



Reflux Digest

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Happy 15th Birthday to PAGER Association!!

In August, 1992, I wanted to find other parents of children with reflux so I could learn from them. I was told by a local gastroenterologist that I would never find 10 parents in the DC area because the disease was too rare. I decided to take out a small ad in a local parenting magazine anyhow. I was desperate to find other parents who understood what we were going through with a sick baby who never stopped screaming.

Fast forward 15 years. . .

Reflux is now considered to be one of the most common childhood medical problems. Our web site at www.reflux.org is the most popular site for reflux on Google and we are being contacted by parents from all over the world.

In many parts of the country, parents have a basic concept of acid reflux in children. But in some areas, children are still suffering too long without a diagnosis. Look what our members have done to improve awareness in their corner of the world:

- Kim Fernandez wrote several articles on GERD including two for her local newspaper – The Washington Post.
- Sara Mazer called her local paper and asked to be interviewed. The article in the Gazette article was great.
- Misty White has invited 150 of her closest friends to a private fundraiser. She collected dozens of great items for a silent auction, including a big screen TV and a laptop computer. We plan to put a lot of the proceeds back into public awareness activities in Reno, Nevada.
- Pam Tyler wanted to educate other Speech Therapists and wrote a nice article about pediatric GERD for the American Speech Language and Hearing Association.

- As a Special Education teacher, Jan Gambino knows how important it is for parents of children with Special Needs to learn about GERD. She wrote a great article for Exceptional Parent. She also educated the asthma community with an article in a national asthma magazine.
- Nurse Beverly Byron knew that pediatric nurses occasionally need to be reminded of all the advances in the recognition and treatment of GERD. She interviewed my family and wrote an article for Nursing Spectrum.
- Bonnie Brown discovered that the teachers in her daughter's school weren't familiar with GERD in children. She arranged for a gastroenterologist to come talk to the staff.
- Every year, several of our members write letters to their family and friends and collect donations to be used for public awareness activities.
- We have a display about pediatric GERD that we loan out to members for health fairs in their community.

What can you do to help parents in your community learn about GERD so they can help their children? Can you plan a small event among your family and friends? Can you encourage donations when you send out your holiday letters? Can you make a donation to our outreach program? This year, we will be reaching out to the Spanish Speaking community.

Over the years, several hundred volunteers have contributed to the success of PAGER Association. Over 70 have received training to answer phone calls and e-mails. This issue of Reflux Digest introduces you to about half of the current volunteer pool. I asked them each to tell you a little about themselves and why they got involved in PAGER. These amazing folks are the heart and soul of PAGER Association.

Beth

Organizational News

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.

2007 accomplishments list

- The PAGER website had a phenomenal increase in web traffic this year. Web traffic just hit 950,000 page views per month with total hits over 1.6 million per month.
 - Google Links = 1,750,000
 - Yahoo Links = 136,475,632
 - MSN Links = 32,335,406
 - Blogrolling Links = 479
 - Total Links = 170,561,517
- The web site now has 300 pages of content and 31,000 discussion postings. Over 40% of the traffic on the site is to the discussion forums. That translates to over 680,000 messages viewed each month.
- By the end of the year, our volunteers will log about 1500 hours for a total value of nearly \$30,000. (You are worth \$18.04 per hour according to the federal government.)
- 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 2007 Kids Create. Parents Relate. Coloring and Drawing Contest with TAP Pharmaceutical Products Inc. for the third year in a row. (If you want a calendar, we need your mailing address.)
- Reflux Digest, 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.
- 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.
- 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.

PAGER Association goals for 2008 include:

- Website Development: Our goal to develop a mirror site in Spanish. This is very expensive and we are seeking corporate sponsorship.
- Parent Education Materials: There is an ongoing need to develop parent education materials, particularly low literacy materials.

- Public Awareness of Pediatric Acid Reflux: Through ongoing outreach to parents and physicians, we can increase public awareness of gastroesophageal reflux, leading to prompt diagnosis and appropriate treatment.
- Volunteer Training: With the revision of the Volunteer Training packet, PAGER Association is ready to train new volunteers. We hope to train several Spanish speaking volunteers in 2008.

