

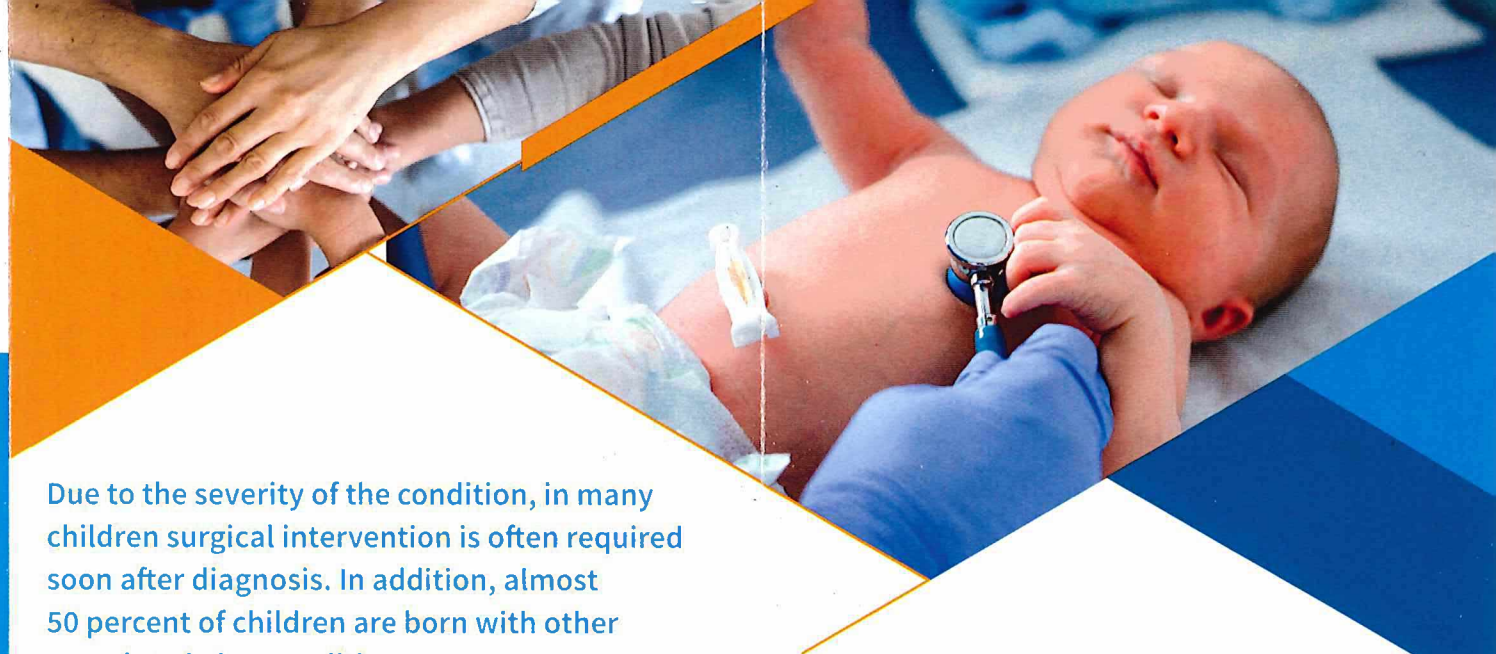


The **ONE IN 5000 FOUNDATION** was established in August 2017 as a not-for-profit organisation to provide assistance and support to anyone affected by the congenital condition called Imperforate Anus (IA), also known as Anorectal Malformation (ARM).

This condition affects one in 5000 births and is slightly more common in males than in females, with the cause still unknown. In a baby born with the condition, any of the following can happen:

- 1** The anal opening may be too small or in the incorrect location – which can cause painful bowel movements or severe constipation.
- 2** The anal opening may be absent, and the rectum enters other organs in the pelvic area (including the urethra, bladder or vagina). This can lead to chronic infections or bowel obstruction (a dangerous condition where stool becomes trapped inside the body).
- 3** The anal opening may be absent, and the rectum, reproductive system, and urologic system form a single channel called a cloaca, where both urine and stool are passed. This can also lead to chronic infections.

**Awareness, Information,
Medical & Support
(A.I.M.S.)**



Due to the severity of the condition, in many children surgical intervention is often required soon after diagnosis. In addition, almost 50 percent of children are born with other associated abnormalities.

As the condition is rarely acknowledged outside an extremely small sector of the community, it therefore does not attract the resources needed. Those affected require ongoing physical and emotional medical care, families need information and support, and doctors and nurses need professional development.

To achieve this objective, we are committed to the following four outcomes: *Awareness* of ARM; *Information* regarding mental health and economic issues; *Medical* advice and best practice; *Support* emotionally and if feasible, financially. These ambitions form the basis of the acronym that we call our A.I.M.S.

