Once in a lifetime, such a book is written.

Over the next 12 months, 30,000 babies across the world will be born with a congenital abnormality known as an imperforate anus (IA). These babies will need an anus to be formed for them and will join the 7 million other people who live on a daily basis with IA which is also called anorectal malformation (ARM). They will begin a battle with an anatomical problem that may never be completely cured, and many will suffer from the social stigma. This may include mental health difficulties due to the secrecy, loneliness and isolation of living with this birth defect.

Despite surgical improvements the mortality rate for IA/ARM in countries across the world is still alarmingly high. Many survivors live in pain and despair because of the immense difficulty in rectifying this problem. To compound these difficulties, IA/ARM is rarely acknowledged outside a small sector of the community and, therefore, does not attract the resources needed. Doctors and nurses need professional development, families need information and support, and survivors need the confidence to speak out about this disability.

**Greg Ryan**, a middle-aged Australian man, has become the first person in the world to write openly about his 50 plus years of living with IA/ARM. His candid, simple narrative is beginning to alter the ways medical and mental health services respond. Greg’s courage to speak out has led to responses across the world. His perception has been massively widened by the number of links he has made since the publishing of his book: **“A Secret Life – Surviving a rare congenital condition”.**

Greg and friends have successfully launched a not-for-profit agency called ONE in 5000 Foundation Inc. to work with **Associate Professor Sebastian King** (Paediatric Colorectal Surgeon) from The Royal Children’s Hospital, Melbourne. After-cost income will be spent in conjunction with Sebastian, helping to organise worldwide supports that will improve the lives for children and their families, allowing them to live positively with IA/ARM. We are encouraging Medical Schools, Educational Facilities, and Libraries to purchase copies of the book.

**Now available** through:

* [www.facebook.com/asecretlifebook/](http://www.facebook.com/asecretlifebook/)
* [www.onein5000foundation.com.au](http://www.onein5000foundation.com.au)
* Greg Ryan: Author e: gregmryan@hotmail.com
* Readings Bookstores: <www.readings.com.au>
* As a kindle E-Book: [www.amazon.com.au/Secret-Life-Surviving-Congenital-Condition-ebook](http://www.amazon.com.au/Secret-Life-Surviving-Congenital-Condition-ebook)

 **“A SECRET LIFE” – TESTIMONIALS**

 *“Mr Greg Ryan, I have just finished reading your very inspirational book “A Secret Life”. First of all,* *please accept my sincere admiration and respect! Also, please transmit my feeling to your parents, who played a crucial role in your long and painful journey. As you can imagine, I had the privilege to learn and be part of many similar stories.   It has been my experience that patients born with bad prognosis type of anorectal malformations and their parents, go through different suffering stages, beginning with the shock feeling of learning that their beloved newborn baby has no anus!!. Something that most people never heard about. Later on, sometimes they become angry and ask themselves “why me?”. Subsequently, parents and children go through the extremely painful path represented by the confrontation with our rather cruel society, attending school, having embarrassing “accidents” and all those terrible events that you narrated so well in your book. Eventually, many parents and patients find a MEANING to all their pain and suffering.  I have the feeling after reading your book that you already reached that point. It sounds like you find a MEANING. This, I think, started when you decided to share your story with others.*

 *After your trip to Orlando, after you met all those teenagers, after you met that child who called you “Mr. Australia” you realized that your story, your presence, your words, your experience meant a lot for many, perhaps thousands of other human beings. Just consider this: imagine that when you were 10 yrs. old, you met an adult who called you and said: “Greg, I know exactly how you feel, I have been there, and I am here to help you”. I am sure that now you know that you have a mission, a beautiful one. You can certainly alleviate the suffering of hundreds of children. You just had a little sample of your mission in Orlando. Congratulations. I look forward to hear more about your work for the benefit of children born with anorectal malformations and their parents. Again, I congratulate you for your strength and endurance. I sincerely hope that you continue using your experience to benefit many children and parents of the world”.* ***Alberto Peña, MD, FAAP, FACS, FRCS |Ponzio Family Chair for Colorectal Pediatric Surgery |Director, International Center for Colorectal Care| Children's Hospital Colorado|Professor of Surgery University of Colorado***