We have been able to accomplish quite a lot this year. Please help us accomplish even more in 2008 by making a donation. You can do so by visiting this site:

<https://www.networkforgood.org/donate/MakeDonation2.aspx?ORGID2=521800883&PcaItemId=9574&SOURCE=SI&XDEG&CMPGN=SCB>

Medical News of Interest

Preventing Nighttime Acid Breakthrough

Researchers from Depomed have been looking at nocturnal acid breakthrough in adult patients who take proton pump inhibitors. In order to prevent night time acid breakthrough, they experiments with giving one evening dose before dinner and another before bedtime. They confirmed that some patients who take a single dose before dinner don't seem to get enough of the drug into their blood stream for it to be effective. In other adults who took a single dose, the medicine wore off at about 2 am. A second dose at bedtime protected the adults from acid breakthrough in the wee hours of the morning. Those same patients didn't receive as much protection if they simply took a double dose before dinner. Depomed is developing a pill that can deliver two doses, one immediately and one four hours later. Watch for more news. <http://investor.depomedinc.com/phoenix.zhtml?c=97276&p=iro-newsArticle&ID=1048046&highlight=>

Counseling Helps Caregivers Stay Healthy

A researcher from the New York School of Medicine studied two groups of adults who were caring for a relative with Alzheimer's Disease. One group was given extra support in the form of free family counseling sessions, attendance at a support group and phone counseling as needed. The other group was offered only "usual" care – they were given information if they asked for it and didn't participate in counseling or support groups. The first group had fewer health problems. "Individualized counseling programs that improve social support for caregivers can have many indirect benefits, including sustaining their physical health," said researcher Dr. Mary S. Mittelman.

http://www.med.nyu.edu/communications/news/pr_243.html

Severity of Reflux

In an interview of physicians in five countries, researchers found that doctors tend to divide adult reflux patients into three broad categories: (1) Patients suffering from 'long term, disrupting GERD, having higher physical but also psychological impact: Patients suffered from GERD for a long time and have symptoms that are disrupting daily life. These patients have already had complications like reflux esophagitis or they are perceived to be at high risk for complications (2) Patients suffering from 'recurrent, distressing GERD,' having psychological and physical impact: Patients' GERD symptoms keep coming back and they start to become worried or anxious. (3) Patients with 'inconveniencing GERD,' having lower impact of the disease: Patients experience symptoms of GERD that are not continuous and perceived to be mostly related to lifestyle.

<http://www.medicalnewstoday.com/medicalnews.php?newsid=73468&nfid=rssfeeds>



PAGER Association is pleased to be an endorsing organization of National Family Caregivers Month and a part of this campaign to bring attention to the needs of family caregivers. National FC Month, celebrated every November, is a nationally recognized time set aside every year to thank, support, educate and celebrate more than 50 million family caregivers across the country currently providing an estimated \$306 billion in "free" caregiving services. In celebration of National Family Caregivers Month 2007, family caregivers are encouraged to take action to improve their own health and well being by speaking up for their rights. Help support family caregivers to take steps every day to make their lives easier, improve the care they give their loved one and convince others to speak up about the assistance family caregivers need and deserve. NFC has a new book called, A Family Caregiver Speaks Up ... It doesn't have to be this hard (http://thefamilycaregiver.org/caregiving_resources/lovehonor_and_value.cfm)

Is Maintenance Therapy Needed After Healing Esophagitis?

A group of Italian researchers studied children with GERD who had erosive esophagitis to see if they needed to continue taking medication after the esophagitis healed. In the small study of 48 patients, it didn't seem to matter whether the children took a half dose of PPI, a full dose of an H2Blocker or no medication after the esophagitis healed. Only one re-developed esophagitis after healing and three others developed very mild reflux symptoms.
PMID: 17319927

