



Reflux Digest

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From the Editor's Desk

This is the time of year when we review our accomplishments of the year and goals for next year. We are proud of our accomplishment and thankful for the many volunteers who have contributed to the work of the organization.

2006 accomplishments list

- The PAGER website had a phenomenal increase in web traffic this year. Web traffic just hit 750,000 page views per month.
- The web site now has 300 pages of content and 20,000 discussion postings.
- Our volunteers logged 1753 volunteer hours for a total value of \$40,400.54. (You are worth \$18.04 per hour.)
- PAGER staff logged about 2,000 hours this year – a small portion of that time was paid and the rest volunteered.
- Membership has increased over 20% and new inquiries for information are up 25%.
- Co-sponsor of the 2006 Kids Create. Parents Relate. Coloring and Drawing Contest with TAP Pharmaceutical Products Inc. As part of the partnership, PAGER Association staff served as judges for the contest.
- A large number of other web sites link to reflux.org - 1,479 to be exact.
- Reflux Digest, the quarterly newsletter of the association is now available on line in the newsletter archive.
- Upgrades to the website include: search engine on the Parent Forums, notification system for responses to the posts and search capability for the member profiles.
- A summer intern developed a new press packet, revised the training book and developed several information sheets about common reflux tests.
- Jan Gambino, Associate Director has a weekly blog (stands for web log or journal) that is available on www.reflux.org and on HealthCentral.com
- PAGER had an educational booth at the annual meeting of the American Academy of Pediatrics and staff attended numerous educational sessions.

- Beth Anderson, Executive Director worked with Dr. Ronnie Guillet to translate a technical article about the use of acid blockers for preemies into plain language and get it published in a neonatology nursing journal. Neonatology Network Journal May 200
- Jan Gambino, Associate Director published an article, *Noisy Asthma, Silent Reflux*, in Allergy and Asthma Today.

Jan Gambino and Beth Anderson are in the final stages of publishing a comprehensive parent handbook on pediatric acid reflux.

We get lots of great feedback from our members and visitors to the PAGER website. Here is a small sample:

- I am so glad your organization exists.
- It is such a relief to find your website.
- The volunteer I spoke to really helped me get ready for the appointment with the specialist.
- Now I don't feel so alone.

Executive Director, Beth Anderson says: "If you lose your mind, somebody on this board will pick it up and return it to you! We have all been there. That's the nice thing about an internet community - you know all of us REALLY understand what you are going through. You might find local friends with great shoulders but in us you have friends all over the world who have great ears. (OK, eyes, but it just doesn't sound as poetic.) Welcome to the world of reflux. There are hundreds of parents here to support you along this journey.

PAGER Association goals for 2007 include:

- Website Development: Ongoing upgrades are needed to enhance the website and automate functions.
- Parent Education Materials: There is an ongoing need to develop parent education materials.
- Public Awareness of Pediatric Acid Reflux: Through publication of the book and ongoing outreach to parents and physicians, we can increase public awareness of acid reflux, leading to prompt diagnosis and treatment.
- Volunteer Training: With the revision of the Volunteer Training packet, PAGER Association is ready to train new volunteers. There is a significant need for local support groups and support networks in the local community. We hope to train volunteers from Canada in 2007.

We have been able to accomplish quite a lot this year. Please help us accomplish even more in 2007 by making a donation. You can do so on the web site at reflux.org and clicking DONATE on the left menu.

