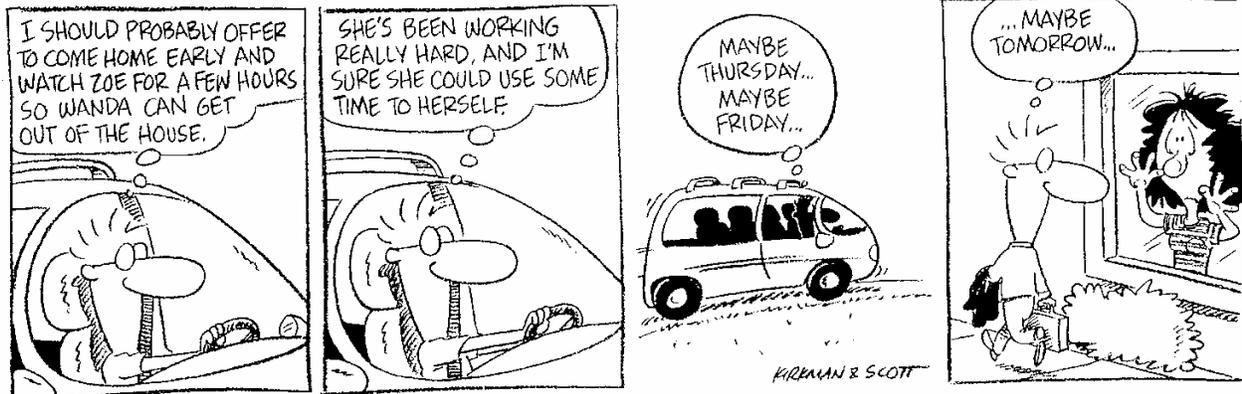




Reflux Digest

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From the Editor's Desk

Welcome to the new and improved Reflux Digest distribution system. Our mailing list is so large that we were having trouble sending the newsletter directly. We hope that using Constant Contact will solve several problems.

You will receive an e-mail that has a short list of the features in the latest issue of Reflux Digest. Then you click a link in the e-mail and it leads you to a special place on our web site where the full newsletter is posted. Subscribers can see the newest issue, but the general public won't be able to see it for a few months because it is hidden and has no link.

Please send us feedback on how this new system works for you. If you see some glitches, please let us know what program you use to read your e-mail and what internet browser program you use to view the newsletter. That will help us fix any glitches.

We have been very busy in the past few months with new staff, new board members, a new project and two new consultants helping us out. We hope you will forgive us if the newsletters have been a bit shorter and less frequent. The changes are all good, but they have taken a lot of time. Read the section on Organizational News for details.

Have a wonderful Mother's Day and Father's Day!

Beth



Calling Creative Parent and Child Cooks!

*GERD-Friendly Meal Makeovers Presents
the Design Your Dinner Challenge*



Dinner by Design and celebrity food expert Ted Allen have teamed up for a second year of GERD-Friendly Meal Makeovers!

This year, GERD-Friendly Meal Makeovers is launching a new contest called the *Design Your Dinner Challenge*, created to help educate families on gastroesophageal reflux disease (GERD), or acid reflux disease, and motivate them to create delicious meal options of their own that avoid common GERD triggers.

About the *Design Your Dinner Challenge*

- The *Challenge* invites families to enter by submitting their original recipes that avoid common GERD trigger foods on www.TheGERDLife.com
- By entering, a parent/child team may be eligible to participate in a live local challenge hosted by Ted Allen and held at a Dinner by Design kitchen
- One parent/child team from each of the local challenges will be selected to participate this fall in a live *Design Your Dinner Challenge* finale
- Other prizes include a year's worth of meals from Dinner by Design, a trip to Chicago and an autographed copy of Ted Allen's cookbook *The Food You Want to Eat: 100 Smart, Simple Recipes*



As part of GERD-Friendly Meal Makeovers, a GERD-friendly recipe will be featured on the Dinner by Design menu each month, so check it out to get inspired and create your own tasty appetizer, entrée, side dish or dessert that avoids common GERD triggers!

