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# PTN News

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Vol. 22, No. 3 - Fall 2014

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A Publication of Pull-thru Network, Inc.

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# Pull-thru Network News

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### **Pull-thru Network, Inc.**

is a volunteer-based non-profit organization dedicated to providing information, education, support and advocacy for families, children, teens and adults who are living with the challenges of congenital anorectal, colorectal, and/or urogenital disorders and any of the associated diagnoses.

*The relevance of anything printed in this newsletter to a particular person should be discussed by the family or the individual with their own physician.*

*Please send any correspondence regarding the Pull-thru Network News to:*

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# MESSAGE FROM THE BOARD OF DIRECTORS

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We hope this issue of the PTN News finds you and your family healthy and enjoying the change in seasons. Many of our PTN kids have returned to school this year, and our teens and young adults have headed off to college. We've had our fourth conference, complete with educational sessions, member networking, parties, and even a real-life desert dust storm!

The Board of Directors continues to work diligently on behalf of our members to bring you the best and most up-to-date information on our children and their conditions. We have strengthened our partnerships with our professional advisors, and are pleased to share educational articles in this issue from Dr. Levitt and Dr. Alam. Our other professional advisors are actively working to develop materials for our members, and welcome your questions or suggestions. We are also pleased that our Institutional Membership is growing, better enabling doctors and hospitals to refer their patients to us for assistance.

We are moving ahead with the formation of committees to help with the work of the Pull-thru Network. Our first committee will be the fundraising committee which is charged with helping us raise funds year-round to benefit the programs (including the conference) of the Pull-thru Network. We will be forming additional committees and must rely on the time and talents of our members to help us make the Pull-thru Network all it can be.

We hope you find this issue of the PTN News helpful. As always, if you have suggestions or would like to provide feedback, we welcome your comments at [pullthrunetwork@gmail.com](mailto:pullthrunetwork@gmail.com).

Sincerely,

*Lori Parker*  
Executive Director

*Hollie Filce*  
Associate Director

*Carmell Burns*  
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*Tricia Mihalic*  
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*Tenley Gritts*  
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# The Latest Research

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One of the services we provide our members is access to the latest research on children with colorectal conditions. It has become more difficult to reprint articles from professional and medical journals, given complex procedures for requesting permission to reprint, and high reprint fees. We will continue to attempt to provide you full-text articles. However, when we find something we feel would be of interest to you, we will provide as much information as we can given copyright laws, and give you information on how to access the complete article. Many libraries (especially university libraries) can get copies of these articles for you.

## **Consequences of Caring for a Child with a Chronic Disease: Employment and Leisure Time of Parents**

*by Janneke Hatzmann, Niels Peek, Hugo Heymans, Heleen Maurice-Stam, and Martha Grootenhuys*

Chronically ill children require several hours of additional care per day compared to healthy children. As parents provide most of this care, they have to incorporate it into their daily schedule, which implies a reduction in time for other activities. The study aimed to assess the effect of having a chronically ill child on parental employment and parental leisure activity time, and to explore the role of demographic, social, and disease-related variables in relation to employment and leisure activities. Outcomes of 576 parents of chronically ill children and 441 parents of healthy school children were analyzed with multivariate regression. Having a chronically ill child was negatively related with family employment, maternal labor force participation, and leisure activity time. Use of child care was positively related to family and maternal employment of the total group of parents. Within parents of chronically ill children, most important finding was the negative relation of dependency of the child on daily care and low parental educational level with family and maternal employment. In conclusion, parents of chronically ill children, mothers in particular, are disadvantaged in society probably due to the challenge of combining child care with work and leisure time.

Use this citation when requesting articles from your library:

Hatzmann, J., Peek, N., Heymans, H., Maurice-Stam, H., & Grootenhuys, M. (2013). Consequences of caring for a child with a chronic disease: Employment and leisure time of parents. *Journal of Child Health Care*, 1-12. doi: 10.1177/1367493513496668 Available online at <http://chc.sagepub.com/content/early/2013/08/16/1367493513496668.full.pdf+html>

## **Concerned about Their Learning: Mathematics Students with Chronic Illness and Their Teachers at School**

*by Karina J. Wilkie*

Chronic illness often goes hand-in-hand with absence from school, and students miss out on learning opportunities at school for extended or accumulative periods of time. Many young people seek to continue their school studies nonetheless. The need to consider viable ways to support them academically arose in the context of a project called *Link 'n Learn* funded by an Australian Research Council Linkage grant (2008–2010). This paper reports on one aspect of the project – an in-depth qualitative case study of 22 participants: senior secondary students with diverse types of chronic illness who were continuing their studies during absence from school and their mathematics teachers. The study found that the students' concerns centred on academic issues – their perceived need for support from and interaction with their teachers. The teachers' concerns focused on medical issues – their students having to manage illness. Facilitators of these students' ability to continue studying included their ambition, perseverance with independent learning, initiative in seeking help, and quick recovery from medical treatment cycles. Teacher-related facilitators included the teachers' willingness to interact using communication media, confidence in initiating contact, and ability to modify their students' learning programme. Other facilitators included a responsive school technology department, technology tutoring from students, and the involvement of family members or tutors. Outcomes for students and teachers of their interactions with each other during lengthy periods of absence, and implications for schools, are discussed.

Use this citation when requesting articles from your library:

Wilkie, K.J. (2012). Concerned about their learning: Mathematics students with chronic illness and their teachers at school. *International Journal of Inclusive Education*, 18(2), 155-176. doi: 10.1080/13603116.2012.760659

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# The Latest Research

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## Outcome of Antegrade Continent Enema (ACE) Procedures in Children and Young Adults

by Maen M. Masadeh, Michael Krein, Joshua Peterson, Molly Bauer,  
Laura Phearman, Graeme Pitcher, Junlin Liao, and Joel Shilyansky

**Objective:** Intractable incontinence affects a large number of children and young adults in the US. The goal of this study is to evaluate the long-term outcomes of surgical access for administration of antegrade continence enemas (ACE) in affected children and young adults.

**Methods:** Patients who underwent surgical procedure to enable administration of ACE from 1994 to 2011 were retrospectively reviewed. Data collected included patient demographics, primary diagnosis, surgical technique, conduit used, complications, follow-up duration, and social continence.

**Results:** Sixty eight patients underwent surgery to enable ACE; mean follow up was 61 months. Enteral conduit (EC) was performed in 19 patients, tube cecostomy catheters (CC) in 49. Meningomyelocele was diagnosed in 60% of patients. Mean age was 11 (1.67–53) years. Complications included tube dislodgement (43%), granulation tissue (46%), site infection (13%), leakage (32%), break in the tube (6%) and tract stenosis (6%). Complete social continence was achieved in 68%, partial continence was achieved in 29%, and no benefit was achieved in 3% of patients. The rate of complications and incontinence resolution following CC was 78% and 66%, and following EC 89% and 74%. The differences were not statistically significant. CC patients developed granulation tissue more frequently (53%) and leaks of fecal material less frequently (20%) compared to EC patients (26% and 53%) ( $p < 0.05$  and  $< 0.01$ ). Although children 7 years or younger developed more overall complications (94%) than older patients (69%;  $p < 0.05$ ), there was not a significant difference in the frequency of any one complication or in the rate of continence, between the two groups. Multivariate analysis showed that EC is three times more likely to be complicated by fecal leakage. CC patients are at greater risk to develop granulation tissue ( $p < 0.05$ ).

