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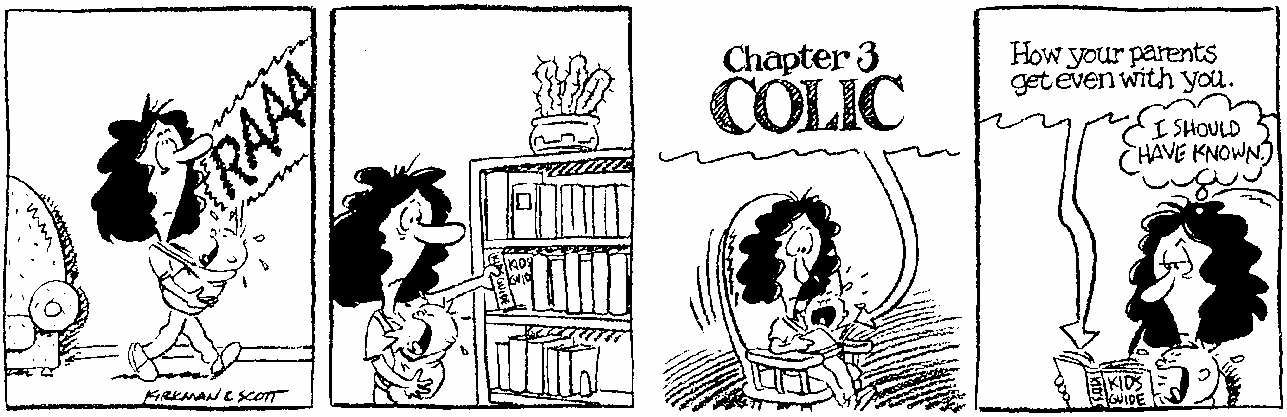

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From the Editor's Desk

Dr. Judith Sondheimer wrote an editorial in the Journal of Pediatric Gastroenterology and Nutrition this July titled, "Am I a Heretic if I Don't Believe in GERD?" She is concerned about the fact that the definition of GERD seems to be poorly defined and creeping. In the first paragraph, she discusses a recent video produced by the North American Society of Pediatric Gastroenterology, Hepatology and Nutrition:

> *The video is excellent and worth recommending to parents. One issue raised, but not solved, by the video is the distinction between infant reflux and GERD. The video says that infant reflux "crosses the line and becomes GERD if the baby has "serious" symptoms such as food refusal, failure to thrive, emesis of blood, breathing problems or dysphagia. Where did this concept come from, and is it legitimate?*

At least a few other pediatric gastroenterologists are asking similar questions. In 2001, Dr. James L Stutphen wrote a very interesting editorial in the same journal. This is the first paragraph:

> *In the past few years, I have noticed a decrease in the number of infants referred to my practice for evaluation of colic. Simultaneously, there has been an increase in referrals of young infants with gastroesophageal reflux disease (GERD). Often, these children are already receiving therapy with*

acid suppressors or prokinetic agents when they reach my office. These healthy infants, of whom many would have had a diagnosis of colic 10 years ago, have usually been referred because their reflux has not improved with therapy. They are referred for more aggressive treatment and further diagnostic investigation of what the parent and referring physician believe is "severe GERD." A decade ago, I would have been the one to decide whether a diagnostic workup of GER was indicated, let alone treatment. Could it be that my "epidemic" of GER represents a simple reclassification of colic as GER?

Both of these editorials bring up the question of whether the definition of GERD is creeping appropriately or not. This is a legitimate question as medications should not be given when the risks of the medicine outweigh the risk of damage due to the condition. Both of these doctors are upset by parents demanding treatment for symptoms that the doctors consider not worth medicating. *"One person's reflux-induced colic is another person's fussy baby,"* says Dr. Sondheimer.

As parents, it can be distressing to watch scientific debates, especially when our children are involved. We were able to laugh when scientists decided that Pluto isn't a real planet and many comedians used this in their monologs. But it isn't half as funny when the debate involves what is reflux or what is colic.

When you have been reading journal articles for many years, it becomes clear that these debates happen all the time. Sometimes the definitions change slowly as doctors start to use a new definition and the new one becomes more common than the old one. Sandifer's Syndrome is a good example of a gradual change in the definition. Sometimes the debates take the form of meetings where medical experts all propose definitions and then put on gloves to duke it out. . .