*“Greg,*

*I wanted to send you a short note to let you know that I have finished reading the book that you gave me at the Colorectal Conference at Nationwide CH. I appreciate your willingness to share the ups and downs of your courageous journey with us. I recall seeing you at Nationwide but couldn’t place you at first, realizing later that we had met at the Pull Thru Conference in Orlando. It is interesting to read your story because I have met both Nate Myers and Justin Kelly at past conferences, so I feel that connection to you as well.*

*Anyway, as a result of reading your story, we will certainly put more emphasis on the mental health needs of our little patients and their families.* ***Donald B. Shaul, MD Pediatric Surgery and Urology
Regional Chief, Pediatric Surgery Los Angeles Medical Center***

*“By sharing his “Secret Life”, Greg has opened the door for change to occur in the care given to* *children born with AnoRectal Malformations. As the parent of one of those children, I know the challenges faced by children and their caregivers. As I read “A Secret Life”, I found many similarities to my own daughter’s life and made the challenges she has endured even more apparent. Greg’s life story helps bring attention to the life-long challenges that these individuals face on a daily basis. As clinicians begin to recognize this, I believe positive change will occur in the care given to patients and their families. I hope “A Secret Life” becomes required reading for all pediatric colorectal clinicians.”*

***Lori Parker Executive Director Pull- Thru Network USA***

 *“I read the story with fascination - it gripped me, and I just couldn’t stop till the end. What stands out for me is the journey from shame to pride - or perhaps more accurately from the unacknowledged shame - the shame that is hidden and hence as inauthentic and its avoidance makes the person live a life that is not authentic. congruent with the inner self they (sometimes only half) know they really are.  Stepping into that space and making the shame visible - becoming however tentatively authentically who they really are, they start to realise what thus authentic shame is actually is hard-wired to do - to bring those who witness it closer - to repair/build/strengthen the social bonds that are so essential for human existence (as social beings)  What he describes so powerfully is the process through which he reaches this state of balance between the shame (always present in the risk of being judged that is the product of our infantile guilt culture) and the pride, dignity self-respect that is (like the king/yang mandala) its essential counterpart - what makes it ‘authentic’.”* ***Dr Tony Webb Doctor of Philosophy Adelaide***

*“Dear Greg,*

 *I felt the need to contact you after reading your book.  My wife Caroline met you at the Colorectal Conference in Columbus, Ohio in November 2017 and spoke fondly of you, and enthusiastically about your book. She said it's a must-read both for physicians and lay people (I'm not medically educated myself).*

*Your book, A Secret Life blew me away. I finished it very quickly and I wanted to let you know how deeply it moved me. How incredible it was to read your story and how amazing it is you do such great work for better guidance for children with the same condition from child to adult. So may doctors around the world be able to make the life of these patients, patients like you, much better now. Thank you for sharing your story”.* ***Lin – Husband of Paediatric Surgeon - Netherlands***

*“Greg, your book is such an inspiration. My son has IA and we are going through the first of many hurdles of bowel management.  We’ve kept his condition tight lipped, but there is a sense that in some circumstances it shouldn’t be such a taboo subject.  From your story, I think of your mom as I can relate to her the most.  There is nothing worse than the feeling of fear for your child, yet you must be composed confident and push them to try to live life normal.  I pray this chapter of your life gives you peace and your mother the comfort knowing she did a fine job”.* ***Nicole – IA/ARM Parent – USA***

*"Greg, I think all I can really say is THANK YOU. Thank you for writing this book, thank you for being brave enough to share your secret, thank you for advocating for our children, thank you for being their voice as you put it...thank you thank you thank you. It was definitely confronting to read, so thank you for the warning as well. I think I went through the whole gamut of emotions. I'm so glad that you have brought to my attention that I need to consider the fine line between respecting my daughter's privacy and the damaging relationship between shame and secrecy. It is something that my husband and I will have to spend a lot of time discussing and getting help with I think, so that we can best support our daughter as she grows. Another thing that struck me was how adrift we felt in the five or so months between my daughter's diagnosis during pregnancy and finding the Facebook support groups. When I read your book, I realised how incredibly lucky we are to have these resources available to us now, so that our child can grow up in an environment of support and community. Thank you for making sure that our children don't have to feel alone in their struggles."* ***Zoe – IA/ARM Parent – Australia***

*"Finally, a book sharing how it can be living with a rare (invisible) condition. As a parent, I am thankful to the author for sharing, and reminding us of the mental as well as the physical side of living with painful secrets. Last, but not least, it is heart-warming to learn what a difference a supportive family, medical support and environment can make. Thank you, Greg Ryan, for letting your secret out, and hopefully make it easier for others to share theirs, and get the understanding and support needed."* ***Birgit – IA/ARM Parent - Norway***