Medical news of interest

Controversies and Cases: Debating the Issues in the Treatment and Management of Pediatric GERD: CME American Academy of Pediatrics, Atlanta, Georgia, October 8, 2006

Carlo DiLorenzo, MD discussed motility and acid reflux. It is important to look beyond acid production and assess the mechanisms of reflux to improve treatment outcomes. The mechanisms of reflux include: gastric motility (movement of food through the digestive tract), airway protection (the ability of the body to prevent aspiration), transient Lower esophageal sphincter relaxation (muscles at the juncture of the stomach and esophagus that controls the movement of food) and capacity (how much food will "fit" in the stomach). Babies have a shorter esophagus and less capacity than an adult as well as an increase in transient lower esophageal sphincter relaxations leading to more regurgitation and reflux. There is a need for the development of safe medications and treatments to address the transient lower esophageal relaxations (motility medications). At present, the treatments are based on acid suppression and do not address the underlying issue of TLESRs. There are medications in development that may reduce TLESRs but it will be likely be a few years before they are available. Dr. DiLorenzo joked that he wishes humans could have superb LES pressure like bats - they can hang upside down all day and not experience reflux.



Suzanne Nelson, MD gave a lecture on the importance of conservative therapy in the treatment of infants with acid reflux. Conservative therapy for acid reflux includes: positioning (avoid upright seating or lying down flat), thickened

feeding, use of a semi elemental formula, small meals spread out over the day and avoidance of tobacco smoke exposure. Conservative treatments may be an under-utilized approach. There is evidence that conservative measures may lead to positive outcomes. In Dr. Nelson's study of infants with acid reflux, more than half did not need medication and had improvement in symptoms with conservative treatment. Further, the majority of the babies did not have significant reflux symptoms by one year of age.

Eric Hassell, MBChB, FACP addressed the question about whether is it better to start a child on a PPI first or on an H2 blocker first. Dr. Hassell gave a most informative and entertaining lecture by actually "debating" himself.

Doctors refer to starting a child on a PPI and going to an H2 blocker after healing occurs as "step down" treatment. "Step up" treatment refers to starting an H2 blocker and stepping up to a stronger medication (PPI) if needed. There are pros and cons to step up and step down treatment for acid reflux.

Pro's of using Step Up Treatment using H2 blockers first and moving up to PPIs:



- H2 blockers work faster than acid blockers (PPIs or Proton Pump Inhibitors).
 - H2s have potential for fewer side effects (PPIs have been associated with: acid rebound, headache, nausea, constipation, diarrhea, gas, abdominal pain and in rare cases, an increase in pneumonia, gastroenteritis, necrotizing enterocolitis, C.difficile infection and Vitamin B12 deficiency.)
 - It is unclear if PPI's are safe for babies since there is evidence that babies under 3 months of age may not have enough enzymes to break down the medication.
 - H2 medications may be used on demand.
- H2 medications are less expensive and come in liquid form, easier to administer to babies and toddlers.
 - H2 medications may be more effective with nighttime reflux control.

Pros of using Step Down Treatment using a PPI first and moving down to an H2 blocker:



- PPIs are more effective for reduction of acid, healing of the esophagus than H2 Blockers.
 - Use of H2 blockers may lead to tolerance or tachyphylaxis so the drug stops working.
 - H2 blockers may lead to susceptibility to infections and acid rebound hypersecretion (overproduction of acid when the medication is stopped).
 - PPIs are safe for long term use with children.
 - PPIs lead to long term healing of the esophagus.
 - Those who benefit from long term treatment with PPI's may avoid surgery.
- PPIs may be used as a diagnostic test to see if the patient has reflux.
 - It can be cost effective to use the most effective medication first, avoiding additional doctor visits and medications.

Step Up versus Step Down is indeed an important issue to parents and physicians and certainly more research and friendly debate is warranted. The bottom line is: there is no one size fits all treatment and more research is needed to study which method works best for which children.

Integrative Medicine and Pain Control: Lecture at American Academy of Pediatrics, Atlanta, Georgia, October 7, 2006

This lecture was done by two speakers who work in unique pain control clinics. Timothy Culbert, MD is at the Children's Minnesota Integrative Medicine Program and Dr. William Zempsky is at Comfort Central at Connecticut Children's Medical Center. The lecture began with a lesson on integrative medicine which is a philosophy of incorporating conventional and complementary or alternative medicine (CAM), teaching the patient to be a collaborator in their own care, and using mind/body/spirit techniques and natural, less invasive approaches when possible. Hospital based pain clinics are traditionally the jurisdiction of the anesthesia department with assistance from other disciplines. Integrative medicine programs are often independent programs that bring dozens of practitioners together. They offer services beyond the traditional surgery and post surgery pain services offered at most hospitals. Comfort Central takes this concept several steps further and offers services like massages to every child in the building, no matter why they are hospitalized. Their services are often paid for by insurance.

