



## A Biliary Diversion Q&A

In the November-December 2001 issue of LiverLink (Volume 8, Issue 6) we ran an informational article on Partial External Biliary Diversion (PEBD) and AGS written by Dr. Karan Emerick who was at Children's Memorial Hospital in Chicago, IL, at the time. In her article, Dr. Emerick discussed results of PEBD in 9 AGS patients and addressed common questions parents have about the procedure. Because parents continue to have questions about the pros and cons of PEBD, we thought it would be helpful to include excerpts from the original article in this issue of Links4Life. Where appropriate we've also included more recent excerpts from a 2006 study of 3 AGS patients and 1 PFIC (progressive familial intrahepatic cholestasis) patient by the Children's Hospital of Philadelphia (CHOP)

and the University of North Carolina at Chapel (UNC; summarized in LiverLink Volume 13, Issue 1).

### How exactly is a PEBD done?

PEBD is performed by making a small incision in the skin of the upper right of the abdomen through which a 6- to 8-inch segment of small bowel is separated from the rest of the bowel. The rest of the small bowel is reconnected together and continues to function normally, minus 6 to 8 inches of length. The separated segment is then connected to the gallbladder at one end and to the skin as an ostomy (just below the surgical incision) at the other end in the right lower abdominal quadrant. Preoperative planning of the location of the stoma is important to avoid interference with the belt line, which is a problem in small children who have a protuberant abdomen.

procedure allows the body to waste bile salts and cholesterol that are being retained by the sick liver. It is possible that PEBD also wastes "other" unnamed products retained from bile that cause itching. The levels of the "other" products in the blood likely fall in parallel to the bile acids and promote relief. The decrease in bile acid levels seen after PEBD has correlated with improvement in pruritis (itching) in the 9 AGS patients who received a PEBD between 1985 and 2001 reviewed by Dr. Karan Emerick. Dr. Emerick and her colleagues think of the mechanism of action of the PEBD as "Super Cholestyramine". All four patients in the CHOP/UNC study experienced rapid and enduring relief of itching, with two adolescents in the study also reporting substantial improvement in the quality of the skin of their hands and feet.

### Why does PEBD work?

By disposing of bile the

## Promote Organ Donation in April

April is National Donate Life Month. According to The Organ Procurement and Transplantation Network (OPTN), as of February 6, 2009, there were 100,678 candidates on the waiting list for an organ transplant in the U.S. Of those, 15,817 were waiting for a liver, 78,380 were waiting for a kidney, 2,767 were waiting for a heart, and 2,012 were waiting for a lung. While only a small percentage of people with AGS need a liver, kidney, heart or lung transplant, the possibility exists and can become critical at any

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### What complications have there been?

Dr. Emerick reported that one patient had minor bleeding at her

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## When's Your Transplant Anniversary?

If you or your child have AGS and I have received a liver or other organ transplant, we'd like to know! Drop us an email with the name of the person who received a transplant, the person's date of birth (just to be sure we have it right), the transplant date, and the type of organ received so we can include Transplant Anniversary wishes in future issues of Links4Life.

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## President's Page

The power of an ocean wave to cleanse and make new is amazing. At low tide we build castles with turrets and moats, scooping and shaping the moist sand to match our dreams. We dig clams, leaving deep holes bordered by wet piles of grit. We draw pictures, write names, and leave prints to mark our passing. Yet within hours the towers, tunnels, mounds, tracks and dimples will disappear. Ocean waves will topple, fill, and level, leaving a smooth gray canvas to shape, explore or simply to admire.



Wouldn't it be magnificent if we had the power of an ocean wave? If we had the power to take away the Tetralogy of Fallot or tiny kidneys, the scarred liver or xanthomas, the itching, the failure to thrive? To take away the AGS?

We try all kinds therapies to help. Take itching, for instance. Who hasn't tried oatmeal baths, milk thistle, silk sheets, ice packs, anti-itch cream, mittens, footed pajamas, magnets, or light therapy? Failure to thrive is another source of angst. To avoid feeding tubes, we'll try protein drinks, milk shakes, fish oil, super calorie shakes, high carbohydrate diets, vitamin shots, you name it. None of it seems to work very well, but at least it makes us feel as though we're doing something positive.



Physicians and surgeons try their hand at improvement, too. They prescribe medications to boost bile flow, bind bile salts and acids, and dull itching sensations. They balloon arteries, patch hearts, reroute blood vessels, and divert bile flow. When organs are compromised and fail, surgeons take the dying organs out and put in healthy ones. Sometimes medical interventions succeed brilliantly, other times they fail dismally. There are no guarantees.

As far as the understanding of AGS has come since Dr. Alagille first wrote about it in the 1960s, there is much that we do not comprehend. I will be the first to admit that I feel embarrassingly powerless when faced with many of the health mysteries my daughter Alaina presents to me. Aches and pains, indigestion, lack of appetite, fatigue – are these associated with AGS or “normal teenage complaints”? I am frustrated and saddened when I hear about a little girl dying during surgery to correct her Tetralogy of Fallot. I share a parent's anger when her teenage son is called a “blue lipped freak” and the confusion of the father of a newly diagnosed infant as he wonders what the future holds for his son.