To learn more about GERD and enter the *Design Your Dinner Challenge*, visit www.TheGERDLife.com.

[Click here to enter the Design Your Dinner Challenge](#)

Medical news of Interest

Rapid Dissolving Reglan

[Salix Pharmaceuticals, Inc](#) has announced that they will begin producing a melt-in-the-mouth formulation of metoclopramide (Reglan) that can be taken without water. It will be called metoclopramide-Zydis®. In most parts of the US, metoclopramide is used only as a drug of last resort for children who do not respond to H2 blockers, PPIs or physical barrier medications

GERD and Behavior Problems in Neurologically Impaired Children

Researchers in Austria studied a group of severely neurologically impaired children to see if behavior problems and GERD seem to be linked. They found that children who displayed autoaggressive (self-injuring) behavior were mostly likely to have GERD. The children with daily agitation also had higher rates of GERD. All of the calm children had normal results on a pH probe. They strongly suggest that all neurologically impaired children with behavior problems be tested for GERD.

Gastroesophageal reflux and behavior in neurologically impaired children. [Journal of Pediatric Surgery](#) September 2007. PMID 17848235

GERD Guidelines

In 2001, the North American Society for Pediatric Gastroenterology and Nutrition produced a 31 page guideline for physicians giving recommendations for diagnosing and treating reflux in children. But a recent survey by NASPGN shows that the majority of physicians who treat children with GERD are unaware of the guidelines.

Knowledge, attitudes and practice styles of North American pediatricians regarding gastroesophageal reflux disease. [Journal of Pediatric Gastroenterology and Nutrition](#) 2007 Jul;45(1):56-64. PMID: 17592365 [Copies of the full guidelines or the summary are available by calling NASPGHN at 215-233-0808. -Ed.]

A similar study of adult primary care physicians published this week shows similar weak areas. The doctors from around the world were surveyed about their knowledge of GERD, their use of guidelines, etc. They were all familiar with GERD and recognize the classic symptoms. But less common symptoms such as laryngitis, sleep disturbance, cough, asthma, erosive esophagitis, strictures, Barrett's Esophagus and esophageal cancer were not as widely recognized as connected to reflux. Only 33% of the doctors use guidelines. The terminology used varied to chart cases of reflux varies widely. [In one country, they still use the term "flap valve" to describe the Lower Esophageal Sphincter.- Ed.] *An international primary care survey of GERD terminology and guidelines. [Dig Dis.](#) 2008;26(3):231-6. Epub 2008 May 6. PMID: 18463441*

The Importance of Mouth Play with Reflux Babies

Mouth play is the opportunity to give the baby with GERD positive input around the mouth area. Babies with GERD have frequent associations with pain, and it's very important to give them pleasurable play experiences around the mouth area.

Mouth play or oral play can be provided by kissing, touching with a dry washcloth, and textured toys. Most babies enjoy putting things in their mouth, and exploring. This is one way they discover a lot about their environment and their body. Most importantly, these exploring times in the mouth give them the tongue and mouth movements to keep progressing from bottle or breast feeding, to spoon feeding, lumpy foods and table foods.

Start by providing mouth play on the outside of the mouth. The goal is to work towards getting into the mouth area, without gagging, crying, turning away or closing lips tightly. Your input should be gentle, and you should always watch your baby's signs to be sure that it is pleasurable. If there are any signs of upset, just stop! Try again later.

Once your baby starts getting teeth, around 4-6 months, it will be important to be able to clean their teeth and gums with a washcloth, or even a baby toothbrush. Brushing teeth is a great way at any age to provide good input to the mouth, and help the reflux child to desensitize a very sensitive area, and keep that acid off of their teeth!

Keep all mouth play pleasurable and fun to help them to be happy eaters! Lisa Otto, OTR (Texas Children's Hospital)

If anybody would like to write an article for the newsletter about their favorite reflux topic, let us know!