Patient to Patient Sharing

Swedish nursing researchers interviewed twelve adult patients who had undergone fundoplication surgery for GERD. The patients were asked to talk about their experiences, thoughts, feelings, consequences of the disease, making the surgery decision, the surgery and the post surgery period. The adults who were interviewed said they wanted information about surgery and possible side effects not only from a health care provider, but also from patients who had the same surgery. "Our respondents emphasized that they were satisfied with the preoperative information they had received, but also pointed out that it was hard to imagine the consequences of the operation. They expressed a wish to have this information from former GORD [GERD] patients. As some of the respondents had had inquiries via telephone from prospective surgery patients, there seems to be an urgent requirement for anticipatory preoperative information."
http://ask.lub.lu.se/archive/00011331/01/nilsson_etal_J_Adv_Nurs_2002.pdf

Ask a Medical Librarian

The medical librarians at the Patient Education Resource Center at the University of Michigan Comprehensive Cancer Center conduct searches for patients and families seeking information on complex medical issues, state-of-the-art treatments, and rare cancers. A patient satisfaction survey demonstrated that the librarians were able to find information that the families were not able to find on their own. This information often affected the medical decisions they made.
PMID: 17443254

Motilin Drug Being Developed

Erythromycin is an antibiotic that also increases intestinal motility and is sometimes used as a GERD medication for patients who do not get relief from acid reducing medications. Researchers have developed a variation of the erythromycin molecule that only affects motility through the motilin receptors and does not have any antibiotic properties. Kosan Biosciences has started Phase I trials with the drug PF-04548043.

H2 Blockers Associated with Mental Decline in Older African-American Adults

Several years ago, researchers studying Alzheimer's Disease noticed several years ago that some medications seemed to prevent or delay the development of the disease. Early studies indicated that histamine 2 blockers might be helpful. More recent studies show that using histamine 2 blockers actually might do more harm than good. A new study of older African-Americans showed that those who used H2 blockers were more than twice as likely to develop dementia symptoms. This particular study was covered extensively in the medical press and alarmed many parents. At this time, there are several contradictory studies and none of them were conducted with children.
PMID: 17661965, 15386717, 11882746, 10851364, 10322244

EE vs GERD or EE + GERD?

Researchers in Texas have been studying adult patients with GERD and eosinophilic esophagitis (EE). They propose a theory that the two diseases are intertwined and can be present simultaneously. In an unrelated study, researchers are using a genetic test of eotaxin-3 levels to try to distinguish between the two diseases. This new test may be more helpful than counting the number of eosinophils in an esophageal biopsy sample.
PMID: 17531015 and PMID: 17900656

A New Symptom?

Researchers in Spain were studying night sweats. They found at least two patients whose episodes were triggered by acid reflux rather than hormone swings, infections or lymphomas. [Do any parents see this in their children?]
PMID: 17907900

Meet the Volunteers

Some of the parents on the message board started a THANK YOU thread to the PAGER volunteers.
<http://www.reflux.org/reflux/webdsc01.nsf/vwID/VASV-797KEY?OpenDocument>

My name is **Lynn Brown** and I live in Derry, NH.

As a volunteer, I answer emails and in the next couple of months I will be starting a new support group for the southern NH area. Currently I am a stay-at-home mom to three beautiful children, but prior to that I was a group counselor. Volunteering for PAGER has been extremely rewarding for me as it allows me to dust off my counseling skills and act in a supportive role to other parents. One of the many reasons why I decided to volunteer for PAGER is due to the support and education that I received from the volunteers and parent forums after my second child was born. He still has reflux, now almost three years old, but also had delayed gastric emptying that he grew out of at two years of age. I had felt alone and it was such a relief to find a community of people who were not only supportive, but truly KNEW what I was going through. I hope that I am able to provide someone else with that same sense of relief through my role with PAGER.

Stephanie Doersam, email volunteer from Linthicum, MD

Before my kids were born I worked as a pediatric physical therapist. I knew of reflux generally but didn't know a lot of specifics and didn't "look" for it. I still work as a therapist part-time but I am now known as the "reflux queen." I know how to spot them. Many of the kids we work with have feeding issues. I help the parents rule out reflux as a cause of the reflux although more times than not reflux becomes a major factor in the feeding issues, irritability, etc. I also think I've become a more effective therapist by understanding the stress and difficulty that a baby who doesn't fit the mold can bring.