Complimentary and alternative medicine techniques are becoming more widely accepted. Studies at pediatric offices show that 2-30% of children are using some sort of non-traditional medicine. Kids with chronic medical conditions are

even more likely to use these techniques – studies show 30-70% of them depending on how you measure. It may also depend on where you live and your doctor's personal beliefs – a study in Ohio and Minnesota showed the 73% of female pediatricians and 58% of male pediatricians consider themselves to be “believers” in CAM.

Because there are few studies of CAM techniques in children who have GERD, practitioners often have to use logic and clues from other conditions. For example, if a technique has worked for adult patients with constipation, it might make sense to try it for GERD in children. Decisions should be based first on safety and second on the likelihood that it might help. Both lecturers stressed that it is completely unfair that children's pain is so drastically under-treated. Because untreated or under-treated pain has been proven to have serious long-term consequences, all children deserve to see pain specialists if their disease treatment leaves them in pain. Integrative pain specialists may have a larger bag of tricks to try.

It is very important to let your primary care physician know if you are using CAM, especially herbal therapies as they can interfere with other medications.

Google as a Diagnostic Tool? – Maybe

For several years doctors have been using computer programs (clinical decision support systems) that take a list of symptoms and suggest a possible diagnosis. Google has become a popular tool for patients who are seeking a diagnosis. A group of researchers decided to put Google to the test and see how often it suggested the correct diagnosis. They used challenging medical cases from the New England Journal of Medicine and asked doctors who did not know the correct diagnosis to use Google to find possible answers. “Googling” your symptoms can be quite helpful IF you figure out the best words to search on. But you still need to sift through a lot of junk to find that one nugget of gold. Google doesn't do that for you. Read more about this at <http://www.bmj.com/cgi/rapidpdf/bmj.39003.640567.AEv1>

Acupoint Stimulation Reduces TLESRs

A group of researchers from South Australia are experimenting with ways to stop transient relaxations of the Lower Esophageal Sphincter, an important mechanism involved in reflux. They applied tiny electrical currents to the wrists of 14 volunteers so did not have GERD, just occasional relaxations of the LES. They chose the wrist because it is an acupuncture point for decreasing nausea. The 14 volunteers were monitored and they experienced fewer inappropriate relaxations of the LES. More studies need to be done to see if this technique leads to fewer reflux events in people who actually have GERD. <http://ajpgi.physiology.org/cgi/reprint/289/2/G197.pdf>

Excessive Milk Production Mimics Reflux

Do these symptoms sound familiar? They could be a sign of reflux or a sign that mom is making too much milk. It can be hard to tell the difference. Consult your doctor or a lactation consultant to help you sort it out.

- Baby cries a lot, and is often very irritable and/or restless
- Baby may sometimes gulp, choke, sputter, or cough during feedings at breast
- Baby may arch and hold himself very stiffly, sometimes screaming
- Feedings often seem like battles, with baby nursing fitfully on and off
- Baby may seem to have a "love-hate" relationship with the breast
- Baby may burp or pass gas frequently between feedings, tending to spit up a lot

Read more about overactive letdown and overabundant milk on this La Leche League site: <http://www.llli.org/FAQ/oversupply.html>

GERD and Bad Breath

Doctors in Brazil studied adults with indigestion and GERD to see why patients with GERD often have bad breath. The researchers found that patients on PPI treatment were more likely to have GERD and they speculate this could be due to bacterial overgrowth that sometimes happens with low stomach acid. [Oddly, parents of children often report the opposite – their children have bad breath when the reflux is out of control. We are not trying to confuse you, just show

you that there isn't always one "right" answer.]

