



# Complex Child E-Magazine

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## Imperforate Anus—What!?

by Tracy Reed

August 8<sup>th</sup> was a day that both my husband and I will always remember. Not only were we going to welcome our fourth little bundle of joy into the world, but it was also a day that we learned about something most people have never heard of, or if they have, it's a “dirty” little family secret: imperforate anus.



### **The Shock of Diagnosis**

Most families remember every little detail of the birth of their child. I vividly remember the birth of my first three daughters with great memories. This time, though, our experience was a bit different. Our daughter was born via C-section, so the birth part wasn't as traumatic as it is during natural labor. As I lay on the table, I couldn't wait to see my baby girl, and I couldn't wait to get sewn back up so we could go cuddle and relax in the room.

Never once in a million years did I think that the nurse was going to come over to me and say, “Well, there are a few problems.” I think the nurse was thinking logically about the shock value before she came over to let us know her strange findings. I'm sure her thinking was like this: go with the least shocking thing first, then work your way up to the very thing that will send these parents over a cliff. Seems logical enough, right? So the first thing that they showed us was that our daughter was born without a thumb. Of course, lying on the table sedated from the epidural, and just having a baby with all those hormones flying out of your body didn't help matters much. I cried on the inside, but thought, “she'll be okay.”

Then onto the next thing...the shocking part. The nurse lovingly flipped our daughter over and said to us, "She also doesn't have an anus." What!?!? Are you kidding me? Who is born without an anus? I mean, who has ever heard of someone not being born with an anus?

I spent countless hours before her birth watching shows like ER, Grey's Anatomy, and even Discovery Health's plethora of health programs. Not once could I dig deep enough into my subconscious to ever remember hearing someone say, "I was born without an anus." I know that people can be born without other body parts--legs, arms, fingers, toes, nose, and even skin--but without an anus? Come on. Thus began our long and arduous journey with a child who has imperforate anus. Mind you, this wasn't our daughter's only health problem, though it did become the center of everything.

Our journey actually began before I was ever even able to see my daughter. She was briskly taken from me to be sent to Children's in Pittsburgh. My husband went along with her as I recuperated in the hospital from my C-section. Not only had I been in shock from it all, but he was also. I'm sure he had that same punch in the gut, the "what the heck just happened here...this isn't supposed to be happening" feeling that I had.

The difficult part was that I wasn't with my baby or my husband. Doctors were coming at my husband from all directions, and he didn't have a clue what to do but just sign the papers for the surgeries they wanted to perform. By the time I made it to the hospital, her surgery had already taken place and she was recovering. So I didn't have the luxury of getting onto my trusty computer and doing my research for her before any surgery ever took place. If you have that wonderful luxury of getting onto your computer right now to research, here is some information for you to turn your child's outcome into a positive one.

### **Acceptance and Research**

The first thing that you need to do is realize that, yes, your child was born without an anus. That yes, it is possible to be born without an anal opening. There are no two ways around that, and you will be in shock. I haven't met a parent yet who wasn't in shock when her child was born without an anus. Even if you happen to be one of the lucky few who finds out ahead of time, the very first sight and the whole concept will still hit you like a brick. It may take some time to get over the shock. I find that even four years later I still have periods of post-traumatic stress about it, but you do get past this eventually.

When you learn to accept that your child has just been born with imperforate anus, you can then take matters into your own hands and start doing some research. There is extensive information available on the Internet about imperforate anus and anorectal defects. Most children's hospital websites will contain at least a little bit of information about the subject. My favorite website to reference is the Cincinnati Children's website, <http://www.cincinnatichildrens.org/svc/alpha/c/colorectal/default.htm>, only because the doctor there pioneered the surgery that will ultimately correct your child's butt. Both Dr.

Pena and Dr. Levitt from Cincinnati Children's tirelessly care for children from all over the world with anorectal malformations. They take their knowledge and pass it on to other doctors, so that they may be able to perform this duty on children who live in other areas. Going to the source makes sense.