On August 6, 2006 an international group of adult GERD experts declared that they have arrived at a new official definition of GERD. The definition was developed over a two-year period using an internationally accepted and scientifically sound process (modified Delphi process). You will never guess what they came up with… Gastroesophageal Reflux Disease is *"a condition which develops when the reflux of stomach contents causes troublesome symptoms and/or complications."*

The World Organization of Gastroenterology strongly endorses the new definition and calls it an "important development in a critical area of gastroenterology worldwide."…. Interesting how the new adult GERD definition looks almost identical to the definition of pediatric GERD that PAGER has been using for many years – reflux that causes problems. So now how do we define "problems?" Or "troublesome?"

So if reflux is hard to define, is colic any easier? Not a chance. In the olden days, colic meant a spasm of any hollow organ of the body. It could affect the stomach, intestines, ureters, kidneys or fallopian tubes. [See Ask.com] Colic in horses is a surgical emergency.

In the 1950's a definition written by Wessel and Illingsworth included an infant *"who develops violent screaming attacks in the evening . . . his face flushes, his brow furrows, and then he draws his legs up, clenches his fist, and emits piercing, high-pitched screams. . . Each attack lasts five minutes or more. . . The attacks occur at regular intervals. . ."*

Colic in infants has been blamed on many specific intestinal problems from lactose intolerance to gas, but putting infants with colic through testing usually proved fruitless. At some point any notion of what causes colic was dropped and it simply became the word to use when a baby cries excessively for no (known?) reason. Wessel's Rule of Threes began to be used and several variations exist – crying for (at least?) three hours, three (or more?) days per week. Sometimes, the definition will include starting at three weeks (?), lasting thee weeks (?) or lasting (up to?) three months (?). All the question marks show areas of debate.

Mushy words like colic and reflux are hard to define with hard science. The debate will no doubt go back and forth for a long time. Doctors refer to this as the pendulum swinging. First doctors think reflux is rare, then they think it is extremely common, then they think it is over diagnosed…… We have a page on reflux.org with some of the more interesting citations that are available on the web regarding reflux and colic. [See the Reading Room]

I don't suppose the line between colic and reflux would be any clearer if we changed from Wessel's Rule of Threes to Beth's Rule of Sixes? This is meant to be funny, not serious! Don't send me letters about how unscientific it is.

Beth's Rule of Sixes – completely unscientific

If you can answer yes to six of these, maybe it isn't "just" colic...

Your baby cries six hours a day
For six days a week
It has been going on for over six weeks
The neighbor six doors down can hear the screaming
You tried six formulas or cut six foods from your diet if nursing
You and your baby need six changes of clothes per day
It takes six hours to feed six ounces
Your baby never sleeps for more than 60 minutes at a time
Your baby spits up six times after each bottle
You keep wondering if you overlooked a 666 birthmark
At the last six appointments doc said "colic" or "babies just cry"
You dread driving anywhere more than six minutes away
Your baby belches like a six year old
Six hours alone with the baby is the max anybody can take
You do six loads of laundry a week - just for you and the baby
By six pm you want a 7&7

Wishing you a few minutes of peace and quiet,

Beth

Medical news of interest

Minnesota Study Shows Very Few Children Diagnosed with GER

Olmstead County is home to the Mayo Clinic in Rochester and the subject of many medical studies to determine how common various diseases are. Several years ago, a study was released showing that many adults in this county have GERD. Recently, researchers got permission to read the medical charts of almost all the children in the county to look for the frequency of gastrointestinal problems. There are two summaries of the study on the web. One report that researchers found less than one child per thousand has reflux documented in their charts in any given year and the other web site reports that more than four children per thousand were diagnosed in any given year. These numbers are quite low compared with other estimates using different methods. Is reflux really so rare in Olmstead County or is it just not being recorded in the medical charts? Any refluxers in Olmstead County – please come forward! *Gastro-esophageal reflux disease in young children: incidence and presentation patterns in a population-based birth cohort. Clinical Gastroenterology and Hepatology. 2006 In Press.* http://lib.bioinfo.pl/auth:Talley,NJ

Oregon Research Shows Pain Level Doesn't Predict Damage Level

A group of adults with GERD were studied to see whether their pain levels could be used to guess whether they have significant esophagitis. This study documents that pain and damage are not correlated. *Heartburn severity does not predict disease severity in patients with erosive esophagitis. MedGenMed. 2006 Apr 6;8(2):6.*

Atypical symptoms are not Unusual

Researchers in Spain did a phone survey of adults with reflux asking which symptoms they have. It turns out that 60% reported suffering from at least one "atypical" symptom such as chest pain, dysphagia (trouble swallowing), belching, dyspepsia (feeling that the stomach is overly full – "indigestion"), globus (sensation of something stuck in the throat), hoarseness, hiccups, chronic cough or asthma. *Prevalence of atypical symptoms and their association with typical symptoms of gastroesophageal reflux in Spain. Eur J Gastroenterol Hepatol. 2006 Sep;18(9):969-975.*

How important is bile reflux?