Katya was a miserable baby. I really thought something was wrong with me, after all I wanted this screaming little monster. Why didn't I like her? I have since learned that there are many many mothers who look around and think that everyone else is obviously very happy with their babies and they must not be all that good. Well, I'm at PAGER to dispel the "Motherhood Myth." Being a Mom is one of the most rewarding things but at the same time it's hard and we don't have to always like it. That doesn't make us bad Moms it makes us real Moms. I think by admitting it we are better able to deal with the stressors of everyday. While I think this myth and the misery that goes along with it applies to many parents, I think parents of children with disabilities are most affected. Anything that I can do to help a parent get through another day without feeling like a horrible parent is worth it.

I really enjoy getting emails and knowing that I'm helping. I think so often no one wants to admit they have a miserable child/baby. I make that okay. I'm an anonymous ear. Often times I think allowing the parents to express their fears and "horrible parent" thoughts is more important than anything.

Carla Williams, parent volunteer, Temple, TX

I originally got involved with PAGER a few years ago. I was emailing moms on a Yahoo message board (fundo families) and a message was posted regarding reflux and PAGER. A few years later, my son was to undergo his second fundoplication and I decided at that point to become a parent volunteer. There was a vast amount of information I had not been told by doctors and nurses regarding my son, I wished I had been armed with questions and confidence prior to his surgeries.

The most rewarding part of being involved with PAGER is to know there are two wonderful moms out there dedicated to making sure this organization continues to run, and I am able to contribute. I also like being able to offer support to parents who just want to vent. I typically feel more comfortable conversing with someone regarding surgery, but I would hate to limit myself to just that sort of call.

Demi Isenstadt, answers e-mails and phone calls from Hingham, MA

Prior to becoming a volunteer for PAGER, I was a parent struggling to find help and support for my second son who had silent reflux. A feeding therapist whom we were working with suggested I take a look at the PAGER website. It was only a matter of time before I was hooked! I thought my second child would be a cake walk but little did I know that GERD is a difficult situation that affects all involved. As soon as the opportunity came to become a volunteer I gladly did the training to be of some help to mom, dads, caretakers, etc.

I was formerly an elementary school teacher and have my masters in elementary education and special education. Before my first child was born I was a first grade teacher for three years at a private all boys school in Brookline, MA.

Being a volunteer has been an important part of my journey with my situation with my son. I hope that I can offer some advice, suggestions or empathy that can help a mom or dad just make it through the day. This organization is filled with parents who are truly dedicated to helping each other and it has helped me tremendously just knowing you are "not the only one" enduring this disease.

Pam Tyler from Newark, Delaware - PAGER member since 1998, volunteer since 2002.

I use personal and professional experience as a mother of a GERDling and speech/language pathologist with experience in feeding disorders to:

- Provide support services through phone contact and electronic mail.
- Monitor PAGER website discussion board.
- Write article on feeding therapy for the website as well as additional articles on feeding topics for the newsletter.
- Write articles/provided presentations to increase awareness of the feeding concerns related to GERD for other speech language pathologists
- Volunteer recognition article from ASHA (American Speech Language Hearing Association) Leader December 2003
- Poster presentation Recognizing Gastroesophageal Reflux in Young Children American Speech Language Hearing Association convention November 2004
- On-line article Gastroesophageal Reflux in Young Children published May 2005 on speechpathology.com

Volunteering for PAGER has been an incredible experience for me both personally and professionally. Personally, I have had the opportunity to heal old wounds. Even with my professional experience in dealing with feeding problems, I felt helpless in dealing with my daughter's GERD and her subsequent feeding problems. Sharing my experiences with my own daughter and passing along information to other families in similar situations been very therapeutic for me. Professionally, I have developed a greater understanding of what it is like to have a child with special needs, which has helped develop greater empathy for the families I work with as a pediatric SLP.

Just knowing there were other families going through the same difficulties our family was going through really made a difference for me. I felt far less isolated after reading stories about other families' experiences in the newsletters

My name is **Amy Arnold** and I am a parent volunteer for PAGER.

