American Pediatric Surgical Nurses Association Inc.

Safety and Excellence in the Surgical Care of Children

PATIENT AND FAMILY INFORMATION SHEET

Anorectal Malformation

What is Anorectal Malformation (ARM) or Imperforate Anus (IA)?

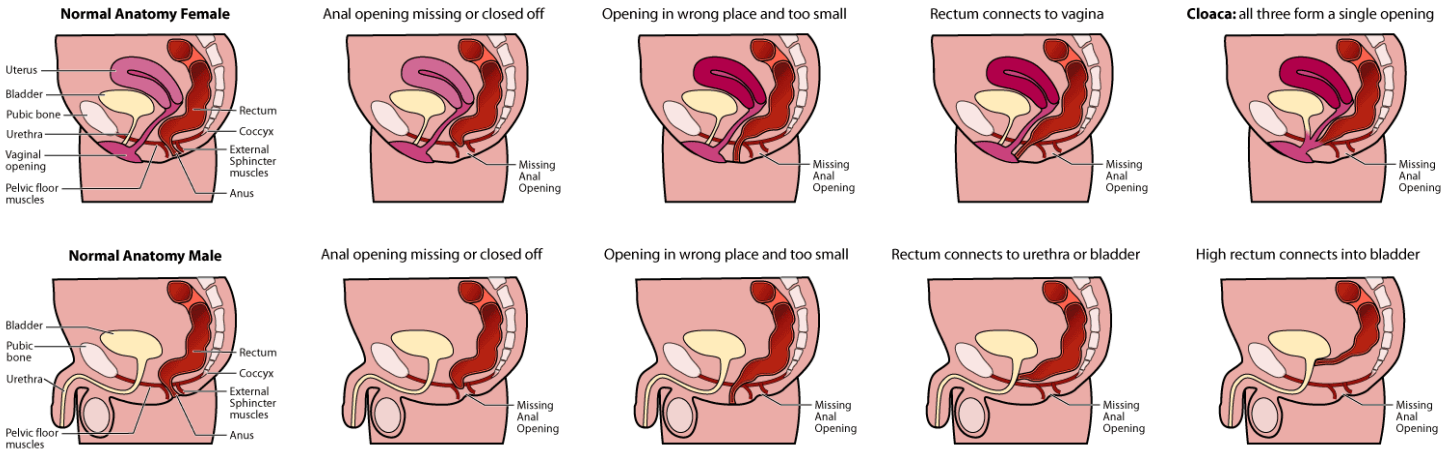
- An anorectal malformation (ARM or IA) is a birth defect of the anus and rectum that occurs during fetal growth.
- This defect can vary from simple to complex and can affect one or more areas of the anus, the urinary system and/or reproductive structures.
- One of the complex conditions in females involves the anus, vagina and urinary system and is called a cloaca.
- Anorectal malformations can also be associated with other defects of the spine, esophagus, trachea, kidneys, heart or limbs.
- Anorectal malformations occurs in 1 out of 4000 newborns.

How do I know if my child has an ARM?

It is most often diagnosed during the newborn physical exam. During the exam it is noted that there is no anal opening or the anus opens in an abnormal location.

Here are some of the symptoms your child may have:

- The newborn male may pass stool through the penis.
- The newborn female may pass stool through what looks to be the vagina.



Fahrion, C. (n.d.) Anorectal Malformations - all [digital image]. UCSF Pediatric Surgery.

How is ARM/IA treated?

- Initial treatment depends on the type of malformation.
- In more complex cases, the baby may not be able to pass stool through the opening and will need a colostomy in the first 1-2 days of life. A colostomy allows the stool to drain through a “stoma” or bag on the belly until the anus is surgically repaired.

PATIENT AND FAMILY INFORMATION SHEET

Anorectal Malformation

How is ARM/IA treated?

- There are several tests to find out the type of malformation and any other conditions that may also be involved:
    - Distal colostogram (a study of the colon to find the exact type of malformation.)
    - X-rays of sacrum (looks at the tailbone to determine if it is normal or abnormal)
    - Ultrasound or MRI of spine (looks at the spine to determine if there is a tethered cord)
    - Pelvic ultrasound or pelvic MRI (looks at some of the reproductive anatomy (for females) to determine if it is normal or abnormal)
    - Kidney ultrasound (checks health of the bladder and kidneys)
    - Voiding cystourethrogram (checks health of the bladder and kidneys)
    - Cystoscopy (tiny camera to look at the urinary tract)
    - Vaginoscopy (tiny camera to look at the vagina for girls)
    - Blood tests (to check the function of the kidneys)
    - Rectal exam under anesthesia (the surgeon evaluates the abnormal anatomy while patient is asleep)
    - 3-D cloacagram (special study for cloacal malformation to look at the bladder, vagina, and rectal structures)

- Surgical Repair
    - After all exams and testing are complete, the surgeon will then discuss with you the best operation for your child.

What happens before Surgery?

- Your surgeon will discuss with you the type of surgery needed to repair the malformation.
- Depending on the type of surgery, your child may or may not need to have the bowel cleaned out to prepare it for surgery. Your surgeon will discuss with you if this is needed or not.

What happens during surgery?

- The surgeon will place the colon in the center of the anal muscle. This is called a posterior sagittal anorectoplasty (PSARP).
- In the case of a cloaca, a posterior sagittal anorectal vaginal urethral plasty (PSARVUP) is needed.

What happens after surgery?

Some children may need a tube to empty the bladder for a few days to protect the urethra, bladder and kidneys during the healing process.

When can I be with my child again?

- You can typically be with your child as soon as he/she wakes up from anesthesia.

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PATIENT AND FAMILY INFORMATION SHEET

Anorectal Malformation

What happens after surgery?