Organizational News

Spanish Language Pediatric GERD Outreach Project

- The Hispanic/Latino population has grown from 14.6 million in 1980 to 41.3 million in 2004. Between 1990 and 2003, the Hispanic population grew by 61%, making it the fastest-growing group in the US.
- About 30 million people living in the United States speak Spanish as their language of origin. Less than half of them feel that they speak English "very well."
- Visits to the doctor for GERD-related complaints among children in Spanish speaking households have grown 60% in the past several years. Health professionals are frequently requesting independent, high-quality health information in Spanish.

In the past, we have made small steps toward helping Spanish speaking parents understand GERD and improve their children's health. This population is growing fast and we decided that it is time to start a full-blown project.

We have developed a multi-phase project that will take several years to complete. It includes creating a mirror web site in Spanish (www.reflujoenninos.org) complete with discussion forums. We will be collaborating with a doctor in the US who conducts many different health education activities in Spanish. We will also be training volunteers who are bilingual, producing written materials and distributing them to clinics.

Phase I of this educational activity is being supported by an educational grant from TAP Pharmaceutical Products, Inc and by a grant from the Demarest Lloyd Jr. Foundation. Phase I is already off to a great start and we are actively seeking funding for the next phases.

Board of Directors

The PAGER board has been undergoing growing pains over the past years as the organization has grown and the number of projects has increased. Starting the Spanish Language Pediatric GERD Outreach Project increased an existing rift among board members who thought it was an amazing opportunity and those who viewed it as a problem. The upshot is that PAGER is currently operating with a temporary board.

During the summer, we will be recruiting a new board of directors. We will be working with an outside consultant who is helping us form a board that wants to take PAGER to the next level and help more and more parents all over the world. We now use a web and phone meeting technology that lets board members participate from their home or office, as long as they have an internet connection. If you are interested in applying to join the board, please send a note to PAGER. The board's job is to oversee the staff and help set priorities for the organization.

Fundraising

Over the years, many PAGER members have held small fundraisers or asked their friends and family to support the work that PAGER does. We are creating a system that will make it much simpler for any PAGER member to run a small fundraiser in their community and have their expenses covered. Look for details in future newsletters.

New Staff

Thanks to our marvelous new staff, all the basic PAGER work is getting done and our To-Do lists are down to a size that no longer provokes nightmares. Jennifer is the Volunteer Coordinator, Lisa is the Message Forum Monitor, Tracey helps Beth in the office and Ligia is a contractor in charge of the Spanish Language Pediatric GERD Outreach Project. They are introduced below.

We will soon be adding a new member to the team. A mother who lives near the PAGER office has experience selling ad space and will be taking over the ad placement duties.

PAGER in the News

Reflux Problems Not Limited to Adults - Babies and children can also suffer from severe gastric distress, experts say. This article appeared in Health Day. <http://www.healthday.com/Article.asp?AID=607428> The article featured Priscilla Dunstan, the famous "Baby Language expert," whose baby had reflux. PAGER was listed as a resource

Meet More of Team Reflux

In the last issue of Reflux Digest, we introduced you to about half of our team. Here are introductions. The new staff members were introduced in the paper version of the last newsletter, but not the electronic version. They are key team members so their introductions are worth repeating.

We are still actively seeking a few volunteers who speak both Spanish and English and have some experience dealing with children who have reflux.

Jennifer Rackley – New Staff

I have been volunteering with PAGER since dealing with our first daughter's GERD five years ago. We also have twin daughters who are now 2 years old, one has GERD and one does not. Unfortunately that means that I have also had a lot of hands-on (or should I say, puked-on?) experience with reflux. In my "pre-reflux" life I worked in clinical nutrition and have a bachelor's degree and some graduate work in that field. I am the new Volunteer Coordinator for PAGER.

Lisa Panzarella – New Staff

Hi. I am a new forum monitor for PAGER. Every night I monitor the forum posts to make sure they adhere to the rules and guidelines of PAGER. I have been visiting PAGER since my son was diagnosed with reflux at 3 weeks old. He is now 4 years old and is reflux free. I am currently a stay at home mom and I am also a registered nurse.