 *“I commend you for putting your whole self out there in such a transparent way. You are brave, you are equal Greg and you are worthy of all of life's gifts. I hope writing this book aides in your continued journey to healing, understanding and acceptance of the great man that you are. I don't know if you will ever comprehend the impact this will have within the community - like the pebble that drops and creates the first ripples in the water, all in ways that you can and might not even expect."* ***Gretchen – IA/ARM Parent - USA***

*“Hi Greg, Your book was great. As you said an emotional read, but definitely worth diving into.*

*Thank you again for sharing your story, I'm so thankful my little Kave will grow up knowing he's not alone. I just hope and pray that I can make him feel like he's enough and help him realize how truly powerful he is.*

*Your story shed so much light on what used to be a very unknown area for us. I've wondered, and possibly even become obsessed with how Kaven will grow up. I constantly struggle within myself to know if I should treat him "normally" or if he's acting a certain way because of his condition. What a brave thing you've done here, and I can't commend you enough for opening up and letting the world know about your life.*

*Thank you, thank you, thank you! Hope all is well, and please take care of yourself. This IA family is so much bigger than we know, and you're a huge part in connecting us all”.* ***Ashley – IA/ARM Parent – USA***

 *“This should be a mandatory book handout for families with new IA babies and for therapists/social workers who work in the medical field as well as staff of colorectal and pediatric surgeons, centers and units around the world. Thank you for writing this Greg! A big hug from your international IA family!!! We love you and appreciate you.”* ***April – IA/ARM Parent USA***

*“This book has lined up the meaning I have been searching for ever since I had my son, born with VACTERL Association 4 years ago. Reading Greg's true and very honest physical and emotional struggles have let be to believe that there's still so much hope for my little boy ahead. It has also showed me the urgent need to educate and sponsor resources for children with IA. As since 50 years, doctors have been providing pretty much the same approach to dealing with all the rare Congenital birth defects, people have to still endure substantial amounts of pain, with ordinary outcomes expected. Greg's book made more sense to me than 4 whole years of arguing with Dr's about what is Normal and what isn't. Comparing a child’s anatomy, life style, life habits and struggles to that of a normal did not and will not work. This book is a huge reason for providing a better life perspective and much more honest choices for my son, by me as a parent, society and his doctors. Forever thankful for the secret life, and Greg sharing it with the world.’* ***Tina – IA/ARM Parent - USA***

*"Well I've read this book cover to cover this afternoon...i couldn't put it down. It's confronting.. painful.. sad.. educational.. interesting.. uplifting.. challenging. REAL. But most importantly Greg it exudes strength page after page an enormous amount of strength. So proud of you for putting yourself out there.. It's an incredible journey...THANKYOU for sharing!"* ***Simone – Australia***

*“Everyone should read this account of Greg’s life. From the day he was born, all the way through school until later in life he held on to an unimaginable secret, unimaginable for most of us. A true account of Greg who faced so much adversity in his life physically and mentally, but his sense of humour and love for family and friends & the Kangas never wavered. This book will serve to help so many IA sufferers & educate the world about this unique & isolating condition. So truthfully written - an honour to read”.* ***Kim - Australia***

 *"I just finished reading Greg's book "A Secret Life". To say that I was moved by it would be a gross understatement. I found myself emotionally touched right throughout from tears to laughter. I haven't read anything like it before and was not only inspired by the sheer bravery but also humbled by its confronting truths. I salute you Greg, you are a great man and deserve to be respected and honoured for all you have achieved.”* ***George – Australia***

*“Hi Greg, Wowsers - what an amazing, brave and inspirational story you had to tell!!!! I’m have just lent the book to my mum - maybe around 3 hours ago now - and she has just text me to say she can’t put the book down! Great read, despite the nature of what you have survived!”* ***Louise – Australia***



*“Hi Greg, Just finished your book. What a story!!! That is the most inspiring account of dealing with the unfortunate things that come to some in life. Why to some, when others sail through life with little or no hardship to face is of course the unanswerable question. One thing I do believe is that hardships are given to only those who can cope. Congratulations on your survival and all you are continuing to do with your life. You are a real HERO !!!!!”* ***Leonie (Louise’s mum) - Australia***