**Conclusions:** Most patients achieved social continence and improved hygiene with the aid of ACE. Younger children also benefited greatly from institution of ACE. CC was associated with fewer major complications such as leak of fecal contents than EC but required regular tube changes.

Use this citation when requesting articles from your library:

Masadeh, M.M., Krein, M., Peterson, J., Bauer, M., Phearman, L., Pitcher, G., Liao, J., & Shilyansky, J. (2013). Outcome of Antegrade continent enema (ACE) procedures in children and young adults. *Journal of Pediatric Surgery*, 48(10), 2128-2133.

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Director: Philip K. Frykman, MD, PhD, FACS, FAAP

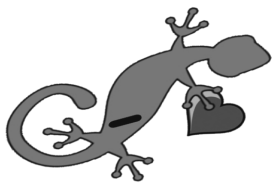
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Contact us at [bowelmanagement@cshs.org](mailto:bowelmanagement@cshs.org)

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# 2014 Pull-Thru Network National Conference

The PTN Conference offers an unmatched experience for families impacted by anorectal malformations. This unique opportunity to spend three days with others who have shared your experience is a powerful, stabilizing force in the lives of our members who have been fortunate enough to attend. Unfortunately, most children with these conditions live in communities that do not have medical experts in this area. Because the incidence of these malformations is so low, parents and their children have often never met anyone with the same condition. While year-round support is available through the PTN Website, List-serv and monthly online chats, it's not the same as physically being together in the same room with someone who understands. The power of this unique opportunity for emotional connections to others is priceless.



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# What Our Participants Said About the 2014 Conference...

## ***From Parents:***

- ♦ “Thanks so much for helping us get here for our 1<sup>st</sup> conference. Can’t wait until 2016.”
- ♦ “Food was great, plentiful & enough choices.”
- ♦ “We had a wonderful time and will come back to future conferences. Child was sad it was over!”
- ♦ “Although I thought I’d heard everything at the 2010 conference, I was wrong. I was pleased to be here with more detailed understanding & experience. I wasn’t ready to hear it all before, I realized I will never know enough.”
- ♦ “The doctors were great & very approachable after the session ended.”
- ♦ “Loved new speakers this time. Very informative & new information.”
- ♦ “I liked the speakers and the opportunities parents had to talk and ask questions.”
- ♦ “Dr. Dickie and Dr. Breech were so knowledgeable & I appreciated willingness to answer questions.”
- ♦ “I am very grateful and appreciative for all the conference coordinators and sponsors, thank you so much.”
- ♦ “I like the fact that families can share meals together and get to know each other. I like the fact that doctors/speakers attend the meals and other events.”
- ♦ “Fun! My child had a great time & enjoyed playing with friends.”



- ♦ “It was amazing to hear the ‘exact’ same stories, thoughts and actions from other moms.”
- ♦ “I came as a guest & have been thoroughly impressed with how well this was organized and the amount of families that came. I will encourage all of my families to join this network & encourage participation in this conference.”
- ♦ “I’m grateful to be here – this is our 1<sup>st</sup> conference. I only wish we started going 10 years ago (at least)!”

## ***From PTN Kids:***

- ♦ “The best part was meeting other PTN Kids & Teens that have the same kind of condition as me. Getting to learn more about my condition.”
- ♦ “The parties were very fun! I enjoyed hanging out with other families during the parties.”
- ♦ “The playroom was set up very nicely and they had a lot of great activities to do! I enjoyed helping & playing with the little ones!”
- ♦ “Thank you for making this convention so amazing! It has been a wonderful experience!”
- ♦ “The best part was getting to know people who understand me and know about my condition.”
- ♦ “The parties were fun and they made me happier to know that I have friends with the same problem.”
- ♦ “The playroom had awesome activities.”





Medical procedures and surgeries can produce anxiety in anyone. Parents must not only deal with their emotions about procedures, but carefully prepare and support their child through them as well. This article featured in the American Psychological Association's website provides valuable insight for parents and children.

This article can also be found:  
[http://www.apa.org/  
monitor/2013/03/patients.aspx](http://www.apa.org/monitor/2013/03/patients.aspx)

# Vulnerable Patients

Psychologists are using distraction, exposure therapy & other strategies to ease anxiety among children who face medical scans, surgeries & other procedures.

By Jamie Chamberlin March 2013, Vol 44, No. 3

For many children having surgery, going under anesthesia is the moment it gets tough. Psychologist Jill MacLaren Chorney, PhD, of IWK Health Centre in Halifax, Nova Scotia, remembers when a 12-year-old girl with a history of orthopedic surgeries was scheduled for another procedure. She was able to cope with her anxiety in the waiting room. But when she was escorted to the operating room door, she burst into tears and refused to go in.

"Despite all efforts by staff, she continued to refuse, her distress increased and her surgery ended up being postponed," recalls Chorney, an assistant professor in the department of anesthesiology at Dalhousie University and a member of the Complex Pain Team at IWK Health Centre.

While cancelling surgery is rare, such nerve-racking episodes can be as stressful for the surgical team as for the child and his or her parents. Even more important is that preoperative stress can have a dramatic impact on how well a child recovers from the procedure, Chorney says. Some research by anesthesiologists has shown that children who are more anxious before surgery may experience more pain and recovery complications after the procedure and have longer hospital stays.

As she tells anesthesiology residents, "How they go to sleep is often how they wake up."

Chorney's own research, published in *Anesthesiology*, has shown that reducing children's preoperative stress - by giving them a practice run with an anesthesia mask and educating them about the procedure, for example - can lessen the amount of pain medication they need after surgery and can reduce cases of "emergence delirium," in which a child comes out of anesthesia thrashing, crying or needing restraint. To improve children's experiences, Chorney and other psychologists have developed research-tested strategies to reduce children's stress and anxiety about medical procedures, including going under anesthesia and having surgery, as well as some uncomfortable and even highly painful tasks, such as having blood drawn, using a catheter, wearing sensors for an electroencephalogram and being treated for severe burns. "Children's experiences with early medical procedures can really shape their medical experiences for life," Chorney says. "We have the potential to do a lot early on in making these procedures less stressful for them."

