information night evening in 2015. If you would like to be informed of the details please contact nsw@oara.org.au



Save the date for the next International Conference in Sydney 2016

We are very excited to tell you that the International Network of Esophageal Atresia have selected Sydney as the host of the next International Conference to be held in September 2016. A huge thank you especially to Dr Usha Krishman for leading the successful bid submission and being such a wonderful ambassador for the Australian OA/TOF medical and patient community. OARA looks forward to continuing our support of the international conferences and inputting into the planning arrangements.



2014 3rd International OA Conference - Rotterdam

It was a privilege to represent OARA at the recent International Oesophageal Atresia Conference held 2-3 October 2014 in Rotterdam, The Netherlands. The conference program comprised presentations in the following areas:

- Tracheomalacia in Oesophageal Atresia
- Prevention of pulmonary infections: role of antibiotic prophylaxis, PEP-mask and other options
- Long gap Oesophageal Atresia (surgical management, motility and digestive issues)
- Dysphagia and dysmotility
- Barrett oesophagus
- (Neuro) developmental aspects
- International registration of surgical, clinical, and follow-up data

A parent support group dinner was held on the night before the conference and this provided an invaluable opportunity to meet with parent support group representatives from mainly Europe and the UK. Topics that we discussed include what more we can do for our adult OA/TOF community, sharing of information and awareness tools and generally sharing our own unique OA/TOF stories. We have agreed to further cultivate our global working relationships via teleconferences between international conferences to further promote consistency and innovation in how we support our OA/TOF community.

Given that this is primarily a conference for medical professionals to share their knowledge and innovations regarding OA/TOF, it was humbling for the parent support groups to receive such respect from the medical community and be given recognition for the important emotional and practical support that we are all striving to provide. In meeting and sharing stories with the emerging Russian support group (via translator), where mothers of OA/TOF babies are not allowed to see or touch their babies for weeks and months at a time due to outdated and autocratic medical theories and care practices, I realised how lucky we are here in Australia to enjoy such a close working relationship with our doctors and nurses who understand that beyond the medical and surgical requirements to treat and manage OA/TOF, there are important emotional and practical needs that must be addressed to ensure the health and wellbeing of OA/TOF patients and their families.

Look out for a summary of the conference's key messages at the National Catch-Up Day on 9 November 2014 and topic spotlights on www.oara.org.au over the coming months.



Melbourne Fundraiser
Golf Day - Get your
clubs ready!

SAVE THE DATE!



Have you always
wanted to spread
awareness of OA
TOF?

**OARA have recently
brought out a range of**



FUNDRAISING FOR OARA

SA held it's first fundraiser in Mawson Lakes. They raised over \$500. A huge thank you to Sonia for organising everything and John, Riley, Michelle, Lexi, Michelle and Elyce. Also a big thank you to donations from Foodland and discounts from Gawler River Meat. Looking forward to our next fundraiser.

Friday 20th February

Melbourne is once again hosting a golf day in aid of raising money for OARA.

A tradition of OARA when it was an auxiliary of Melbourne RCH is back!

So dust off those clubs and get your evening wear ready for a day of golf and an evening of fun!

Keep a look out for more details on the website soon!

OARA National Catch Up Day is this Sunday 9th November.

This is a nation-wide social event, open to all our members, friends and family. There are local events set up in each state, so if you haven't yet, please head on over to our *Facebook page* and confirm your attendance at your local catch up. The details can also be found on our *website*.

Special Notice: Western Australia's picnic will commence at 10.00m not 10:30am as previously advertised, contact your rep for more information.

awareness products! These include badges, wristbands and water bottles to name a few. The details on how to purchase are on our website, you can buy in bulk and sell to family or friends and in the process start the discussion on what is OA TOF.

The state reps will also have them available at the National Catch Up Day, however we won't have EFTPOS or credit card facilities at the events, so don't forget to bring some cash and pick up something great to help spread awareness of OA TOF and the great work of OARA.