<http://www.gi.org/media/releases/ACG%2006%20Halitosis%20and%20GERD.pdf>

Apparent Life Threatening Events – Check for Reflux and Low Iron

Dr. Ramond Pitetti is an emergency room physician in Pittsburgh. He has been studying infants with Apparent Life Threatening Events or ALTE's who stop breathing or have pauses in breathing. Many of these babies are brought to the emergency room after their parents witness them choking or not breathing. According to Dr. Pitetti, the good news is that most of them start breathing spontaneously following an event. But he still pays close attention to these babies and hopes they will help us learn why babies who die of SIDS don't revive themselves. He has found quite a few are suffering from low iron and suspects some have low serotonin levels. Children with the lowest iron levels were most likely to have had multiple apparent life threatening events. He also finds that quite a few have reflux although vomiting during an episode is a common event in babies, even in those who do not have reflux. Some babies reflux first and then choke while others go limp for a minute and their stomachs empty due to the limpness. It can be quite a challenge to figure out what happened in those panicky seconds. Dr. Pitetti always recommends checking iron levels and will often recommend that babies with reflux who experience a scary choking event be kept upright at all times. *Prevalence of anemia in children presenting with apparent life-threatening events.* PubMedID 16204136

Caregiving Causes Physical and Mental Stress

A study of caregivers who provide care for sick adults found that providing care takes a harsh toll. Nearly three quarters of those surveyed said they didn't see and doctor when they should and over half said they would like help with logistics and admitted that they were not asking for the help they needed. The study was conducted by National Alliance for Caregiving (NAC) and Evercare, a division of United Health Group.

<http://biz.yahoo.com/prnews/060925/nym043.html?v=71>

Organizational News

Care Central and PAGER bring you the Caregiver Tool

It is so hard to ask for help and keep in touch with friends and family when you have a sick baby. We found a way to make your life just a little bit easier.

We often tell our members to keep a list by the phone of practical ways that you need help. If somebody calls for an update, hit them with the list and sign them up for a task. But what if you are too exhausted to talk on the phone or you can't hear over the baby's shrieking? There is way to set up a secure, private web site in just a few minutes. On that site you can post medical updates and a list of ways that you need help. Is the baby going to the doctor for a test next week? Let your family know and recruit a babysitter for your older child at the same time. If you don't have time to create or update the site, let a friend or relative do this for you. The tool is very simple and you don't have to be a technical wiz.

The Caregiver Tool is for any health problem or event. Be sure to send this link along to anybody you know who is facing a major health issue. Find the link by going to www.reflux.org and looking for Caregiver Tools on the main menu on the left. It is in the GERD section.

Other web site improvements

Do you want to find other what other parents are saying about medication, formula or a medical test? Now you can search member profiles and the discussion forums on reflux.org. Not all members fill out their profiles so you will find more results on the forums.

Here are some search tips: If you are looking for very broad results and want to see every posting on a topic, type multiple words into the search bar and then click "Any Words" (For example, [fundoplication fundo surgery] with "Any words" will get you dozens of postings on surgery, regardless of which term the poster used. If you get more than 20 results, you will have to click "Next 20" to see them in batches of 20.) If you want a very narrow search, put in several words and then click "All words." This will get you just a few postings that contain all of the words. (For example, use [hiccups teething drool] to find a post with all these terms that you remember reading but can't find.)

The web site now has a home for old newsletters. More back issues will be posted as we have time.

Be sure to check Jan's weekly blog.

2006 Kids Create. Parents Relate. National Drawing and Coloring Contest for Tummy Aches

It was an honor to co sponsor the 2006 Kids Create. Parents Relate. National Drawing and Coloring Contest for Tummy Aches with TAP Pharmaceutical Products, Inc.. PAGER directors, Beth Anderson and Jan Gambino helped with the judging. The quality and variety of the entries was very impressive. Winners will be notified soon so visit the PAGER website at www.reflux.org for the names of the winners. A combined total of more than \$35,000 in educational prizes were awarded to the 12 winners of this year's contest. Congratulations to all of the wonderful artists!