## *Dora in the OR*

To help children stay calm in the operating room, pediatric anesthesiologists at Chorney's IWK Health Centre rely on a strategy used by children's hair stylists and parents on long car trips - cartoons. When the hospital installed state-of-the-art video screens in operating rooms last year so trainees could observe surgeries, Chorney and her colleagues wired the technology so anesthesiologists could use it to show children cartoons while they underwent anesthesia. The cartoons had a dramatic effect on children's anxiety, even on top of tried-and-true techniques used by pediatric nurses and anesthesiologists, such as humor and soothing talk. In Chorney's study, published in 2012 in *Anesthesia and Analgesia*, she and colleagues found that a quarter of the children who watched a video of their choice showed no anxiety during anesthesia, compared with only 5 percent in the control group. Only 2 percent of children in the cartoon group showed extreme anxiety, such as screaming and crying, compared with about 10 percent in the control group.

In addition, children who chose a cartoon in the waiting room to watch during anesthesia showed no increase or change in their anxiety from the waiting room to the operating room, while children in the control group grew more fearful as they waited.



"These were children who were already getting quite a bit of great interactions from staff, but we added something on that gave everyone something else to focus on," says Chorney.

Lynnda M. Dahlquist, PhD, of the University of Maryland, Baltimore County, is exploring whether video games might also help children cope with intense procedures, such as burn care and bone-marrow aspirations. In a study in press at the *Journal of Pediatric Psychology*, Dahlquist, along with then-graduate student Karen Wohlheiter, PhD, compared how healthy preschool children fared in two different conditions. One group played a Wii game, such as "Finding Nemo," with their free hand immersed in ice cold water; the other group watched pre-recorded footage of the same game without interacting with it with one hand immersed in ice cold water. Consistent with research that finds that tasks that require more executive cognitive processes are more effective in minimizing pain, the children who played the game showed more pain tolerance. And, it didn't matter how much experience they had with gaming. "It seems to benefit kids from a wide range of ability," she says.

Dahlquist is also testing whether virtual reality helmets that allow children to play video games could help them better manage painful procedures, and which children might benefit most. She is gathering data on the types of games that might be most effective — fast-paced action games or more mellow ones. Her hope is that such games could be particularly helpful for medical settings without a mental health professional on staff to help children cope with their anxiety over a procedure.

"The beauty of an electronic distractor is that you don't need a highly trained clinician administering it," she says. "The game itself is intriguing and engaging."

#### *Making the Extreme Routine*

Children with chronic or life-threatening medical conditions often need more than a temporary distraction: They need help adjusting to frequent, regular medical procedures such as having to catheterize themselves, use a nebulizer or lie still for radiation treatment or an MRI. Helping these children — particularly those who also have intellectual and developmental disabilities — is the focus of the Pediatric Psychology Consultation

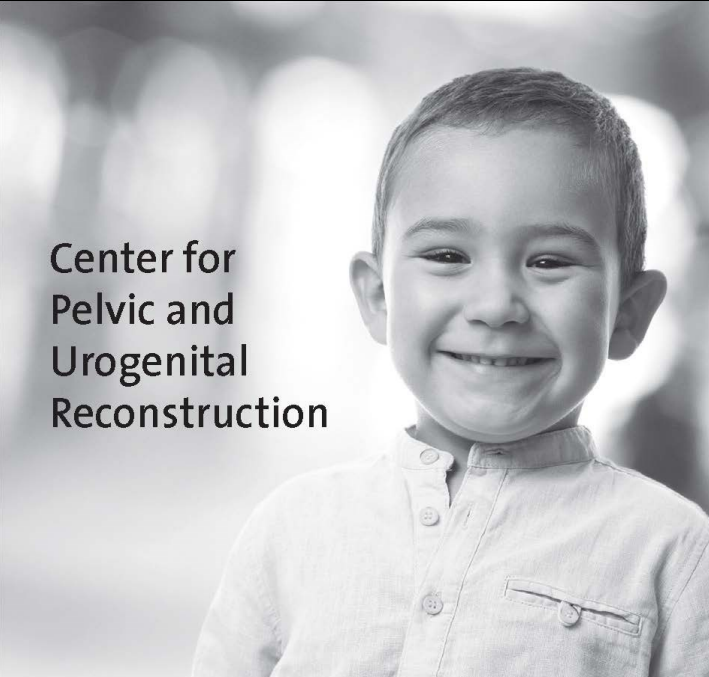
Program at Kennedy Krieger Institute in Baltimore, directed by psychologist Keith J. Slifer, PhD.

Drawing from pediatric and behavioral analysis research in counterconditioning, differential reinforcement and exposure therapy, Slifer and his colleagues use simulated medical procedures to gradually expose children to the "sights, sounds and smells associated with their medical care." Children may touch and feel the equipment first, then wear it, then use it. Or, they may be rewarded after the procedure with stickers, prizes or other reinforcers as they make progress.


To help children with obstructive sleep apnea adjust to sleeping with a continuous positive airway pressure (CPAP) mask, for example, Slifer and his colleagues first introduce them to the sleep clinic, then have them watch as the equipment is placed on a parent or a doll, then have them put on the equipment a little at a time as they enjoy an activity, such as a cartoon or story. The children do this over and over until they can help put on the mask and fall asleep with it on.


"I've never met anyone who said they like a CPAP machine, but if you make it as routine as putting on their pajamas and pair positive things with it, even young children and those with intellectual and developmental disabilities can learn to tolerate it," says Slifer, who is also an associate professor of psychiatry, behavioral sciences and pediatrics at Johns Hopkins University School of Medicine.

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Part of his program's approach includes teaching children coping skills they can use during a procedure, such as controlled deep breathing, visual imagery, or distraction with an activity they like, such as an iPad or video game. They also provide them "break cards" they can give the nurse when they want to halt the procedure briefly.

"Children are surprisingly judicious about their use of the cards," he says. "It can calm them down a lot just knowing that they have that little bit of control."

The team's research, published in *Epilepsy and Behavior* and other journals, has shown that using behavioral techniques not only increases compliance among these children, it reduces the need for potentially harmful alternatives, such as frequent sedation.

Among the many challenges of this work is that reinforcement isn't one-size-fits-all, says Slifer. One child with severe visual impairment, for example, was unable to tolerate equipment for a sleep study because he wasn't interested in traditional reinforcers, such as stickers or prizes. Eventually, the team found that he liked to throw a ball and hear it bounce off the wall. After that, for every sensor wire of an electroencephalogram they placed on his head, he earned a ball toss.

"One of the cool things about working in this area is that there are endless opportunities for creativity," says Slifer. "If you like to dream things up, the sky's the limit."

#### Further Reading

Bennett, H.J. (2008). *Harry goes to the hospital: A story for children about what it's like to be in the hospital*. Washington, DC.: Magination Press.

Christophersen, E.R., & VanScoyoc, S. (2013). *Treatments that work with children: Empirically supported strategies for managing childhood problems* (2nd ed.). Washington, DC: American Psychological Association.