Tracey Butler – New Staff

I started as a volunteer with PAGER in 2002 and then worked for PAGER as an office assistant. I left in 2003 to pursue a Master's degree in counseling and returned this past October. I'm Beth's "Girl Friday" and wear many different hats in the office. I help with bookkeeping, office management, and maintaining the ever-growing PAGER database which now has over 8,000 contacts - woohoo! Like many kids and adult members of PAGER, I too have acid reflux. My quality of life has been seriously impacted but thankfully, I now have a medication and diet regimen that works for me. I'm really glad to be supporting this great organization!

Lisa Otto, OTR – Volunteer and New Board Member

I am a Mom of 3 GERD kids, all diagnosed early on, as newborns. I have been in touch with PAGER for ~10 years! I currently work as an Occupational Therapist at Texas Children's Hospital, feeding children. I continue to educate health care professionals and parents on a regular basis and am very passionate on education of GERD. It deserves a lot more awareness! My kids have been my best educators! I have learned more from our own reflux house than anywhere else!

Erica Hale

As a volunteer, I email and talk on the phone mostly with mothers of older children with acid reflux. Parenting a child with GERD is challenging, frustrating and isolating and can really wear you out. It is so rewarding to be able to reach out and talk with a parent who is going through this difficult experience, knowing that sometimes just knowing you're not alone is enough to get you through another day! Volunteering helps me, too, because I feel like I've been given an opportunity to take a situation that has been difficult and painful and turn it into something helpful and validating. PAGER has been a blessing in my life!

I live in Salt Lake City, UT. As an at-home mother and former school administrator, I have been on the reflux roller coaster with two of my three children. My middle child was diagnosed as a toddler, she was a tiny 16 pounds at one year old and finally made it back on the growth chart at three years old. She is now a happy, healthy eight year old and is reflux free. My son (who also has Celiac's disease) was diagnosed with GERD the month he turned eleven, and after some ups and downs seems to be stable on his medication. He had screaming colic (cried for up to 20 hours a day!) from birth to four months of age, and has probably had reflux all his life...I am thankful that awareness about pediatric GERD has come so far since my kids were babies. PAGER has been a Godsend for me during the ups and downs of dealing with reflux and I am glad to get a chance to give back to this great organization!

Ligia Ryon – Contractor and Project Manager

Hola! I am Ligia Ryon and my job is to find the best ways to bring the valuable information and support PAGER offers to the Spanish-speaking community. Our goal is to translate the site --at least partially for now-- and to work with Latin organizations to reach the public in the most appropriate manner. I am from Colombia and feel lucky to have the chance to work on a project that will benefit the Latin community. I am truly impressed by the terrific work done by PAGER. I would love to hear from anyone who might want to serve as a volunteer once we get the site running --Spanish language required--.

Melissa Willard

Hi! I am the mother of Maggie, a 16 month old reflux survivor. I too feel like a survivor after going through the whole ordeal. I feel so blessed to have made it through reflux with my daughter.

I truly enjoy sharing our story with other people going through reflux. It's a great feeling to know that maybe I helped someone know that they aren't alone and that there is hope!

Kim Komos

I'm from Northeast Ohio, and I am a parent volunteer for PAGER. I am available by phone and email. I use my personal experience with reflux to help others.

I am a mom with three refluxers. Two are very mild and have gotten better as they have grown up. My daughter is very severe. She is now 17 so I have many years of dealing with reflux issues. She had her Nissen at 16 months old, and a feeding tube for 8 years. She battles every day with reflux related issues. I understand the helpless, confused and frustrated feelings of a parent trying to find answers.

Sara Henson – New Board Member

I was a reflux baby and have a reflux baby. My "refluxer" is Noah, two years old, and who has reflux episodes only occasionally now. I met Beth through Volunteer Maryland! and believe strongly in patient advocacy and peer support.

Terry Jarrett – New Board Member

I am the owner and inventor of the Tucker Sling. I have two children with severe reflux who were not able to lie flat. I can relate to the pain and suffering the parents and kids go through and want to do what I can to make the situation better for other parents.