To align with these objectives, the *ONE in 5000 Foundation* has been represented at International Paediatric Colorectal conferences in USA, London, Paris, Vienna, Zurich and Melbourne. This has enabled us to build important personal relationships with leading paediatric colorectal surgeons and patient organisations from around the world. This has resulted in a collaboration of projects such as research studies, global webinars, and co-authoring of a chapter in an internationally released paediatric colorectal textbook.

Our website www.onein5000foundation.org provides a global online resource for the ARM and wider community.

We offer the opportunity for patients and parents to describe their own experiences, share medical educational ARM videos, and respond to a FAQ section. We also have a *Medical* section which details a global list of paediatric colorectal and mental health medical professionals and their hospitals.

We have been able to assist in funding and organising much needed surgeries for children from Ghana, Africa. Subsequently, we have set up a program, in collaboration with *Rare Disease Ghana Initiative*, where we forward unused stoma supplies obtained from our worldwide network to Ghana for distribution.

Our organisation has a very active and influential online presence on social media platforms such as Facebook, Instagram, Twitter and LinkedIn. Under the *ONE in 5000* banner, we have reached thousands of people globally. This includes members from the ARM community, our medical network and many from the general public.

We also have been able to establish closed Facebook Support Groups in Australia, United Kingdom, France, Canada and New Zealand, where families have been able to connect with others in their own respective countries in privacy and for personal support.



We are affiliated with the following local and international organisations:

- + Colorectal and Pelvic Reconstruction Service (CPRS), *The Royal Children's Hospital Melbourne*
- + Rare Voices Australia (RVA)
- + Continence Foundation of Australia (BINS4Blokes Campaign)
- + eUROGEN - European Reference Network (ERN), *International*
- + Global PaedSurg, *International*
- + Pull-Thru Network (PTN), *USA*
- + Pediatric Colorectal and Pelvic Learning Consortium (PCPLC), *USA*

'On the 28th March 2018, the founder of our organisation, Greg Ryan, was invited by Senator Anne Urquhart of Tasmania, to attend Parliament House in Canberra as her guest. Senator Urquhart gave a parliamentary speech in the Senate Chamber in which she detailed Greg's journey of living with the condition. Senator Urquhart also shared her thoughts on his internationally published memoir "A Secret Life -Surviving a Rare Congenital Condition", and the work of the ONE in 5000 Foundation. Most importantly, this was the first time that Imperforate Anus/ Anorectal Malformation had been mentioned and discussed in any Parliament in the world.'

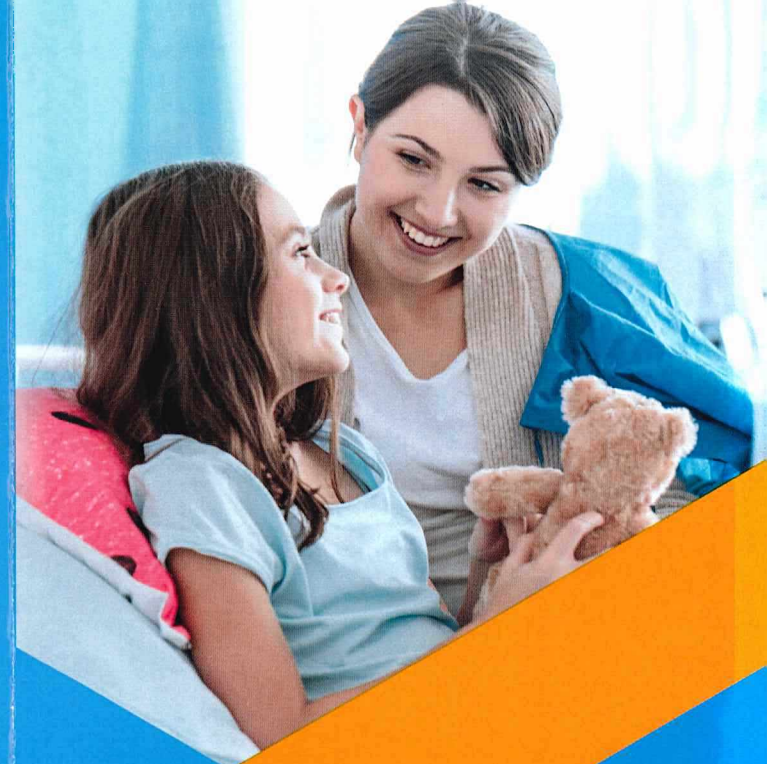
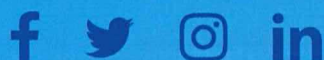
ONE in 5000 Foundation Incorporated
is fully registered with the
Australian Charities and
Not-for-profits Commission.

ABN: 18 393 396 753

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Donate to ONE in 5000 Foundation Inc.
via our website using Paypal.

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**A global resource for
the Imperforate Anus /
Anorectal Malformation
community**