I talk to parents of refluxers via e-mail and the telephone since I am located on the west coast, far from PAGER headquarters. I was a chemist and am now in graduate school pursuing a degree in health care (which I put on hold for two years while dealing with my own refluxer). PAGER was instrumental in enabling me to get my daughter's case of reflux properly diagnosed, for which I am forever grateful. I wanted to become a volunteer because I was so confused, depressed, and frustrated as a parent trying to find answers. I figured I wasn't the only one who felt that way, and now that life has calmed down substantially, I can try to help other parents who need information or just someone to commiserate with.

Tammy Yeh, Sacramento, CA

I am a volunteer who is trying to put together a group of mothers/families in Sacramento, CA to give people information about PAGER and VATER Syndrome (which my son has). I am available by email, telephone, and mail and look forward to hearing from anyone going through reflux issues and other problems, even if just to chat.

I remember I was looking on the Internet for information about the VATER Syndrome since no one really knows about it and found that PAGER had more information related to the symptoms Colin was having. I know he is going to have more future issues and discoveries that we don't even know about yet, but when I connected with Jan, she gave me hope that I was not alone. Jan stayed in touch with me during the period of time Colin was in the hospital, when he came home, and even now as I have become a volunteer. It just feels good to know there are other people in this world going through the same or similar situations and that we are not alone, and do not have to be alone, either.

My son (Colin Michael Soucy) was born on Thanksgiving morning and I had hoped that it was going to be a normal pregnancy considering all the appropriate tests were done with the doctors and there were no indications of any problems. Unfortunately for me and my son, there were serious complications and I had my first cesarean section to give birth. Then came the telephone call from the surgeon, stating he made an error during surgery on my son - that he

cut my son's trachea in the wrong location to begin with during the time that he should have been cutting the esophagus, and my son had gone without oxygen for "several minutes" (which we came to find out was 7 minutes), that he was being placed in the neonatal intensive care unit at University of Davis Medical Center, in an induced coma to keep him from moving and the surgery sites time to heal.

There is so much more to this story but what you really want is probably not to hear all of that. Any way, jumping forward, Colin was released from the hospital in July 2007 finally and so far minus a close call with refluxing, he is doing wonderful and I am still surviving.

During the time Colin was in the hospital, I started looking up the information about his feeding issues and other problems related to his stomach and found PAGER which is where I am today. Without meeting Jan and feeling comfort during my times of need, I don't know what I would have done to survive Colin's days/nights in the hospital. Even now, just knowing I can go to the website and look up information or get in touch with Jan brings me peace of mind. That is why I want to help out another family/person and I even put a flier together for Colin.

Rose Roccamo is a trained parent volunteer from Bucks County, PA

I typically take e-mail calls for frustrated mothers of children relating to all aspects of reflux - sleep, meds, weight, etc... I remember a woman who contacted me a few times a day for months. She told me she could not have gotten through that time without my support. I love giving help to others after knowing how much I needed it, and had to learn it all on my own.

Kelli Nemer, Potomac Falls, VA

I became involved in PAGER to help others. When my children were diagnosed with reflux there were not support group to go to and it was really great to share your experiences with someone who could understand and have applicable suggestions. Most of the communications I do is through e-mail and phone calls. We also have support in our meetings however, not all make those on a regular basis. It is very rewarding when you provide a suggestions and you get a call or e-mail that state Thank you, I did that last night and guess what it provided some relief to my child!!!

Stephanie Petters, PAGER parent volunteer from Atlanta, GA

I am a SAHM and tend to volunteer my time to things needed in the community as well as to Attachment Parenting International. Prior to being a mother, I was a Resource Scheduler, Project Manager, and Quality Assurance Manager in the computer industries.

PAGER was my lighthouse in the stormy waters of reflux and food allergies with my daughter. Through their parent support forums I felt supported, comforted, and realized I wasn't alone. I also developed confidence in myself as a parent and in regards to advocating for my daughter so that I could more effectively get quality medical care for her reflux and food allergies. Through PAGER's enormous amounts of articles and reading materials, I was able to answer my questions, my doctor's questions, and able to bring materials to the office that solidified my stance in getting results. I truly couldn't have lasted those years without PAGER and will be eternally grateful to this organization. It was with this gratitude that I decided that I wanted to help other parents who were me a few years ago. Who were lost in the dark without support and in danger of burning out. I wanted help guide them to the lighthouse for safety and security. Unfortunately, too many demands came upon me and I had relinquish this role but I see my strobe still being able to flash in the future.