Ed Freeman, MD – New Board Member

As a physician, I see people all the time who are suffering from lots illnesses but more importantly lack of credible information on how to help themselves. To this end, I am happy to be a part of an organization that is dedicated to informing and educating people on such a widespread disorder. Having watched this organization grow, I know there is a dedication to help educate as many people as possible about reflux. I co-authored a paper on the side effects of reflux drugs with Beth and I look forward to contributing more.

Sudha Kaistha – New Board Member

I am the mother of one child with reflux and a heart condition. He is now 20 and there was little information about reflux available when he was a baby. I want to work with PAGER to be sure all parents get information.

Cathy Fox, M.S., OTR/L – New Board Member

I am a Pediatric Occupational Therapist specializing in Feeding and Swallowing Problems for 24 yrs. I started multiple feeding programs across USA and have been on several evaluation and treatment teams. I am a long time GER sufferer! My 3.5 yr old nephew had and has GERD and was diagnosed as Failure To Thrive until he was fully treated.

Thanks

TAP Pharmaceutical Products, Inc awarded PAGER an educational grant to kick off the Spanish Language Pediatric GERD Outreach Project.

Volunteer Demi Isenstadt has connections at the Demarest Lloyd Jr. Family Foundation. She asked us to submit a proposal for the Spanish Language Pediatric GERD Outreach Project. The foundation awarded PAGER \$5,000.

Long time PAGER member Aumi Hatfield collected used printer ink cartridges. She sent them to Empties4cash.com and mailed us a nice donation!

Roni MacLean and Jean McNeil set up a donation system through Six Degrees, a charity donation site associated with Network for Good. This system allows you to put a charity badge on your e-mails that helps generate donations for PAGER. We have also set up a new donation system through Google. They do not charge a processing fee for donations to non-profit organizations. So now you have two ways to donate online.

[JOIN](#)

[DONATE](#)

We received nice donations from Janet Reed and Ted Tilton, Ann and Michael Boland, Rebecca Swadling and Jeffrey Krol, Natalie Matteucci, Josephine Hines, Candice Highsmith, Michele and Timothy Strasz, Thomas and Kathleen Lawson, Sheila Canlas, Joni Ferneau, Peter and Marsha McNamara, Martha Gustafson, Joseph Kraus, Camilo Rodriguez, Ellen Lepping, Anne Teresa Flack, Carl Lemmel, Marcella Walsh, David Elfin in honor of Amy, and monthly donations from an anonymous source.

Reviews

"An Infant Massage Guidebook for Well, Premature & Special Needs Babies." covers two different colic relief routines and has photos accompanying the routine by a National Geographic photographer. The book is hardcover, 125 pages, autographed limited edition, for \$24.95. It is available from <http://www.littlelocalcelebrity.com/>

Benefits of Infant Massage on the Gastrointestinal System:

- Incorporates specific techniques tailored to relieve discomfort from colic and gas pains in the abdomen and underlying intestinal tract.
- Improves gastrointestinal tone, reducing cramping and spasm.
- Facilitates elimination through large intestines by mechanically stimulating peristalsis from the esophagus through the intestines.
- Infant Massage also promotes longer, sounder sleeping patterns, improved disposition to company and peers, and improved habituation: the ability to focus on stimuli and ignore background, which is directly correlated with mental abilities in later development.

"The Reflux Book – A Parent's Guide to Gastroesophageal Reflux" is finally in print. It is written by Beth Anderson who happens to be the Founder of PAGER. The cost is \$20.00 and Beth donates \$2.00 from each sale to PAGER. It covers everything from preemies to teens and has helpful info on everything from symptoms to surgery. The book is complete yet easy to understand because it is written on an 8th grade reading level.

Todd Eisner, MD Gastroenterologist and writer for HealthCentral.com wrote this review:

Throughout the book, the general theme is to provide an informative resource for parents of children afflicted with this disease, while doing so in a non-threatening way. While many medical books for the layperson tend to scare those that read it with the attitude of an alarmist, The Reflux Book has a straight-forward and positive approach. It should be read by all who are close to a child with gastroesophageal reflux disease.