When can my child eat again?

- Children with a colostomy, may eat sooner than those without. Your surgeon will monitor for when the colon "wakes up" and will then start a clear diet and then normal foods.

- Children without a colostomy need more time for the incision (stitches) to heal before eating. Your surgeon will determine how many days until your child will be able to eat regular foods. During this time your child will receive IV fluids that will help with hunger, hydration and nutrition.

Will my child have pain?

- The amount of discomfort also varies depending on the type of surgery needed.
- With a PSARP, the incision does not cut through muscles and nerves which means there is very little pain and usually only requires 1-2 days of pain treatment.
- Sometimes there is a need for an incision to be made on the belly. This cuts through muscle and nerves which increases the amount of discomfort and will require more pain treatment.

When can we go home?

- If the child has a colostomy, he/she usually goes home in 2 to 3 days.
- If the child does not have a colostomy, he/she usually goes home in 4-7 days depending on how the incision is healing.

How do I care for my child at home?

- Incision and Skin Care:
  - Clean the surgical area with warm soap water. It may be helpful to use a syringe to squirt soapy water over the incision and then carefully patted the area dry with a soft cloth. While the incision is healing, never rub or use baby wipes that have chemicals.
  - Your surgeon may give you an antibiotic cream to put on the surgical area for a few days as it heals.
  - No tub bathing for 1 to 2 weeks- or as directed by your surgeon.
  - If a bladder tube is used, no tub bathing until tube is removed.
  - For belly incisions, follow your surgeon's instructions for care.
- Activity Restrictions:
  - Avoid straddling the legs for one month.
  - Use two diapers for extra padding protection for one month.
  - Nothing such as medications or thermometers should be placed into the surgically repaired anus until your surgeon allows.
- Bowel Pattern
  - It is important to watch for signs of constipation. Depending on the malformation, constipation is common. If it is not well treated, the colon will become stretched and may not work as well.
  - Your child should have a soft stool every day.
  - Laxatives may be needed to have a daily soft bowel movement. Laxative use should be discussed with your doctor before starting.
  - If your child does not have the ability to potty train, discuss bowel management options with your care team.

PATIENT AND FAMILY INFORMATION SHEET

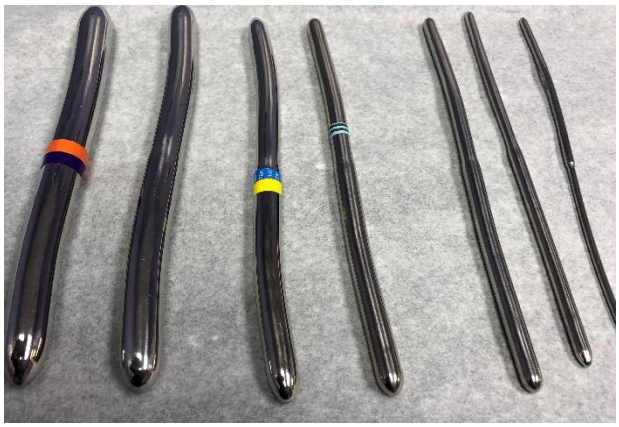
Anorectal Malformation

How do I care for my child at home?

- Diet:

  It is important to learn which foods cause your child's stool to be either more formed or more loose. This will allow you to adjust the diet to help promote the right consistency of stool. Daily intake of water and foods such as fruits, vegetables and whole grains are often helpful to prevent constipation. Discuss the appropriate dietary needs with your surgeon or nutritionist.
- Medications:
  - Give pain medications as directed by your surgeon.
  - Give laxatives as directed by your surgeon.
- ANAL DILATIONS
  - Anal Dilations are often started at 2 to 4 weeks after surgery. This is to prevent narrowing of the anus as it heals.
  - Important things to know:
    - Dilators are smooth medical rods used to keep your child's new anus from closing up.
    - The surgeon will pass the first dilator through the new anus 2-4 weeks after surgery.
    - The surgeon or nurse will teach you how to do the anal dilation for your child at home.
    - It is important to do these correctly for best healing and prevention of another surgery.
  - To find the final size of the anal dilator your child will use, see chart below.

When Starting Dilatations, Your Child Is:	Final Desired Dilator Size
1-4 months	#12
4-8 months	#13
8-12 months	#14
1-3 years	#15
3-12 years	#16
13 years of age and older	#17



Anorectal Malformation

Once you find that the dilator goes in easy two times a day and does not cause discomfort, you may start to taper (reduce) how often you dilate your child's anus. While you taper, you will still use the goal size dilator.

- Month 1: One time a day for a month.
- Month 2: One time every other day for a month.
- Month 3: One time every third day for a month.
- Month 4: Two times a week for a month.
- Month 5: One time a week for a month.
- Month 6-8: One time a month for three months.

If the dilatation gets harder, causes discomfort, or is bloody at any time during the above schedule, go back to dilating two times a day. When you can easily put in the dilator without discomfort, start the taper schedule again from the beginning (one time a day for a month).

When should I call the office?

If your child experiences any of the following, please call our office:

- Fever over 100.5 F
- Pain not relieved by medications as recommended
- Redness or swelling of the incisions
- Increase or decrease in bowel movements
- Serious diaper rash
- Vomiting or decreased oral intake of fluids/ foods
- Decreased number of wet diapers (urine)

Your child will need to follow up with the surgeon. You will receive specific instructions for follow up when your child is discharged.

Please don't hesitate to call our office if you have any problems or concerns.

Surgeon: _____

Nurse Practitioners: _____

Phone Number (daytime): _____

Phone Number (after hours): _____

Social Worker: _____

Supply Company: _____

Thank you for allowing us to care for your child.