I remember walking down memory lane with a mother who was in contact with me through email and then meeting her at monthly meeting and seeing what a difference the information she received meant. How just sharing a cup of coffee connected us those few months in regards to a shared mission... providing the best for our little angels. This mom needed information and support since her firstborn didn't experience these things. She was able to "just hang in there" and to know that soon "this too shall pass". Her season did end and her child did outgrow the reflux. Thankfully.

Moira Callaghan made/took calls and e-mails from parents of children suffering from GER/GERD before her family relocated to Moscow, Russia

Before I gave birth to my daughter, now six, I was teaching in an elementary school (grades 1 and 2). While I had planned on staying home with my daughter before she was born I was not quite prepared for the challenges I would face in caring for an infant suffering from GERD.

When my daughter was diagnosed with reflux I began reading anything and everything I could about it. Through my internet research I came across a dated LLL article that provided some suggestions on how to nurse a child suffering from reflux. In desperation I decided to phone the author hoping the number listed was still valid. That phone call changed everything for me. It turned out I had contacted the former LLL leader and serving PAGER board member Laura Barmby. Her sympathetic ear and supportive words were just what I needed. She ended the call by promising to mail me some information and politely asked me to make a donation to PAGER and perhaps consider joining. Within hours of receiving the packet in the mail I pored over the information, joined the organization and was a daily visitor to the website. I took advantage of the volunteer support PAGER offered, which helped me through a very difficult year. By the time my daughter was 13 months I became a volunteer myself.

Over the years I have talked with numerous parents of children suffering from GER/GERD. I often wonder if my words have been helpful. In the past year I had to relinquish my role as a PAGER volunteer due to an overseas move. Shortly after I arrived and settled in I received this message. It meant a lot to me:

"Dear Moira, You may not remember me but about a year ago you gave me some fantastic advice that got us through the nightmare we were having with our daughter's reflux. I thought you might like an update. She is now 18 months old and still on medication. She is doing really well. The medicine has the reflux completely under control now. My friend recently had a baby and has had some difficulties (not reflux related) but when we were talking about what got us through it all your name came up. I really can't thank you enough for the support and advice you gave us. I'm sure you stopped me from losing the plot altogether. You certainly gave me the strength and confidence to keep going back to the doctors until someone listened."

Anette Pic is a volunteer who lives in Delaware.

I joined PAGER over 8 years ago when my daughter Rebeca at 5 days of age almost died from a severe reflux episode. Two hours after she nursed I laid her down to change her diaper. When I picked her back up her nose and mouth were filled with regurgitated breast milk. Her chest collapsed and she turned blue. She was rushed by ambulance to the hospital where we spent the next three days. These episodes continued for many months to come. One night in a desperate attempt to find out as much as possible about reflux I found PAGER at about 2:00am. Although I emailed a list of questions I did not hear back. So I sent my money in to at least get a news letter. In the mean time I had contacted the Leche League and was given Laura B.'s name and number....ALAS I also found a human voice for PAGER. I spent the next several months on the phone with many PAGER staff members in an attempt to understand reflux. In the mean time we discovered out then 2 year old as had reflux not the "over sensitive gag reflex" we were told she had. Beth and Laura also kept encouraging me not to give up. I found a great GI doctor who saved Rebeca because she was refusing to eat at 4 months due to severe esophagitis. She had been internally bleeding since birth and had finally decided it was not worth the pain of eating. Laura gave me the suggestion to nurse her while she slept. I did and it work most of the time but I never slept. To complicate matters Rebeca had central apnea and obstruction apnea. After about a year I decided to start giving back to PAGER because I never would have made it without their help. I have four children all of whom have reflux in varying degrees. My youngest is 4 and he is currently battling stomach ulcers and esophagitis.