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## The Colorectal Center at Primary Children's Hospital

Located in Salt Lake City, Utah, the Colorectal Center provides support and care for children and adolescents with Anorectal Malformations, Hirschsprung's Disease, and other issues related to bowel function. We provide comprehensive care for patients as they grow. Our program includes:

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- Bowel management program
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[primarychildrens.org/colorectalcenter](http://primarychildrens.org/colorectalcenter)

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# ***Overcoming Her Diagnosis:***

Anorectal Malformations and Cloaca

By Chelsea Mullins October 13, 2014

5 years ago my future mother-in-law said something to me that has stuck with me all of these years. It was a question that made me evaluate where I had been and how to have a better outlook on the condition I was born with: anorectal malformation (ARM) and cloaca.

She asked me a simple question: *Do you want to be known as someone who is defined by her diagnosis, or someone who has overcome it?*

I chose to overcome it. I'm not saying that it was easy, because it most certainly was not. But I realized that the years of tormenting myself had done nothing to help me. The years of questions like, why me? What am I? Who am I? What do they think of me?

10 years of fighting with who I am and being angry that it happened to me didn't help me move forward and consider who I wanted to be.

After some time had passed and a lot of self-reflection, I came to the realization that I wanted to help people by becoming a nurse. I wanted to eventually be a wife and mother.

So Dr. Bruce Tjaden, my reproductive endocrinologist at the Center for Reproductive Medicine in Wichita, Kansas, walked me through my gynecologic and obstetric options. I had been seen by Dr. Peña, the founding director of the Colorectal Center at Cincinnati Children's, since I was four years old, where he performed multiple reconstructive surgeries to help correct the anorectal malformation and cloaca, which included multiple posterior sagittal anorectoplasties (PSARP).

Dr. Tjaden answered all of my questions from the medical perspective, like what sex will be like for me, what my chances are for conception and can I give birth to a baby?

In order to potentially fulfill those goals, he explained that my vaginal stenotic ring would need to be removed, due to the shortening of my vaginal canal. Because this procedure is not his area of expertise, he encouraged me to explore my options. I found Dr. Lesley Breech's name on the Cincinnati Children's website, and I set up a consultation with both Drs. Breech and Peña. We reviewed multiple options and completed testing.

When I was 25 years old, my husband (boyfriend at the time) and I decided that having a redo PSARP and vaginoplasty was the best option for me. This was a very extensive surgery where they took a piece of colon and elongated the vaginal canal to allow for sexual intercourse. Eventually when I was married and ready to have children, Dr. Breech walked me through my options for becoming a mother.

Because of multiple abdominal surgeries, pregnancy was not an option for me. But, using a surrogate might be. We tried in vitro fertilization (IVF) with a gestational carrier in April of 2012. My husband and I knew this was the only way we would have a biological child. One of my co-workers was extremely gracious and offered to carry. This started the process. We only did IVF once. Unfortunately, I did not respond well to the ovarian stimulation and was only successful in retrieving and fertilizing one embryo. We transferred that

embryo back and found out a few weeks later that we did not become pregnant.

This was very difficult time. We questioned why? But then the picture became clearer. Adoption may be the answer in expanding our family.

We adopted a baby girl seven months later. The birth mom was absolutely amazing. She gave me as close to the childbirth experience as I could have. She allowed me to be in the labor and delivery room and I even held her leg while she was pushing. I got to cut the umbilical cord. And we left the hospital with a beautiful baby girl who has been the light of our lives.

I was also able to find a suitable, rewarding career path. I am an infertility nurse practicing with a Reproductive Endocrinology and Infertility Clinic. It has been incredibly therapeutic to help patients who are in similar situations as I was. There is comfort in camaraderie and it feels amazing helping someone's dreams come true.

I'm sharing my story because I want other females out there to know that there is a light at the end of the tunnel. Regardless of your age, having an ARM and cloaca is challenging and can be isolating. But you don't have to let it define you as a person. You can overcome this.

Seek professional counsel if you are feeling isolated, angry, or depressed. I wish I had done it sooner. I found journaling helpful to relieve some of the weight on my shoulders when I couldn't speak with someone. I wrote a blog during our infertility process and made it public after. This allowed outpouring of support and other people bearing there difficult situations in creating their families. It created more friendships and confidants to help during those tough times.

Choose supportive friends and partners. I picked them carefully and was always cautious to whom I revealed my condition. My closest friends growing up threw parties for me each time I had a major surgery. I waited for a very long time – even a year – before I told my partners the full scope of my gynecologic situation. I'm not saying the length of time is right or wrong, what I am urging you to do is to consider what is important to you and stick with it. Privacy and finding an understanding partner were paramount to me.

Don't be afraid to explore your gynecologic and obstetric options. Sit down with your OB/Gyn and outline what you hope to achieve and what is possible, based on your specific condition. While pregnancy wasn't an option for me, it can be for many other females with cloaca. In fact, Dr. Breech told me that many young women with cloaca should be able to carry a baby. Reconstructive procedures may be necessary to make this happen, but it is possible.

Above all, please know that it can and will get better. Believe in yourself. You have overcome more than a lot of people will in a lifetime, already! Enjoy life. Sometimes, just letting go, will allow you to find a different part of who you are.

*Photos were taken by Alison Moore Photography.*

*Reprinted from the Cincinnati Children's Hospital Blog with permission of the author.*

# Sacral Nerve Stimulation: A Promising Therapy for Fecal and Urinary Incontinence in Children

by Marc A. Levitt, M.D.,  
Surgical Director, Center for Colorectal and Pelvic Reconstruction, Nationwide Children's Hospital, Columbus, OH  
marc.levitt@nationwidechildrens.org

An exciting new technology has become available for patients with fecal and urinary incontinence. It is called sacral nerve stimulation (SNS) or sacral neuromodulation. It can be compared to a pacemaker for the heart, but in this case it is a pacemaker or stimulator for the anal canal area and lower part of the colon and the bladder. It seems to help with anal canal sensation, the squeeze of the sphincter muscles, and the movement of the colon to improve constipation, as well as urinary control. We have known for a number of years that neuromodulation using SNS has helped adult patients with similar problems, particularly those with spinal problems. Recently, Nationwide Children's Hospital presented our work with SNS with pediatric patients at the American Pediatric Surgical Association meeting.

Here is the data presented there:

*Between May 2012 and February 2014, 29 patients were evaluated before and after sacral nerve stimulator (SNS) placement. A prospective data registry containing clinical information along with the patient-reported measures showed: The median age of patients was 12.1 years and the median follow up period was 17.7 (12.9, 36.4) weeks. Nearly all patients (93.1%) had GI complaints and 65.5% had urinary symptoms as well. The most common diagnoses were idiopathic (66%) and imperforate anus (27%). Six of 11 patients with a pre-SNS cecostomy no longer required an antegrade bowel regimen and developed voluntary bowel movements. Reductions in anticholinergic medications for urinary symptoms were noted as well. Significant improvements were demonstrated in all four patient-reported instruments for the overall cohort. (see Figure 1) Five patients required reoperation (for minor bleeding, skin infection, and battery discomfort).*

**Figure 1.** Patient reported outcomes were tested before and after placement of sacral nerve stimulator, based on these scoring mechanisms.