Conor's Story: A tale of challenges, chewing and cherished moments.



Conor was born in March 2008 with type C OA/TOF. He had his initial repair at one day old and spent five weeks in Sydney's Children's hospital, NICU. He experienced all the normal reflux and colds which most OA TOF kids endure. At one and two years of age, he had his first dilatations and a number of admissions to hospital for aspirations and bad chest infections which lead to a couple of stints in ICU.

In early 2011, at age three, he had a Ph Impedance study and an endoscopy which indicated that his reflux was quite bad. To address his reflux, he had a fundoplication in the June of that year, and subsequently went straight off his reflux medication and I thought we were so lucky to have no more issues.

Since the beginning of last year, I had noticed a pattern emerging for a little while, that Conor had been sick every four weeks. It used to be much worse, temperatures, appetite loss, really bad chest infections, but now it was more like a cold but with an awful TOF cough thrown in. In the middle of last year, we started on a daily nebuliser and PEP therapy in the hope that would lessen the frequency of the infections, but it didn't really seem to make much difference. Conor continued to have these monthly infections, however we knew he wasn't aspirating reflux, as that had been tested. Earlier this year his respiratory doctor sent him for a lung CT to check if there was any damage evident. It was this scan that doctors discovered, quite by accident, a recurrent fistula. Conor had a barium study and a laryngobronchoscopy

(LBO) which confirmed the new fistula was indeed there.

My understanding is that this is very rare to occur and when it does occur it's usually in the first 12 or so months of the child's life. The doctors hadn't seen it before and were quite amazed it was there. There were a few options to fix this and the doctors thought they had a good chance of repairing it via endoscopic cauterisation. They basically burn the fistula on the trachea side and add some 'glue' in the hope that the scar tissue will close the hole. This was done in mid-september this year and Conor then spent three days intubated in ICU and home a few days later. It's not very invasive and apart from secretion build up, he was quite well afterwards. We went back mid-october for a repeat LBO to check if it had been successful. The hole was only half closed so they wanted to try again. We weren't quite ready for that to happen, sure there was a chance it wouldn't work and it would need to be re-done but I didn't think it would happen right at that moment. As the first time, Conor went back to ICU and was intubated for a couple of days. This time for the procedure, they extracted some fat from his tummy, liquified it and injected into the fistula on the trachea in the hope that would help close the hole. He was also kept on nasogastric (NG) feeds for seven days. We are due back mid-november to see if this has worked. The doctor was happy to attempt the fix this way only twice, but if it hasn't worked this time, he will need more invasive surgery.

For us this was picked up by accident, it certainly wasn't what they were looking for on the CT scan. Sure he had colds each month but not enough to take him to hospital, we hadn't had an admission since before the fundoplication three years earlier. A bronchoscope late last year didn't find this either. Conor goes to school and he doesn't need extra support, he went to preschool last year, again with no special attention. His eating is pretty much on par with other kids his age, we don't need to take him to hospital when he is sick anymore and we felt quite lucky that we had it so good.

Apart from these monthly colds we had no issues. I guess my reason for sharing Conor's story, is that it is important to be alert but not alarmed and continue to get your child checked regularly. I didn't think we had any issues that needed regular checking and I have never said "no" when scopes, xrays and CT scans were suggested to us, but I wonder if they need to be more regular. Was three years too long to wait and even then, would this have been found? I thought we were clear of any issues associated with OA TOF, but I will certainly be paying more attention to any signs he may display in the future. If you would like more information, please contact Katy on katy.moylan@pickles.com.au.

Katy will continue to up date us on Conor's progress, so stay tuned for Part 2 of his story.....

Thank you Katy for sharing your story and if you have a story that you would like to share with the OARA community, please email mail@oara.org.au.

O.A.R.A P.O Box 502, Pakenham, Vic 3810

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