Section 1 of the book is a basic overview. The book starts out with an excellent introduction to acid reflux. In Chapter 1, normal digestion is discussed, and then reflux is defined. Reflux is compared to colic, and parents are reassured that reflux is very common. Chapters 2 and 3 give a great description of symptoms your child may be experiencing, and clues that should prompt a trip to see the child's physician. You will again be reassured to know how common acid reflux is, and how your child's doctor might go about making the proper diagnosis.

This is a small part of a long review that you can read by clicking this link <http://www.healthcentral.com/acid-reflux/c/66/20699/reflux-book>. You can also read a sample chapter at www.refluxbook.com

"Colic Solved" by Bryan Vartebedian, MD, a pediatric gastroenterologist who has a child with reflux. This is an excerpt from Amazon:

COLIC—THE DIAGNOSIS FOR ALL OCCASIONS Unfortunately, not everyone has a pediatric gastroenterologist as a father. In many cases, babies are left alone to cry, either by parents who don't know how to advocate for them or by doctors who don't know where to turn. In fact, in Hannah's case the diagnosis was colic because there was nothing else to explain her problem and the symptoms loosely fit with something that her pediatrician had been taught many years ago.

So What Is Colic? The quest for the cause of colic or even an agreed-on definition of it over the last half century has amounted to something of an optical illusion. Like one of those abstract images that you must stare at for minutes on end before actually identifying the picture, colic has been something of an elusive diagnosis among pediatricians. And the many who never quite see it ultimately agree that they see it just so they won't have to continue squinting.

I'll have to admit that from early on in my career I was never able to see the pretty picture when it came to the illusion of colic. While I've evaluated and treated thousands of irritable babies, the problem is that I've never seen colic and can't get straight answers about what it is or what it looks like from those who claim to have seen it. Like the UFOs that seem to land everywhere but at Harvard and MIT, colic has evolved into one of our culture's greatest urban legends—a mythical explanation meant to explain the seemingly unexplainable.

A Baby Cannot "Have" Colic The problem comes with the fact that colic is a description and not a disease. This descriptive term has, in turn, been morphed into a real and recognizable condition that served an important role for parents and pediatricians in our not-so-distant past. Much as fables and myths help provide order and explanation for different cultures, colic was once a comfortable resting place for weary pediatricians dealing with weary parents. And when medical science failed to offer any better explanation, it served to conveniently absolve the pediatrician from any further responsibility to parent or child.

Because colic represents a pattern of behavior and not a disease, a baby cannot "have" colic or have it "diagnosed." Much like fever or weight loss that typically represent signs of some other problem in a child, colic doesn't stand on its own as a diagnosis. To use the words diagnosis and colic together suggests that intelligent, established criteria, backed up by clinical research, were used to come to that conclusion. But unfortunately, such criteria or compelling clinical studies don't exist. In the words of a distinguished researcher on the topic of infant irritability recently quoted in the *Journal of Pediatric Gastroenterology and Nutrition*, "The term colic implies a mechanism responsible for the distress displayed by these infants. Such a mechanism has never been demonstrated."

"Acid Reflux in Infants and Children," is written by Tracey and Mike Davenport. The book is available from Amazon. Here is a summary from Tracey's blog on HealthCentral.com

[It is] my third book aiming to "get it right" for both healthcare providers and parents of infants and children with acid reflux.

Soon after the second book -- Making Life Better for a Child with Acid Reflux -- was published, we realized that many of those looking for this information were tired, stressed and short on time. We wanted to help them more quickly find a great resource.

That's why we changed the title to more appropriately reflect the information presented in the book, though it has the same pertinent information as the second book. This newly titled book still contains chapters from the medical gurus in the reflux world, and it covers everything from the psychological impact to medication descriptions. The book has sold world wide.

Digestive Health SmartBrief is an online newsletter for consumers who are interested in gastrointestinal diseases. It is produced weekly and contains summaries of interesting medical articles and news. Those of you who want even more medical news than what we put in Reflux Digest might want to look at this newsletter. It covers many other diseases.