Test
Fecal Incontinence Quality of Life Scale
- Lifestyle
- Coping/Behavior
- Depression/Self-perception
- Embarrassment
Fecal Incontinence Severity Index
PedsQL GI Symptom Scale
Vancouver DES Symptom Score

It appears from this initial study that the early results demonstrate improvements in both gastrointestinal and urinary function after SNS placement. We are learning a great deal about this new technology, and at a very rapid rate. It is anticipated that many patients could benefit. Patients with anorectal malformations, particularly those on enema programs that are very close to having continence are ideal candidates. This technology also may apply to the large number of Hirschsprung patients with fecal incontinence, and also to patients with spinal issues such as spina bifida.

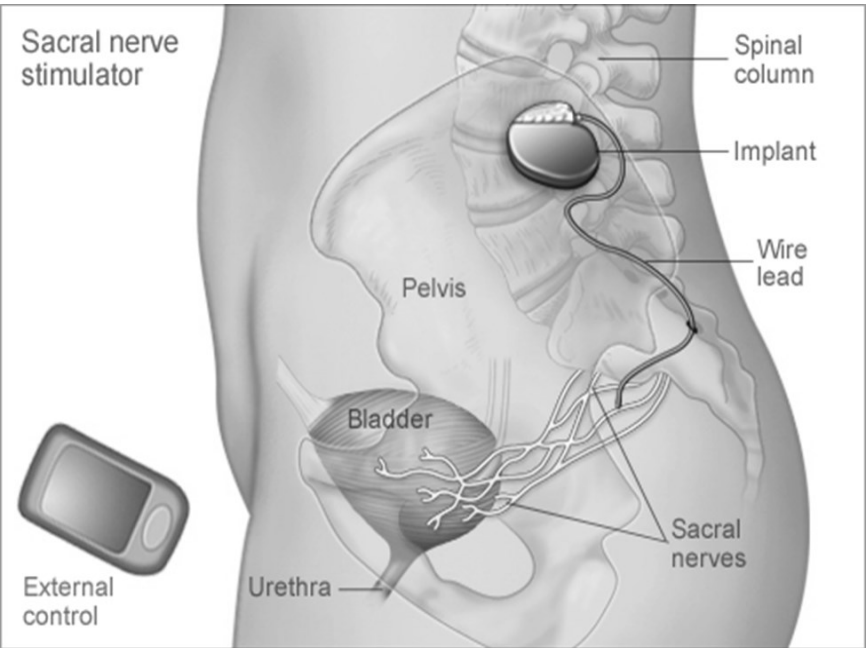
With regard to the anorectal malformation population, we know that the quality of the sphincter muscles, the quality of the sacrum, and the characteristics of the spine (tethered cord etc.) are the key predictors of continence in addition to the height of the malformation. (We call this grouping of issues the ARM Index.) SNS with its ability to improve sphincter function, anal canal sensation, and the motion of the colon could help many of these patients improve their continence potential. For a patient currently on a bowel management enema program, perhaps with SNS they could develop voluntary bowel movements and come off enemas altogether. For a patient on high dose laxatives, perhaps with SNS their laxative dose could be

reduced or eliminated. In addition, those with urinary issues, like poor bladder emptying might be able to void better and might no longer need intermittent catheterizations. This is a very exciting development for many patients.

The actual procedure involves placing the patient in prone position on the operating table. The sacrum joints are identified using fluoroscopy, and InterStim™ SNS System (Medtronic, Minneapolis, MN) pacing leads are inserted into the 3<sup>rd</sup> sacral foramen. A pocket under the skin of the buttock is then created and this is where the SNS battery is positioned. The wire leads can be put in temporarily, and the patient can be observed for two weeks to see if there is a response. If no response the leads can simply be removed. If there is noted improvement the battery and wires can be implanted.

I look forward to learning more about this technology as it is applied to more patients.

**Figure 2:** Diagram of the SNS device



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# Delivering integrated care for children with colorectal problems

The Center for Colorectal and Pelvic Reconstruction is the first in the world to formally integrate all specialties involved in pelvic reconstruction in kids, including a bowel management bootcamp for fecal incontinence.

Experts from colorectal surgery, gastroenterology/motility, urology and gynecology collaborate to deliver a level of coordination and resources on a single visit, which has not been offered before to children with these problems.

Our team is led by Marc Levitt, MD, who has performed more colorectal surgeries than any other practicing pediatric surgeon in

the world, and Carlo Di Lorenzo, MD, Chief of Gastroenterology, Hepatology and Nutrition, director of the Motility Center, and an internationally-recognized expert in pediatric motility issues.

Whether your child is facing reconstructive surgery or has had surgery and is now facing other challenges, such as incontinence, our team is ready to help.

Visit [NationwideChildrens.org/PTN-CCPR](http://NationwideChildrens.org/PTN-CCPR) for more information or to contact the team.



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# **Urologic Concerns in Anorectal Malformations: Part 1, The Newborn**

by Shumyle Alam, M.D.,  
Medical Director of Urodynamics, Columbia University Medical Center, Columbia University Medical Center,  
Morgan Stanley Children's Hospital, New York, NY

Patients with ARM or IA (Anorectal Malformation or Imperforate Anus) represent some of the most challenging cases a pediatric provider will see in their career. Some patients will require multiple surgeries and the outcomes regarding overall long term health are ill defined. Many surgeons, including Dr. Pena state that "there are many roads to Rome...." What they mean is that there may be more than one correct way to treat the patient with ARM. They are partly correct, but the lack of a defined or uniform treatment plan may confuse families as they search for information about their children. Similarly older patients seeking to learn about their condition are also very confused by our lack of uniformity or consistency with care. This short article will hopefully begin to address some of those concerns.

The term "spectrum of disease" is very important to understand when thinking about ARM. Simply put, there are differences among children with ARM. An example would be the "Low Imperforate Anus" (IA) or "High IA" group. Some children will have significant associated problems involving the genitourinary tract and others will be relatively unaffected. Knowing when to recognize that the child has a urologic problem or needs an evaluation however is very straightforward. The short answer is that ALL children with IA will benefit from a urologic evaluation!

The best time to get a urologic evaluation is as soon as the diagnosis is made. In general we will obtain a kidney and bladder ultrasound after 1 day of life. It is important to not obtain this study in the first 24 hours as the test can be falsely negative ( Fail to detect a problem) due to the normal dehydration status of the baby. A spinal ultrasound is also indicated and in a baby girl with cloaca, a pelvic ultrasound (Part of the Kidney and Bladder ultrasound) is helpful. Almost all children get these studies as this is what is recommended by Dr. Pena, Dr. Levitt, and me. Unfortunately, not all of the studies and children are seen by a pediatric urologist at his time. In major centers that specialize in the care of complex children, urology is usually a part of the team.

