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The OARAcle

Welcome to the winter edition of the OARAcle! We hope this newsletter finds you and your family well. It certainly has been a cold winter this year, which can be a harrowing time for parents of OA/TOF children or adults with the condition. So it is nice to see the signs of spring on the horizon.

There have been a few extra articles added to this newsletter, so I hope you have a comfy chair and a drink on hand to find out all about what's been happening and the upcoming events for OARA.

THANK YOU

We would like to take this opportunity to thank those who have generously donated to OARA over the last 12 months. These funds are invaluable to the work of OARA in providing support to those born with OA/TOF.

DID YOU KNOW?

OARA is run solely by a small team of dedicated volunteers. The OARA team consists of parents or relatives of OA/TOF children/adults and those with an interest in the condition and not-for-profit organisations.

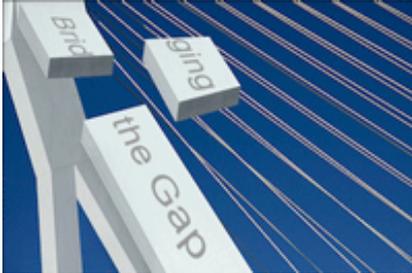
Thank you to all those who participated in our online survey conducted throughout the month of April. Recently, we had a planning day to reflect on the past year and look to the future of OARA. We took on board all of the feedback from our survey and there are many projects that we would like to see implemented but time is often a limiting factor.

If you think you could help out with volunteering your time, please email secretary@oara.org.au

Make sure you have joined the [OARA Ltd facebook](#) group and [Twitter @OARALtd](#) so that you can be updated about these initiatives in the future.

Welcome Alistair!

OARA would like to welcome Alistair Wilkes as our Marketing and Public Relations Coordinator. Alistair has experience from working and volunteering with a range of not-for-profit organisations in Australia and abroad. So far, Alistair has already contributed greatly to OARA behind the scenes and we look forward to working with him as we continue to build awareness to OA/TOF in Australia. You can contact Alistair by email media@oara.org.au



The 3rd Oesophageal Atresia International Conference

Preparations are underway for Olivia to represent OARA at the International Oesophageal Atresia Conference in October. We look forward to sharing with you her news and insights from the conference. Please tell us how you'd like to receive this information – fact sheets, morning tea presentation. Email secretary@oara.org.au with your suggestions.



First ever TOF OA International SURVEY

Please take a few minutes to complete a survey to help build an international picture of life with OA/TOF.

This survey is the first of its kind. It has been organised by EAT - The Federation of Esophageal Atresia and Tracheo-esophageal fistula support groups - the international organisation of which OARA is an associate member.

EAT will present the results at the forthcoming 'Third International Conference of Esophageal Atresia' which will take place later this year in Rotterdam (2 and 3 October 2014). We will also publish the results following this conference. [Complete SURVEY here.](#)

EAT is primarily a European federation of support groups. Their website is a great resource for families and medical professionals, so we encourage you to have a look. There are also many other links found on our website. [More information](#)

The Australian Rare Disease Survey

You are invited to participate in **The Australian Rare Diseases Survey of Adults**. This study is being conducted between **21 July and 1 September 2014**, by the Office for Population Health Genomics, Department of Health WA in partnership with Rare Voices Australia (RVA), The Genetic and Rare Disease Network (GARDN), Genetic Support Network Victoria (GSNV) and the Association of Genetic Support Australasia (AGSA).

We invite you to participate in the survey if you are:

- Aged 18 years or older and living with a rare disease in Australia, or

- A carer or paid support worker is permitted to complete the survey if the person aged 18 years or older living with a rare disease does not have the intellectual and/or physical capability to complete the survey



For more information visit the [Rare Voices Australia website](#)

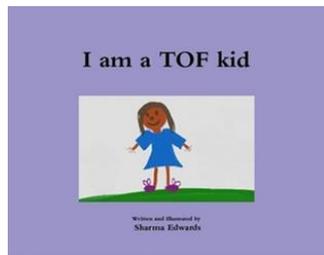
To participate in this study, please click on the link below to the online survey. The survey is anonymous and takes about 20-25 minutes to complete. We ask you to complete the survey by 5pm (AEST) on 1 September 2014.

Survey Link: www.surveymonkey.com/s/AustralianRDSurvey



GYM OPEN DAY

Esther O'Halloran organised a fundraiser at her gym raising over \$500!! OARA would like to thank her for her efforts and all those who supported and donated.



I am a TOF kid.

Is a great resource for children wanting to know more about their condition and/or educating those around them about OA/TOF. The book has been available for 5 months and has already sold a total of 276 copies in many countries all over the world, such as the UK, the US, Canada, The Netherlands, New Zealand, Ireland and South America. Sharma Edwards has now donated over \$500 to OARA from the sale of the book, which



MERCHANDISE COMING SOON

Look out for our new OARA wristbands, badges, drink bottles and more coming soon to a State Rep near you!!