In my spare time I run kids here and there. I also am the President of the Children's Celiac Support Group at the A.I. duPont Hospital for Children. During all of the reflux stuff with the kids I found out I have celiac disease.

I also wanted to make sure I mentioned that Beth's help when I was learning about reflux was huge! You provided me with so much emotional support as well as great advice and suggestions. I would not have made it without you and Laura and Jan. I honestly do not feel I have helped anyone as much as you all helped me.

My name is **Jennifer Rackley** and I live in Harrison, Arkansas. Mommy to: Melina (7/24/02) ~ Reflux free! Ella (5/3/05) ~ Current refluxer and Ava (5/3/05) ~ Never had reflux!

I mainly answer e-mail questions and check in on the message boards from time to time. Before our first child was diagnosed with reflux I was a clinical nutritionist working in the rehab setting. After the birth of our daughter Melina and the reflux problems that followed there would have been no way to continue working! I was very blessed to be able to stay at home with her and now with her twin sisters (one of whom also has reflux).

I got involved with PAGER because I wanted to be able to help other parents who were dealing with reflux. When our oldest Melina was "in the thick of it" I always felt misunderstood. Melina was "failure to thrive" and could have died without proper treatment! Even with everything we were going through the majority of the comments we received were "well, all kids spit up". No one understood why last minute plans didn't work well for us or why we couldn't have her around people who had colds. It was very isolating and I never want another parent to feel like they are alone in this struggle!

Over the years I have gotten way more back than I have ever given with regard to volunteering for PAGER. The parents continually validate the things that I went through with my girls when they tell me their own stories. It is very rewarding to offer a suggestion to a parent and find out that your suggestion led to a happier baby! I had one mom tell me that she finally felt like someone understood what she was going through. That meant the world to me.

Being a PAGER volunteer opened up a whole new world of resources to me as well. One of our twins Ella was diagnosed with reflux after an apnea episode. As Ella got older we found she also had delays in large motor skills. Jan Gambino was one of the first people I contacted. Jan shared her child's story and got me in touch with another PAGER volunteer who was a physical therapist, Stephanie Doersam. Stephanie gave me some wonderful information and I was able to get Ella into PT here in town through a state funded program. I am thrilled to say she is running circles around us now!

Thank you Beth and Jan, for everything you have done in establishing PAGER! I look forward to working more with PAGER in the future!

Donations

Faye Blanchard and Alejandro Pinzon sent a donation in honor of Andres, "Thanks, Jan for all your help and support."

From the Trenches

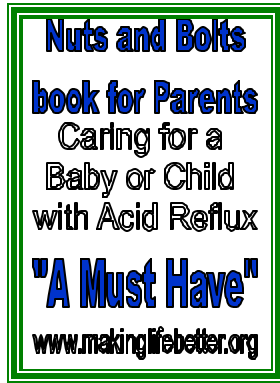
Here's a cute story for from Anette Pic. I have had my daughter Rebeca's reflux wedge for over 8 years now. It had been passed around often but has collected dust for the last 4 years. Since we just finished our basement and storage space is less I decided it must go. I tried to donate it but good luck finding someone willing to take used medical equipment. I put it out at the trash last night. Rebeca saw it and gave me 100 questions on why I would get rid of it. I assured her it served many children but it was time to say goodbye to the wedge. Later that night my phone rang at 9:30 pm. A neighbor who provided us with so much support when we were going through the roughest time with Rebeca called to ask if that was the wedge out at the curb. I sheepishly said yes waiting for her 100 questions. She asked if it was in good condition and I said "yes". She then told me how her daughter had just had her 4th baby in June and he was a refluxer and was already on prevacid. She asked if I would please walk out and get it from the curb and she would pick it up in the morning to mail to her daughter. Well, the wedge is now on it's way to Utah! I told Rebeca in the morning. She smiled and was happy to help someone but sad to see the wedge go.

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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. We had so many bounces this year we were temporarily blacklisted by a two of the big ISPs. 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.

Get the practical help you need

Volunteers are standing by to take calls from parents. Our 23 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"

[JOIN](#)

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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.

Forgot your screen-name or password?

Drop us an e-mail from the same account you used when you signed up.

Contact and Subscribe info

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