The concept of a team has greatly impacted our ability to care for complex children. Examples of team or multidisciplinary care include Cystic Fibrosis, Organ Transplant, and Cerebral Palsy. We started such a team together with Dr. Levitt and Dr. Pena in 2007. Since that time the team concept has spread to different hospitals around the country and now the teams are beginning to coordinate care amongst hospitals. As a parent you must insist that there is a team taking care of your child and that all the members communicate with each other. It is very important that the parent and the patient feel that they have a say and are able to speak up regarding their care and treatment.

The newborn period can be a very confusing time for families as they struggle to understand the diagnosis and deal with such issues like colostomy bags and the uncertainty about surgery. This is hardly the time when families think about the kidneys or the bladder! I will attempt to provide some guidelines below to illustrate the need for urologic care and follow-up. We will focus on problems in the newborn period for IA only in this article and leave childhood, adolescent, and adult concerns for another article. Cloaca and cloacal exstrophy will also be covered separately.

Tethered Cord: Any child with tethered cord, low lying conus, fatty filum, lipomenigocele, spina bifida, or myelomeningocele will need a urologic evaluation and follow-up. The main concern is the potential for a neurogenic bladder and baseline evaluation including an ultrasound and a voiding cystourethrogram (VCUG) are advised. An urodynamic investigation is helpful but does not have to be performed routinely before one year of age. Any spinal finding adds an increased risk to the development or diagnosis of a neurogenic

bladder. Currently the Sacral Ratio helps only to define the potential for bowel control and predictions regarding the bladder are not as straightforward.

Urinary Stream and Wet Diapers: Much has been made of this term. I often hear doctors ask "do you see a stream." Obviously this is most pertinent with males. Parents have different ideas of what a urinary stream means. Basically a stream simply means that the child voids. It does not necessarily imply they are healthy or that they have a normal bladder. It is possible to have a significant neurogenic bladder and still have a stream. Wet diapers are a sign of voiding but not always a sign of healthy voiding. We want to see a wet diaper every 2-3 hours; prolonged dry intervals do not mean that toilet training is around the corner. It may suggest a neurogenic bladder in the child with IA. Soaking wet diapers are also worrisome and need evaluation especially if this is a consistent pattern.

Colostomy: I recently had a case of a child who came to see me with a transverse colostomy. This is not the correct colostomy to perform and can endanger the bladder and urinary tract for many reasons. The proper colostomy is located in the left lower quadrant and the bag should only cover the larger stoma. Sometimes this is difficult as the children are very small but the quality of the colostomy will tell you about your surgeon's comfort and experience with treating ARM. Unfortunately when the colostomy is not properly done, the rate of urinary complications and kidney issues including damage seems to increase.

Urinary Tract Infection (UTI) in the First Year of Life: There are no circumstances where a UTI is normal in the child with IA. Contamination is possible if the sample is obtained with a bag or the colostomy is non-diverting. The causative organism is very important to know and an ultrasound should be done to reassess the bladder and kidneys in the setting of a documented UTI. A urology consult or repeat evaluation is advised, especially in the setting of associated fevers.

Contrast Enema: A contrast study to see exactly where the fistula (connection between bowel and urinary tract) is located is a mandatory exam. My practice is a referral practice and the most common cause of injury or harm to the urinary tract is seen in the setting where this study was not done. This study relies on a properly done colostomy to be able to be appropriately performed. A stoma located in the right upper quadrant or near the upper abdomen will hamper this study and potentially hurt your child. This study is critical to define the type of ARM which we will now discuss.

Female with Recto-vestibular Fistula: Your doctor will have to differentiate this from recto-vestibular fistula with absent vagina. The diagnosis cannot be made by exam alone and typically will require a trip to the operating room for a cystoscopy. This can be done at the time of repair only IF your surgeon has cared for this before. Unfortunately when associated with absent vagina the chance of neurogenic bladder and kidney issues is dramatically increased. The absent vagina patients will need careful urologic follow-up and testing. The straightforward recto-vestibular fistula patients only require an ultrasound and spinal ultrasound at birth. The child should be followed through toilet training with renal and bladder ultrasounds performed at 6 or 12 month intervals. Intervention with a VCUG should be made if any UTI's or changes on the ultrasound.

Males Without a Fistula: This condition is seen in association with Down's syndrome and warrants urologic evaluation. Ultrasound is usually sufficient to follow and the urologist should continue to see your child until after toilet training. Toilet training may be quite delayed in this group but does not necessarily mean an increased risk of problems.

Males and Females with Recto-perineal Fistula: These patients require a screening ultrasound in the newborn period and can be seen yearly until toilet training. Constipation is generally the biggest concern and cause for UTI or delayed toilet training in this group.

Male with Recto-bulbar Fistula (Low IA): Again this diagnosis is made with the contrast enema study. The child with this fistula only needs an ultrasound and a spinal ultrasound at birth and a repeat bladder and kidney ultrasound around the time of repair and colostomy closure. They should be followed until after toilet training by a pediatric urologist. Some of the patients in this category will actually void through their mucous fistula (the smaller of the two stomas). This is normal and does not necessarily mean there will be a bladder problem but in this setting I have recommended prophylactic antibiotics as the chance of infection and possible testicle infection is slightly increased.



Hypospadias: Hypospadias in the male with ARM is very different from hypospadias without ARM and needs to be treated differently. The major concern is associated neurogenic bladder. If your child has a tethered spinal cord, high ARM (recto-prostatic or recto-bladder neck), or a severe hypospadias associated with a significant penile curvature and an opening closer to the scrotum) one should hold on the repair until the bladder evaluation is completed. Unfortunately I have seen many complications when this is not done. Proximal hypospadias where the penis is quite curved and the opening is low is sometimes associated with a complicated pull-through procedure and should be done by a surgeon who has encountered this before. There may also be urethral abnormalities that MUST be discovered before the pull-through. Evaluation by an experienced team is strongly suggested before any attempts at repair.

Male with Recto-prostatic or Recto-bladder Neck Fistula: Some of these patients can benefit from laparoscopic surgery. Relative contraindications for this approach include: Severe hypospadias, not performing a contrast study, history of abdominal exploration. These children will require a VCUG in addition to their ultrasound studies and careful urologic follow is strongly advised.

Testicle Infections (Epididymitis or Orchitis): A scrotal and testes ultrasound is mandatory. A urology consult is needed and a VCUG must be performed. Often times this condition is associated with a structural (anatomic) problem or a neurogenic bladder.

Undescended Testes: Many males with ARM will have the appearance of having retractile testes in part from some anatomic differences with the scrotum. Unless the testicle is "high" non-palpable many of these will self-correct by one year of age. The high testes can be brought down after 6 months of age but must be coordinated with your child's other surgeries especially the colostomy closure. It is ill advised to combine any genital surgery with the colostomy closure as most children will get a diaper rash which could become infected if genital surgery is also done at that time.