SHARE YOUR OA TOF JOURNEY

In the past, our newsletters have featured a story about a OA/TOF adult or child and have always been very well received. If you would like your story and photos to be published on our website and linked to our newsletter, please email mail@oara.org.au

is a wonderful effort and we thank her again for thinking of OARA with this initiative. If you would like to order a copy follow the link on our website.



TOARA'S TRAVELS

T = TOF or Tracheo oesophageal fistula

O = Oesophageal

A = Atresia

R = Research

A = Australia

Toara has been travelling around Australia creating smiles on children's and families faces affected by OA/TOF.

Toara's journey began in October 2012 by spending time with Tamisha and her sister's having fun in the Melbourne sun at Arthur's seat. Charlie and family celebrated Charlie's first birthday with Toara and went shopping. From there it was Toara's first plane trip to Sunny Brisbane to meet Sophie and visit her kinder. Christmas 2012 was spent with Jimmy and his family, then Toara was off to meet Caleb going to a cousin's 10th birthday and visiting Daddy at work. Toara got to travel with Kiara's family to their new home from Brisbane to Sydney and saw some fireworks on Australia day.

In February it was Sophia's turn for a visit from Toara and they went for walks and bike rides. Toara spent time with Samara in Sydney when they visited the hospital, by holding Samaras hand and keeping her brave.

In April, Conor and Toara went to pre school and soccajoey's.

In June Toara boarded another plan this time to Tasmania to meet Oliver and family to celebrate Oliver's 5th birthday. They had fun opening presents together and eating cake. Whilst in Tasmania Jax also got a visit and went on a road trip to Hobart. Then it was time to go back to Melbourne to be checked on by Tamisha and have a wash before heading to Berwick to have an adventure with Hamish on the Puffing Billy. Riley and Toara played at home during a cold Melbourne Winter. Riley then delivered Toara to Kaytie in September. They spent Father's day together and danced to music. Toara enjoyed a visit to celebrate Kaytie's cousin, Maddy's first birthday. Toara then did a return trip to Queensland to see some familiar faces such as, Sophie visiting the museum, playing with Jimmy and having a slide with Caleb. Then it was time to make new friends with Pepper and her cousin playing at their house. Toara had lots of cuddles with Amelia before visiting Makayla. Makayla loved making Toara be a baby in a pram. A stop in NSW to meet Kayden and spend time with his family.

Cruiz met Toara when Tamisha passed Toara to Cruiz at Kinder who meet in the same Kinder class. Now it is time for Toaras next adventure, thankyou everyone for spending time with Toara and spreading awareness.

OARA wishes to thank Emily McClellan for facilitating TOARA's travels and making sure she is being looked after and travelling from family to family. If your family would like a visit from TOARA please email or phone Emily upsonfamily@optusnet.com.au / 0430 083 333.



South Australia Report

We recently had an OARA catch up with 4 OA/TOF children in attendance. We spoke about the possibility of an annual gathering at the start of next year which will hopefully see many more families join us. A huge thank you to Sonia for organising a fundraiser which is planned for early September at Mawson Lakes. We have tried this fundraiser many times without success for various reasons, but this one is definitely happening. I have met an amazing doctor at the Women's and Children's Hospital who is very enthusiastic about supporting OARA. I found out that we have had 6 children with repairs done at the hospital in the last 12 months, and a brochure pack is going out to each of these families. I am researching the possibility of incorporating a OA/TOF nurse in the hospital. We are looking at the possibility of a Golf Day to fundraise for the education for this nurse. For more information on any of our fundraisers, please contact Carlie, sa@oara.org.au or visit the OARA website.



Western Australia Report

The WA families currently catch up on the first Monday of every month. Taking turns to host at each other's houses until the group grows large enough to need a regular venue. The catch ups are invaluable, watching our toflings play with each other & sit down and share a OA/TOF friendly relaxed morning tea together. Other siblings & family members are of course always welcome too. Sharing stories and tips/tricks with each other is fantastic! We have already made some life long friends and the kids realise they are not the only one like them. For the next WA catchup email Erin the WA Rep for the date & location perth@oara.org.au



New South Wales Report

Sydney Children's Hospital at Randwick hold a bi-monthly multi disciplinary TOF Clinic through their outpatients department. Patients have the opportunity to meet with a Surgeon, Respiratory doctor, Gastroenterologist, ENT, Physio, Dietician and Speech Pathologist as well as a Social Worker, depending on what is required for them at each scheduled appointment. The clinic runs for about 3 hours and schedules in 4-6 patients only – and conveniently the doctors rotate between the patients. The clinic has been running three and a half years and is the only one of its kind in Australia. A great opportunity to meet other OA/TOF families while you are there.

For more information or to organise a catch up in your area, please contact Katy Moylan nsw@oara.org.au

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

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