From the Trenches

Dear PAGER,

Thanks for the calendar and all the info these many years. My son Ben is a GERD fighter and now 14 years old. We've learned so much since he was an infant and there were so few resources out there and food allergy alternatives. Keep me posted on advocacy efforts to promote research and drug free alternatives

Michelle

Dear PAGER,

I just wanted to say that you never know. . . I found it ironic that I just got a PAGER newsletter in the mail and had not thought about PAGER for awhile. I recently took my 5 year old to the GI doctor, we hadn't been for 2 ½ years. My son had reflux and N-G tube when he was a baby. He started eating well around age 3 and we took him off of reflux meds and he seemed fine. He has always had other health issues too - allergies, asthma, and chronic sinusitis but no

symptoms of reflux for several years. After allergy and asthma meds and lots of antibiotics I wondered if he still has reflux and that could be causing all of these symptoms. We did a barium swallow and it was plain as day that he is refluxing. Now we will wait and see if his chronic sinus problems will resolve.

Jodi Moore, Leesburg, VA jandrmoore@yahoo.com

Dear PAGER people

I just wanted to draw your attention to the potential cardiac effects of children being treated long-term with common medications for gastro-esophageal reflux. In particular, domperidone (Motilium), which is widely used as a gut motility agent in the UK but not in the USA, has recently been found to extend the QT interval and therefore may lead to the very serious condition known as 'Long QT syndrome' or LQTS, one cause of sudden death in young people.

I know PAGER is largely based in the US, but I expect many parents from other countries use the site as a reliable information resource (as I myself did when my son was younger) so they may benefit from this information being posted on the PAGER site. [*Domperidone is being imported by US doctors and parents for reflux. It is also being used for increasing milk supply in nursing mothers. – Ed.*]

One article discussing the use of domperidone is <http://circ.ahajournals.org/cgi/content/full/circulationaha;102/16/1883> *Domperidone Should Not Be Considered a No-Risk Alternative to Cisapride in the Treatment of Gastrointestinal Motility Disorders*. Look at the links at the bottom for more information.

My story is that my son Paolo was diagnosed with severe gastro-esophageal reflux at about 6 months old, although he had been showing signs of reflux from about 6 weeks and it just took a long time to get a referral to a doctor who took us seriously. Shortly afterwards, he was admitted to hospital with heart failure due to pericarditis - an infection of the heart lining. I later read that children being treated for reflux are at a higher risk of serious infections, as the lowered acidity in their stomach means they lose some of their front-line defenses against pathogens. This certainly hadn't been spelt out to me when Paolo was prescribed his anti-reflux medications, but then, as is already made clear on the PAGER website, all parents have to choose between the possible side-effects of the medications, and the risk of continuing the situation prior to medication. I certainly opted for the former as I didn't want to prolong the latter. Furthermore, we make those decisions based on whatever information we have at the time, however incomplete it may be. So I don't feel guilty about my decisions, but I hope that this story may help other parents to make a more informed decision.

Anyway, Paolo's body and his medications went through a fairly predictable pattern. He was initially prescribed ranitidine (a H2RA) and domperidone (to promote gut motility) but after a while his body seemed to stop responding to the ranitidine despite increased doses relative to body weight. So he went on to omeprazole, still in combination with domperidone, and this worked well until his reflux seemed to have abated. We slowly weaned him off, finishing around his 2nd birthday. (It all sounds so simple, but of course there were the usual ups and downs on the reflux rollercoaster, which I don't need to go into for the purposes of this story.) I was suspicious about whether domperidone was necessary in Paolo's case as he was breastfed throughout the period of being treated for reflux, and never had any tests to check whether gut motility was a problem. I think the doctors here seem to prescribe it automatically, in combination with a H2RA or PPI, without really checking if it is indicated.