Penoscrotal Transposition: This occurs when the scrotum appears to be slightly above the penis. This is a cosmetic procedure and can be repaired anytime. Your urologist must be aware that the urethra is sometimes abnormal in this case and great care should be taken to not injure the urethra with the repair. For this reason I usually wait until after one year of age before repair.

Summary: Any of the above conditions when associated with a tethered cord becomes a higher risk condition and requires urologic follow-up. Your pediatric surgeon and urologist should function as a team. You must make sure that they are in communication and that the number of surgeries with general anesthesia is limited and the care of your child is coordinated. Lack of coordinated care or failure to provide holistic care can result in unexpected problems or late diagnosis of conditions.

This is the first of a series of articles designed for families and patients to understand urologic issues related to ARM. We will focus on childhood with the next article. All points being made are attempting to summarize some of the more frequently asked questions. Please direct any questions, concerns, or suggestions to The Pull-through Network at [pullthruNetwork@gmail.com](mailto:pullthruNetwork@gmail.com). I will be happy to address these in future issues of the PTN News.

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## Ask The Experts

When you have questions or need more information  
the Pull-thru Network Advisors have the answers!

Pull-thru Network's advisors are an invaluable resource to assist PTN members with general questions regarding specific medical procedures, tests, diagnoses, medications, and school issues. Take advantage of their expertise by submitting your questions by email to [PullThruNetwork@gmail.com](mailto:PullThruNetwork@gmail.com). Your questions will be sent to the experts and their answers will be compiled and printed in the next available issue of the newsletter.



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# GOOD NEWS

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From Michael Lando, PTN Adult ~ "I had Malone surgery 1/2012 which was very successful. I had surgery 5/10/13 for spinal stenosis (decompression and fusion L-3/4) which I could not have had before my Malone surgery."

From Kim & Dev Pradhan, parents of Ani, age 17 ~ "Ani is 17, starting his senior year in high school this fall, graduating from Youth Rally this summer, and has been managing his own enema routine for 5 years. His last surgery was 6 years ago when Dr. Pena repaired his Malone. He has some bad days when he needs to stay home from school. For this, having a 504 plan for him has been vital for his success in school. We can call the "homebound office" for our school district on bad days and he receives his assignments online. He has placed very high in choir competitions in our area. In a few months he will be making his college applications, planning to choose a major in communications or broadcasting. In all, a typical teen's life with its ups & downs, but we are so proud of his resilience and willingness to try - sometimes with a push - new situations. "

From Chelsea Mullins, PTN Adult ~ "Doing well! Kidney reflux & UTI's finally under control thanks to Dr. Alam & Dr. Vanderbrink!"

From Gaile & Neale Griffiths, parents of Aled, age 10 ~ "Aled had his bladder augment, Mitrofanoff and ACE in July 2011. Aled loves to give presentations to the medical community and families of those who have had these surgeries and those who have the same condition as himself. He is the Childrens Ambassador for the Mitrofanoff Support Group UK, who he has given several presentations for."

From Cristiane Zampieri-Gallagher & Jose-Luis Gallagher, parents of Yasmin, age 3 ~ "Our daughter, "Yaya", is doing fantastic! She is 3 years old as of July 12, 2014. She had 8 surgeries (7 in her 1st year of life)! She is absolutely amazing and we are now living a normal, healthy, fun life thanks to great doctors we found along the way. What a blessing!!! God is Good!"

From Bonnielynn Sullivan, parent of Patrick, age 18 ~ "Patrick graduated from North Olmsted High School on June 1, 2014! He plans to spend the summer in Texas with his uncle blacksmithing! He's grown into such an amazing young man - we are so very proud of him!"

From Betsy & Ken Brown, parents of Jenny, age 16 ~ "Jenny just turned 16. She took laxatives for 15 of those first 16 years. For whatever reason, she no longer needs them! Incredibly grateful!! Didn't change diet or anything - a miracle as she suffered from terrible constipation previously."

From Allison & Tom Benassi, parents of Jamie, age 10 ~ "Jamie just turned 10 and boy has she come so far. She handles all her urology needs and we just set up for her bowels. Nothing can hold her back!!"

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## ***SEND US YOUR GOOD NEWS!***

One of our favorite parts of the PTN News is our "Good News" section. We include pictures, updates, and stories from our members. These rays of hope give encouragement to all of us and are wonderful ways to celebrate the accomplishments of our remarkable children. Please don't forget to include YOUR good news when you send in your membership renewal. You can also send your pictures and good news to us via email at [PullThruNetwork@gmail.com](mailto:PullThruNetwork@gmail.com).

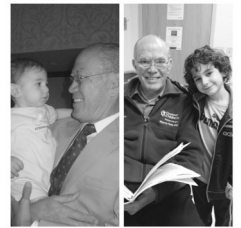
# GOOD NEWS



From Gena & Ashley Heffner, parents of Hannah, age 11 ~ "Hannah just started her very last year of elementary school! She is a happy, beautiful young lady who continues to adapt to the changes life throws her way. She has recently decided to devote time to the battle against drunk driving in honor of her late brother, Michael Paul Iler, who was killed by a drunk driver on March 2, 2014. She recently placed in the top 10 of nationals in dance with her lyrical solo "All My Flaws."

From Teresa Menke, grandparent to Christopher, age 11 ~ "Christopher has had his trapdoor for 5 years now. He still has "accidents" but not as often. School has been good about letting him use the bathroom whenever needed, but this year he has had some issues with a few kids, so we have decided to try homeschooling through Texas Virtual Academy. Wish us luck!!"

From Traci Smith and Mehdi Ziabakhsh, parents of Darius, age 7 ~ "Our son, Darius Ziabakhsh (7 yr old), who has been seeing Dr. Pena since he was born, has been through many surgeries, hospital ER visits and many hospital stays in Cincinnati (we're from NJ) at the Cincinnati Children's Hospital. Obviously we have stayed at the Ronald McDonald House (RMH) there so many times I couldn't even count. This year, Darius and his best friend, Faith (another patient at CCHMC) were chosen to be part of this year's RMH Red Tie Gala video of the year! We are heading to the RMH Red Tie Gala in October for Darius and our family to finally enjoy and celebrate what he has overcome and to raise awareness and funds for the RMH of Cincinnati. We are so proud of how strong he is and how far he's come. We are so blessed to be his parents."



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# ***REQUEST TO PARTICIPATE IN RESEARCH FROM CINCINNATI CHILDREN'S HOSPITAL***

May 19, 2014

Dear Parents,

We are conducting a research study to obtain information from families whose daughters have an anorectal malformation so that we can improve care for these patients. The information that you share will help us recommend practices that we hope will better serve families faced with similar health care issues in the future. There is no direct benefit to you or your daughter whether you choose to fill out and return the questionnaire or not. There will be no change in the care that you or your daughter receives.