TAP will be supplying us with calendars for all PAGER members. Be sure we have your mailing address.

Excerpts from the press release:

The Pediatric Adolescent Gastroesophageal Reflux (PAGER) Association and Prevacid® (lansoprazole) created the Kids Create. Parents Relate. National Drawing and Coloring Contest for Tummy Aches in 2005 to encourage children to use drawing and coloring as a tool to communicate health issues to their parents. The contest was designed to help educate parents and children about gastroesophageal reflux disease (GERD), also known as acid reflux disease, in the pediatric population by encouraging children to draw or color how they feel when experiencing frequent stomachaches or other pediatric GERD symptoms. ClubMom® and Kaboose™, two prominent online resources for parents, joined as partners in the 2006 contest.

"It can be difficult for some children to describe how they feel using only their words," said pediatric gastroenterologist Susan Maisel, M.D. "Hopefully, the contest helped to give parents, children and healthcare providers a communication tool to use when dealing with health problems, such as GERD. It is also important to raise awareness about the symptoms of pediatric GERD, a common yet often overlooked condition."

Both winners' artwork will be included in the Kids Create. Parents Relate 2007 Calendar, along with the artwork of the other 10 winners. Additionally, all the winners' artwork will be featured on www.prevakids.com through next year. "There were so many wonderful entries, it really was difficult to pick a winner," said Beth Anderson, director of PAGER. "The grand prize winners did a fantastic job conveying painful symptoms they experience."

Volunteer News

A big Thank You to our wonderful PAGER Parent Volunteers who contributed over 1700 hours of service during the past year. Parent volunteers answer phone calls and emails from parents, coordinate support groups, give out literature at conferences and parenting events, speak to moms clubs and assist with fundraising. Some of the volunteers work behind the scenes by monitoring the Parent Forums on www.reflux.org and assisting with office work, writing materials and maintaining the database. We are grateful to our volunteer accountant, David Schriver for providing a much needed service to our organization. The PAGER Board of Directors need special recognition for their ongoing guidance and tireless work.

Meet the advertisers

Our newest advertiser is FLAVORx, the folks who bring you the wonderful flavorings that help mask the taste of icky medicines. Here is an excerpt from the advertiser profile. You can read the whole profile at www.reflux.org, in the Products section of the reading room.

...I started the company out of love for my youngest daughter Hadley who was born with a seizure disorder and cerebral palsy. The medicine that was so crucial to her existence was intolerable to her which made it impossible for her to take. My family was in the hospital repeatedly because Hadley was not getting the medication she so desperately needed and would start having seizures. My father and I owned a pharmacy and knew that flavoring medicine had been done for hundreds of years just never in any sort of systematic way. So we took Hadley's Phenobarbital and some concentrated candy flavorings and started to work with them to see if they could make the medicine palatable enough

for her to swallow. We tried different concentrated flavorings, and finally after several weeks we found that Hadley would accept the banana flavor and although she didn't love taking her medication but she took it without complaint. This was the start of FLAVORx...

From the Trenches

Excerpts from three postings by a mom whose child complained of burning feet

My 4.5 year old complains a lot that her feet are on fire. She is always begging to take her shoes off in the car b/c her feet are soooo hot and especially at bedtime too she cries that her feet feel on fire. Sometimes she will lick her hands and try to cool her feet down by putting her spit on them. I used to think this was nothing...and just placated her by wrapping her feet in a cold rag or putting sarna lotion on them. Both seem to give her some relief. It has become such a big and constant issue these days I started to research "burning feet" on the internet and came across the term peripheral neuropathy...I think that is what she is experiencing. I wondered if it could be a side effect of the PPI and if I need to be concerned about it. We have been on PPI pretty much since 9 months of age and increased it to 15 mg twice a day back in Spring. Now I can't remember if the complaining coincided with the increase or not. Anyway I am sick at thinking of now having one more thing I am going to have to explore with doctors and put my daughter through more crap than she already has had to deal with. Any feedback would be appreciated.