## **Anorectal Malformations**

So what is an anorectal malformation or imperforate anus? Anorectal malformations are, in broad terms, "defects that occur during the fifth to seventh weeks of fetal development. With these defects, the anus (opening at the end of the large intestine through which stool passes) and the rectum (area of the large intestine just above the anus) do not develop properly."<sup>1</sup>

There are various types of imperforate anus and no two are alike. "All attempts at classifying congenital defects run the risk of becoming arbitrary, because it must always be remembered that the surgeon is dealing with a spectrum'...from fairly simple and straightforward to more complicated and complex. And the interventions required to treat them will vary depending on the type of malformation."<sup>2</sup> If you want to know what that all means in simpler terms, it means that there are simple anorectal malformations, and there are some very complex ones, and there are those that are in between, and there are even some that can't really be explained.

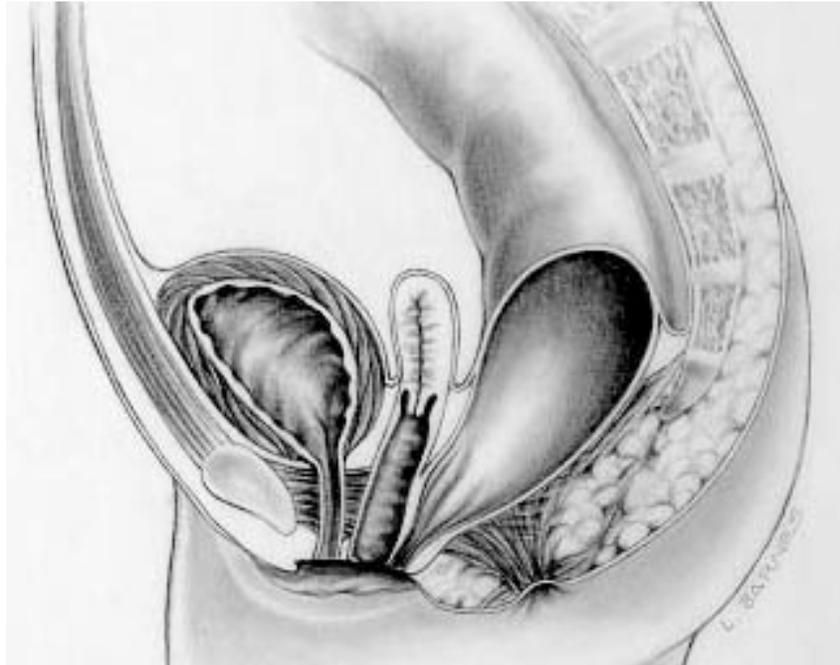
The first thing you want to obtain is the precise diagnosis, so that the best outcome can occur. There are numerous types of anorectal defects. Let's start with the defects that typically have the best prognosis, though most still require surgical correction:<sup>3</sup>

- **Perineal fistula:** seen in both girls and boys, the rectum opens into the perineum, lower than expected
- **Rectovestibular fistula:** commonly seen in girls, the rectum opens at a tiny orifice right outside the hymen
- **Rectal atresia:** narrowing or obstruction of the rectum inside the body, seen in both sexes
- **Rectobulbar urethral fistula:** in boys, a channel connecting the rectum and the lower part of the urethra
- **Imperforate anus with no fistula:** seen in both sexes, an uncommon defect in which the rectum ends before it exits the body

Typically, these children have the best prognosis for fecal continence after surgery, though they do have to be monitored for constipation, impaction and soiling. Do not be surprised if your child will need a laxative to help keep him from becoming constipated. Constipation is common, and unfortunately many will be dependent on laxatives for life to keep things moving along.