A team in China studied a group of children with acid reflux and a group of healthy controls to determine how many had bile reflux or high levels of gastrin. The refluxing group was divided into those with reflux esophagitis (RE) and those with non-erosive reflux disease (NERD). Both bile reflux and gastrin levels were more of a problem for the kids with NERD than for the healthy kids. Those with RE had even more episodes of bile reflux and higher gastrin levels. The authors speculate that bile and gastrin may be important factors in the development of GERD, NERD and RE. *Roles of bile and gastrin in the pathogenesis of childhood gastroesophageal reflux disease. [Article in Chinese] Zhongguo Dang Dai Er Ke Za Zhi. 2006 Aug;8(4):287-90*

Oral and Dental Issues in Children

A group of children with reflux were compared to a group of healthy children. The investigators noted a significantly higher rate of dental erosion, salivary yeast and salivary mutans steptococci in children with reflux compared to the group of healthy children. *Oral and dental manifestations of gastroesophageal reflux disease in children: a preliminary study. Ersin, et al, Pediatric Dent. 2006 May-Jun:28 (3): 279-84. PMID 16805363*

Long Term Outcome of Surgical Procedures

The study compared three surgical techniques for acid reflux: laproscopic Nissen, Toupet and Thal. A group 238 neurologically normal children with reflux were studied. The children ranged in age from 5 months to 16 years of age. For all three surgical techniques, the average surgery length was 70 minutes. . A total of 12 children (5%) had complications during the surgery. A total of 13 (5.4%) had complications after surgery. Six children (2.5%) had to have the surgery repeated. Coincidentally, the surgery re dos were evenly divided: 2 Nissen, 2 Toupet, 2 Thal. Five years later, only 9 children exhibited reflux symptoms (3.7%). The authors concluded that all of the surgical techniques for acid reflux are an effective treatment for pediatric acid reflux. *Long-term outcome of laproscopic Nissen, Toupet, and Thal antireflux procedures for neurologically normal children with gastroesophageal reflux disease. Esposito, C etal. Surg Endosc. 2006 Jun; 20(6) : 855-8. PMID: 16738969*

Organizational News

American Academy of Pediatrics

PAGER Association will have an educational booth at the American Academy of Pediatrics in Atlanta in October. The PAGER staff will hand out information about PAGER to the 5-6000 doctors who attend the conference each year. The staff also sits in on sessions to keep up to date on trends and treatments. Thank you to the Digestive Health Foundation for a generous grant to attend the conference. If you are at the conference, drop by booth 867. The PAGER staff will be getting together with a few local parents one evening. Send an e-mail to Stephanie Petters if you will be in the area.

The Reflux Book

PAGER Association Executive Director, Beth Anderson and Associate Director, Jan Gambino are pleased to announce the upcoming publication of The Reflux Book, a parent handbook filled with information on every aspect of pediatric acid reflux. We will announce the publication date and ordering information in the near future. Many of you have asked us to write this book.

The Reflux Mom has a Blog!

Jan Gambino, PAGER Associate Director has a blog!! No, it isn't horrible disease – blog is short for "web log." It is a bit like an online journal or short magazine column. Jan says, "I hope you will read my blog. It will be a combination of personal stories about raising two children with reflux and my experiences as the associate director of PAGER Association." It will appear weekly on www.reflux.org and on the HealthCentral site www.acidrefluxconnection.com. PAGER will be collaborating with HealthCentral on several other exciting projects. More next month…..

Korean Television Program on Reflux

In the United States there are very strict guidelines for the cleaning of endoscopes. Korea has recently seen some outbreaks of illness traced to dirty scopes and they are trying to put similar guidelines in place. Beth and Katie Anderson were interviewed for Korean television as Katie contracted a severe infection from a scope many years ago.

American Girl Doll Raffle

We have a winner! Ellen Schmidt of Dexter, Minnesota is the winner of an American Girl doll. The raffle raised $300.00 for PAGER Association. Thank you for everyone who participated. Thank you to The Pleasant Company for the generous donation of the doll.