The questionnaire has been approved by our hospital's Institutional Review Board (IRB), a large committee that reviews studies to make sure that they protect the rights and privacy of the children and families involved. It should take you approximately 5 minutes to complete. Your name is not associated with the questionnaire and all responses are anonymous. Please do not put your name or any other identifying information anywhere on the questionnaire. Completing this questionnaire is completely voluntary and you can stop filling it out anytime you want.

By completing the survey, you are giving your consent for this information to be included in our research study. The link to the survey is <https://www.surveymonkey.com/s/XTGRFJ7> We appreciate your feedback and encourage you to contact us if you have any questions. You can reach Debbie Morse at [debbie.morse@cchmc.org](mailto:debbie.morse@cchmc.org) or 513-803-0090.

Sincerely,

Debbie Morse

Christie Stewart

Sarah Braukman

Kathleen Whitehead



**Females with Anorectal Malformation (ARM): When is the best time to inform parents/guardians of associated gynecologic anomalies?**



## **Want to share your feedback?**

If you are a female born with an ARM or her parent, please help us improve interdisciplinary care by filling out a short anonymous survey. Go to the Pull Thru Network webpage for a link or contact us at [gynecology@cchmc.org](mailto:gynecology@cchmc.org).

### **BACKGROUND**

- Due to the limited gynecological treatment available to ARM patients worldwide, many patients and families have difficulties obtaining comprehensive treatment for their malformation.
- Anecdotal clinical experiences suggest that few parents/guardians of females with ARM have a discussion with a health care provider about possible gynecologic anomalies associated with ARM.



### **HEALTH BENEFITS**

- Promotes trust between the health care provider and family
- Enhances the ability of the parent/ guardian to make informed treatment decisions
- Earlier diagnosis/detection of gynecologic complications thereby reducing risk to reproductive organs and fertility

### **RISKS**

- Potential for the inability of the parent/guardian to process large amounts of information
- Possible short term negative emotional impact on parents/guardians

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# Pull-thru Network's Professional Advisors

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**Michael Allshouse, DO**

Pediatric Surgery  
Children's Hospital of Central California  
Madera, California

**Elizabeth Harrison, RN, MSN, CWOCA**

Nurse Consultant—ET  
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Los Angeles, California

**Shumyle Alam, MD**

Medical Director of Urodynamics  
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**Marc Levitt, MD**

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Cincinnati, Ohio

**Charles Vinocur, MD**

Pediatric Surgery  
Al duPont Hospital for Children  
Wilmington, Delaware

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## Donations to the Pull-thru Network

As an all-volunteer organization, we rely on the support of our members and other generous donors. A big thanks to those who have made donations to the Pull-thru Network. We appreciate your support! Thanks to those listed below who have made contributions May 2014 - August 2014!

**Up to \$50**

Dr. Michael Allshouse  
Linda & Fred DePorter  
Summer Farmer  
Rachel & Major Hayden  
Michael & Ruth Lando  
Maddie Martin  
Chelsea & Derek Mullins  
Jocelyn & Timothy O'Neill  
Alison & Douglas Thornton  
Cammie Webb (scholarship fund)

**\$50 - \$100**

Karen & Scott Brownlow  
Dan Davidson (in honor of Ryan  
Matthew Hood)  
Brian & Jill Dejewski  
Rodney J. Klima, DDS (scholarship  
fund)  
Maria Scialino  
Peter Wright

**\$101 - \$500**

Bulldog Wrestling Club (scholarship  
fund)  
Robert Bray  
Steve & Holly Demeritt  
Johnson & Johnson Matching Gifts  
Program  
Moshin & Seema Hisamuddin

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*All donations to the Pull-thru Network are tax-deductible.*

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# Pull-thru Network Member Services

## PTN Member Networking

There are times when talking to someone who shares the same problems, issues or concerns can make a big difference. Pull-thru Network has the largest database in the world of people affected by an anorectal malformation and their families.

Only members who have indicated that they will network with other members are included in the names to be released (see the PTN Privacy Policy).

Pull-thru Network can match you with other PTN members based on geographic area, child's age or gender, diagnosis, surgeries, internet access, etc. All information is confidential and only given to other members of Pull-thru Network.

Call or e-mail  
the PTN office to request  
a networking list.

309-262-0786 PullThruNetwork@gmail.com

## Pull-thru Network Family Assistance Program

The Pull-thru Network Family Assistance Program is a way to help PTN members with exceptional needs receive assistance in order to cover some of their costs when obtaining medical treatment for their child.

The program is primarily intended to provide financial assistance to families for travel to a medical center. Additional assistance may be granted in certain situations for hotel accommodations. This will be evaluated on a case by case basis.

There are criteria to be met and the family must be a member of Pull-thru Network.



## Lending Library

PTN maintains a library with books on a variety of subjects and will lend books for up to one month.

The only charge is the cost of the return postage.

A list of the books is available from the PTN office.  
PullThruNetwork@gmail.com

## Pull-thru Network Website [www.PullthruNetwork.org](http://www.PullthruNetwork.org)

### Information and Education:

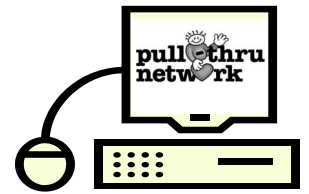
- Glossary of medical terms, diagnoses, tests and procedures
- Medical articles from past issues of the newsletter
- Past issues of the newsletter available to read on-line
- Information on upcoming conferences and seminars

### Support:

- PTN Teens section
- Forums/Message Board
- Multiple ways to network and connect with other PTN members

### Advocacy:

- School and daycare accommodations information and resources
- Insurance information
- Information on current research



## PTN Live Online Chat Sessions

Monthly online live chat sessions with other PTN members are held in the members-only chat room at the PTN website. Please join us every fourth Sunday at 8pm central time to interact with other families in a safe, private environment.

## PTN Email Support Group (Yahoo group)

Participating in email support group (through Yahoo), is another way to connect with members and get feedback, offer help, and stay in touch with other families who have "been there/done that".

To subscribe, send an email to PullThruNetwork@gmail.com and ask to be added to the PTN Yahoo Group. You can receive the emails individually (regular subscription) or combined in one email at the end of the day (digest).





# Seattle Children's is proud to support the Pull-Thru Network



Seattle Children's, a national leader in complex pelvic conditions, provides comprehensive care for children and teens, birth to age 21. Our team of experts creates an individualized plan for each patient for diagnosis, treatment and support.

As the Northwest's only Reconstructive Pelvic Medicine Clinic, we bring together the expertise of providers from Adolescent Medicine, Gastroenterology, Gynecology, Urology and Pediatric Surgery. Our team approach means your child gets care each step of the way from people who know your child's care plan. We arrange clinic visits so your child can see all providers in one day, instead of having to make multiple trips.

To learn more about our clinic, visit [www.seattlechildrens.org/rpm](http://www.seattlechildrens.org/rpm) or call, 206-987-2794, option 4.



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USA

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**Moving?** Please remember to notify PTN of your new mailing address,  
e-mail address and phone number. **Thank you.**

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