Then last December, at around 3 ½ yrs old, Paolo had his first seizure. I grew up with an adopted sister with epilepsy, and Paolo's seizures certainly looked like the classic 'tonic-clonic' type. (This kind of seizure used to be called 'grand mal'.) This was pretty frightening, and we went in and out of our local hospital for the next week or so. After a while, the anti-epileptic drugs he was now taking seemed to have the tonic-clonic seizures under control. He was also, however, having lots of little 'jerks' where he would very briefly lose consciousness, make a little exhalation and perhaps fall to the floor or drop whatever he was holding. The medics in the hospital didn't seem too concerned about these seizures (which we thought were of the 'myoclonic' variety) and eventually they persuaded us to take Paolo home for Christmas.

Over the last two months Paolo's tonic-clonic seizures have not returned but he is still jerking and falling many times a day, and a concerned cardiologist, who is a friend of the family, asked if anyone had ruled out the possibility that the seizures might be caused by cardiac malfunctions rather than a neurological cause. This had not been ruled out, so we paid for an electrocardiogram (ECG) and were quite worried when it returned showing a prolonged QT interval, a symptom which has been associated with sudden death.

Further reading shows that 'Long QT Syndrome' may be genetic, but also may be acquired, with domperidone

being one of the drugs having the effect of lengthening the QT interval. There is no family history of sudden death or cardiac arrhythmia. So that reduces the likelihood that Paolo had a congenital problem that just wasn't picked up earlier, and increases the possibility that the long QT was acquired due to use of domperidone.

I am now trying to get a specialist to see my son for more extensive cardiac tests. If he is diagnosed with LQTS we face the likelihood of him being on beta-blockers for the rest of his life, and even then there may still be the possibility of sudden death, as beta-blockers can't completely prevent these fatal cardiac events.

It seems rather sad that Paolo took domperidone for less than two years but this may now determine how he can live the rest of his life.

I hope this story has been useful, and if I can be of any more help please do contact me.

Yours faithfully,
Samantha Nimmo
United Kingdom

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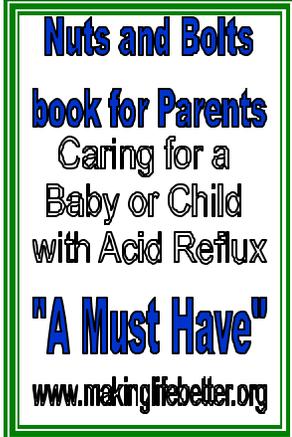


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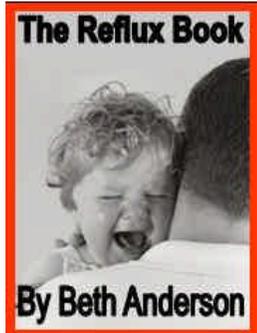


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Nuts and Bolts
book for Parents
Caring for a
Baby or Child
with Acid Reflux
"A Must Have"
www.makinglifebetter.org

www.makinglifebetter.com



The Reflux Book

By Beth Anderson

www.refluxbook.com



Tucker Sling
for babies and
children who need to
be elevated

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We need your current contact info

Every time we send an e-newsletter, we get a lot of bounced messages because people switch e-mail accounts. We had so many bounces this year we were temporarily blacklisted by a two of the big Internet Service Providers. A clean e-mail list is vital. Please keep us updated with your e-mail **and** street address. Sign on to www.reflux.org and correct it yourself using the "sign on" link on the green bar. Or send a note to gergroup@aol.com with your new AND OLD contact info. If you want off the e-mail or mailing list, send a note specifying which and tell us who you are so we can find you in the database.

Get the practical help you need

Volunteers are standing by to take calls from parents. Our amazing volunteers are well-trained and all have gerdlings of their own. Send an e-mail or call 301-601-9541.

Participate

This is YOUR newsletter. What would you like to see? We try to have a mix of news and “human interest” pieces – stories from the media or from our members that relate to acid reflux. Send us clippings, comics, internet sites, interesting products or your GERD story. Send them note to gergroup@aol.com

Sharing is nice

Please pass this newsletter along to friends and family who have reflux. We hope they will subscribe once they see what we offer.

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