Volunteer News

Jamie Chen was our summer intern. She lives in Maryland and attends Columbia University School of Journalism. Jamie wrote a magazine article, several patient brochures and updated the volunteer manual. She did a wonderful job and we are grateful for her contribution. We wish her luck in her career and hope she will come back and see us next summer!

Carla Williams has been writing letters to stores and foundations asking for donations. Just this week, we received a pledge of support. Let us know if you know of a company, store or foundation that donates money or raffle/auction items. Remember, PAGER Association is a non profit 501(c) (3)organization so all donations are tax deductible.

Volunteer Training this Fall

Now that the PAGER Volunteer Manual has been updated, Jan Gambino will be training volunteers this fall. Trainings take place via phone by appointment. PAGER Association volunteers answer phone calls and emails from parents around the corner and around the world. Some volunteers conduct support groups in their community and develop a circle of support network. Other opportunities include: fundraising, events, office work and speaking to groups such as moms clubs. Contact Jan Gambino at refluxmom2@earthlink.net or 301-601-9541 if you would like to apply.

From the Trenches

Fundoplication Success Story

When we receive positive stories about fundoplication surgery, we make it a point to highlight them.

◆Hi everyone. I usually don't take such effort to get into forums like this, but I felt like I needed to state the benefits to a Nissen and G-tube. My son was born at 27 wks. gestation. He had MANY medical issues, and was life-flighted to Children's medical Center where he stayed in NICU for eight months before coming home for the first time. He had an Ng tube and quickly learned how to pull it out (making me quickly learn how to place it back in.) He came home on 24 different medications, including Reglan and Prevacid. He constantly threw up. He was back and forth in his weight gain and the anguish of placing and replacing that tube daily was really wearing on me. I was TERRIFIED to put him through that surgery!! I did not want to do that to him, he'd been put through enough already. We really had no other choice, he underwent the surgery soon after his first birthday, and though he continued to gag, he never threw up again! He has gained weight consistently, and was able to begin bolus feeding up to 12 oz. at a time. He is now 5 yrs. old, still with g-tube, but trying to take his first bites of solid food. He has all but stopped the gagging, and we are able to give him night feedings with a pump, so that he is more hungry during the day, which makes learning to eat more likely. Every situation is different, and I feel that frustration and fear for all of you, our prayers are with you and your children. Just know that there are benefits to these medical procedures, and that one day of fear can lead to a lifetime of better habits for our kids.

Daycare Concerns

◆POSTING from REFLUX.ORG DISCUSSION BOARD: I go back to work in four weeks and I am worried about how my son will do in daycare. . . Has anyone had experience with their refluxer and daycare? Do you find that the daycares are experienced in dealing with reflux babies?

◆ANSWER: The ladies in the infant room were literally my lifesavers during our worst reflux days. Knowing that Annie was in excellent hands while I was at work was a huge relief. They worked with her sitting up skills trying to get her stomach muscles strengthened which can help reflux. They even brought one person from another room to help with the other babies while they spent 30 minutes trying to get Annie to take her bottles. Her feeding issues (refusal to eat) were issues that her daycare worked with us on until she was around 2. They made stipulations for Annie (allowing her to be supplemented with baby food past 18 month), working with her to be more social during feedings, etc. Granted, she was held back from moving to the next room longer than some kids due to her eating issues, but I was fine with that. Now, she eats like all the other kiddos in her class, and feeding her isn't the top priority of the day anymore. I hope and pray that your daycare experience was a good as ours. Good luck.

Formula formulations? Can they make a difference for a few children?

There have been a number of postings about Ready to Feed vs. Powdered formula. Here are a few:

◆I think this may be our miracle!!! I'm afraid to jump to that announcement just yet, but it's been about a week. The only thing we changed was the formula. We are doing the RTF Alimentum instead of the powder. I just can't believe that it's making that much difference!! I'm getting some sleep and feeling human again.

◆Ready to feed??? No idea at all!! No doctors could even tell us why it made such a huge difference. They basically acted like I was nuts. I've heard that the RTF is exactly measured compared to the powder. Another thought is that it's less airy. Who will ever know? All I know is it took way too long for us to try it, it was an easy fix and it worked. It's well worth the extra cost.

◆My non-reflux kid was an interesting example of this. She could NOT handle the concentrate or ready-to-feed as it made her really spitty, and she was not normally a spitty baby. On the powder, no problems at all. I always attributed it to the concentrated RTF being a bit thicker/richer? But I don't really know why. I suppose some kids might do better on concentrated RTF because they are a bit thicker, so might stay down a bit better? But I think it really just depends on the baby.

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.

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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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