Depending on the surgeon, sometimes a colostomy (see the accompanying article: <http://www.articles.complexchild.com/dec2010/00258.html>) is placed after birth to

facilitate stooling while allowing the child to grow before corrective surgery is performed. Other times, doctors will do surgery immediately if they feel that the child is healthy enough for it at the time. Those who have repairs done shortly after birth or after a certain period of time will have to start anal dilations at home to keep the anus from closing. Extensive details on this procedure can be found at <http://www.cincinnatichildrens.org/svc/alpha/c/colorectal/treatments/anal-dilation.htm>.



Rectovestibular Fistula, the type of defect the author's daughter has.  
Note that the rectum (far right) exits right near the vagina,  
and not at the back as it should.

Next on the list of defects are those that unfortunately do not have the best outcomes for the child, requiring surgery and often resulting in ongoing complications. These defects include:

- **Cloaca:** in girls, fusing of the rectum, vagina, and bladder into one channel
- **Rectobladder neck fistula:** in boys, a connection between the rectum and the neck of the bladder

Unfortunately, even though medicine has come a long way, these defects usually require children to attend a bowel management program to come up with a plan to keep them from soiling. Plans may consist of the parent doing daily enemas, laxative use, or medications such as Immodium. In some severe cases, some choose to have a permanent colostomy done, and a few choose to even stay in diapers.

The best thing for any parent to remember when dealing with imperforate anus is that all children are different. Even with the best surgery, the best outcome doesn't always happen as it should.

For example, my daughter was born with a rectovestibular fistula that includes a partial duplication of her colon. This type of defect tends to have a good prognosis, though children with this defect almost always tend to be towards the constipated side. Yet with the right surgery and proper placement of the anus, my daughter still suffers from hypermotility, takes high doses of Immodium, is on a strict constipating diet, and requires daily enemas, as she has not obtained bowel control as of the current time. We also think that her colon duplication plays a huge part in this hypermotility. Of course this would frustrate any parent, especially when you have doctors telling you it shouldn't be this way. In the end, imperforate anus is unpredictable. It's even unpredictable to the doctors who make it their life mission to study, treat, and care for these children.

### **Finding Doctors and Getting Support**

Unfortunately, there is no steadfast answer to living with a child with imperforate anus. The best thing to do is to find the very best doctor to do the surgery, as there is only one time to do it right, and learn as much as you possibly can. Prepare yourself with questions, and find solace in groups that are geared towards families living with a child with imperforate anus. Do not ever think that you have to go at this alone, because you are not alone. Know that with time, surgery, and lots of understanding, your child with imperforate anus will grow up to be just like any child out there. She just may have to use the bathroom differently.

### **Imperforate Anus Groups**

- Pull Thru Network : <http://www.pullthrunetwork.org>
- IA- Parents on Yahoo: <http://health.groups.yahoo.com/group/IA-parents/>

*Tracy Reed is a stay at home mom who has lots of fun taking care of her four beautiful daughters, ages 12, 11, 7 and 4. Her 4-year-old Maggie was born with VACTERL Association, which commonly includes anorectal malformations (the "A" for Anus in the acronym VACTERL). She was born with a low imperforate anus with rectovestibular fistula that was repaired at two days old. We love life and live everyday to the fullest, even when we are still trying to figure out Maggie's bowel routine. You can contact Tracy at [sonlightuzer4ever@yahoo.com](mailto:sonlightuzer4ever@yahoo.com) or visit her daughter's Caringbridge page at [www.caringbridge.org/visit/margaretreed1](http://www.caringbridge.org/visit/margaretreed1).*

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<sup>1</sup> <http://www.cincinnatichildrens.org/health/info/abdomen/diagnose/anorectal-malformations.htm>

<sup>2</sup> <http://www.cincinnatichildrens.org/svc/alpha/c/colorectal/helping/default.htm>

<sup>3</sup> See the following links:

<http://www.cincinnatichildrens.org/svc/alpha/c/colorectal/conditions/anorectal/females.htm>

<http://www.cincinnatichildrens.org/svc/alpha/c/colorectal/conditions/anorectal/males.htm>