I posted about a month ago asking if anyone's child complained of Burning feet I did talk with my pediatric GI and he said yes he had heard of that but it was rare but he knew I had a scheduled an appointment with a pediatric neurologist and told me to tell that doctor to run a B-12 blood test on my daughter. In the meantime I had been researching B-12 deficiency and found that use of PPIs over two or more years can cause B-12 deficiency b/c dietary B12 needs acid to be absorbed by the body and long-term PPI's can deplete the stomach of the acid needed to properly absorb B12 from food. I also found that a Urinary MMA/Creatinine Ratio Test (uMMA) was a superior test for detection of Vitamin B12. Now this is a non invasive test done from a random spot urine sample. The neurologist did not order that and I found a website www.b12.com that allows you to send a sample overnight to a lab in Ohio and have it tested. In my research studies show that many blood tests for B12 are inaccurate and the Mayo Clinic now uses the urinary MMA test to better diagnose B12 deficiency. I had never heard that long-term use of PPI's could cause B12 deficiency and I have to wonder why physicians are not putting children taking PPI's on vitamin B12 supplements that do not need stomach acid to be absorbed. And if I understand correctly B12 supplements are very safe??? I hope to have some answers this week!

Just wanted to post and let everyone know that I did have a follow-up appointment with my daughter's ped neurologist and ped GI. They were both very receptive to the fact that I had a uMMA test done on my daughter showing that she was mildly B12 deficient. My pediatric GI said he is not completely convinced that the PPI is the cause of the B12 deficiency and my daughters symptoms of neuropathy in her hands and feet but he did think we should take her off PPI for a while and also give her B12 supplements by Nascobal (B12 nasal spray) and retest her in a few months to see if her B12 levels have come up. Interestingly enough, since stopping the PPI last week my daughter has not complained about burning feet or hands so I think it is possible that the PPI was the cause. It will be interesting to see what her B12 levels are in a few months and if her neuropathy symptoms completely disappear while off the PPI. He has her dosing the B12 nose spray as one spray per nostril every 4 weeks. It does appear that B12 deficiency is considered rare due to prolonged use of PPIs but I suspect that there will be more studies coming out over the next few years that may show it is more prevalent than once thought for people on PPI long-term (2-3 years or more). Especially if more doctors start using the uMMA test over the traditional B12 blood test.

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Important Details

We need your current contact info

Every time we send a newsletter, we get a lot of bounced messages because people switch e-mail accounts. 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

Get the practical help you need

Volunteers are standing by to take calls from parents. Our 40 amazing volunteers are well-trained and all have gerdlings of their own.

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 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.

Why ads?

Because they help defray the cost of our web site, newsletter, volunteer training, travel to medical conferences and insurance. If your corporation wants to sponsor an issue or place an ad, please contact us.

Why subscribe?

When you [subscribe](#) to Reflux Digest, you receive FREE news about GERD as well as advance warning of meetings, contests, new publications, etc. If you are receiving this newsletter directly from PAGER, you have already subscribed. If you got this newsletter from a friend and want one every quarter, go to www.reflux.org and register for a newsletters.

Why Join or Donate?

When you [join](#) PAGER or make a [donation](#), you are allowing us to offer much-needed support and information to parents and patients. You also help us to be able to collect the cool information we bring you. Donations are tax deductible. Suggested donation is \$25+ to call yourself a "supporting member"

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Spam Free Guarantee

We do not share, sell or rent our mailing list and we do not place pop-up ads on your computer. PAGER makes a small request for donations in every newsletter and we will send you one e-mail per year asking you for a year-end donation.

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