I fervently hope that in my lifetime we will fully understand this rare disease. That more effective treatment methods will be found so children with

AGS will outlive their parents and go on to have healthy children of their own. That we will know what causes it, so that children will no longer be born with AGS and have to live their life battling its many challenges. That the power of an ocean wave will be ours to take away the AGS, to cleanse and make new the lives of our children so that they have a smooth canvas upon which to shape their dreams.

Until next time,

## Roberta's Ramblings: Alone

by Roberta Smith

It was the 13th of February when I held the hands of



a gal in her late 30's while she was in the middle of a heart scan. Not because she was claustrophobic but because she was full of anxiety and couldn't lay still. She called out to someone, anyone to console her. I asked her about her heart condition and made small talk to keep her talking and calm. I asked her about her kids. There were three. Their ages were 8, 12, and 18. The oldest son was going to go into the Marines. Her youngest son was at home while the others were in school because he was probably not going to live much longer. My heart froze. I wasn't sure what to say to her for a moment. I asked her why. The information I got was so close to home I couldn't speak without tears. Her son had a rare genetic disorder that had taken toll on his little heart.

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*Links4Life is published four times per year for members of the Alagille Syndrome Alliance, a national support network for people with Alagille Syndrome (AGS), a rare genetic disorder. The primary purpose of Links4Life is to provide general information. Links4Life does not provide medical advice, nor does it promote, endorse, or recommend any product, therapy, or institution. Its contents should not be used for diagnosing or treating health disorders. Readers are advised to seek advice from licensed health professionals regarding AGS or other disorders. Statements and opinions expressed in articles are not necessarily those of the Alliance.*

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stoma that resolved in 2 days, one patient developed a small scar from a stitch at the operative site, and one patient developed a bowel obstruction due to scar tissue 1 year after the PEBD and required a second surgery to remove the scar tissue.

**H**ow difficult is the stoma to care for?

The stoma is about the size of a quarter and sits on the right side of the abdomen. A child drains about 60-120 ccs per day (over a 24-hour period) of bile that is collected in a flat small bag (about 4 inches wide and 5 inches long) adhered to the child's skin. The bag is usually emptied once per day, is not visible under even a cotton t-shirt, and never makes noises. The bile varies in color from light gold to goldish-brown to greenish-gold, is somewhat oily, and does not have an odor while in the ostomy bag, but has a distinct odor when the bag is emptied. Children with diversions can live a normal life and participate in whatever they would like to do including swimming (a small patch is placed over the ostomy with a waterproof dressing). Parents find the ostomy easy to deal with compared with not having slept for years and having watched their child scratch constantly.

**H**ow do children feel about the stoma?

Young children see it as part of themselves and adjust well (similar to G-tubes). Older children are so relieved to have the itching improved that they willingly accept it. One 10-year-old patient when asked if he would like to get rid of his stoma 6 months after its placement declared, "Don't even think about it!"

**D**oes PEBD affect liver transplantation in the future?

The PEBD does not have any effect on the child's ability to have a successful liver transplant in the future and is "reversible" should the results be unsatisfactory.

**D**o children need any itching medicines after the diversion?

Most children still itch slightly, especially in the winter and may need some supplemental medication at that time. However, all of the children in Dr. Emerick's study reported a new ability to sleep well, concentrate better and feel better about themselves after the procedure because the degree of itching had improved significantly.

**W**ho should consider PEBD?

**W**AGS patients with mutilating pruritus (Grade 4 itching, which is mutilation of skin with bleeding and scarring due to scratching) and/or patients with excessively elevated cholesterol levels (cholesterol >600 mg/dl) and disfiguring xanthomas who have not had medical therapy. The effect on cholesterol is most marked in patients with the highest levels. The CHOP/UNC study concluded that PEBD is a safe and technically straightforward operation that may be effective for the relief of intractable itching and other symptoms in patients with AGS

**W**hat about an Internal Diversion or Ileal Exclusion as an alternative to PEBD?

The CHOP/UNC study noted that ileal exclusion showed encouraging results in initial reports, but subsequent studies have failed to demonstrate a consistent long-term improvement in more than half of patients. The study further noted that this may be because of an adaptive increase in bile acid absorption in part of the intestine. The study concluded that newer techniques such as ileal bypass require further study before they can be recommended for routine use in patients.

Citations to recent articles on PEBD and AGS:

*Bile composition in Alagille Syndrome and PFIC patients having Partial External Biliary Diversion. Emerick KM, Elias MS, Melin-Aldana H, Strautnieks S, Thompson RJ, Bull LN, Knisely A, Whittington PF, Green RM.*

*BMC Gastroenterol. 2008 Oct 20;8:47. PMID: 18937870 [PubMed - indexed for MEDLINE]*

*Relief of intractable pruritis in Alagille syndrome by partial external biliary diversion. Mattei P, von Allmen D, Piccoli D, Rand E. J Pediatr Surg. 2006 Jan;41(1):104-7; discussion 104-7. PMID: 16410117 [PubMed - indexed for MEDLINE]*



**W**ould you like to be more involved in the Alliance? Do you have time to dedicate to a great cause? Then we'd love to put your talents to work as a member of our Board of Directors! We're particularly interested in new members with a passion for:

- ❖ Creating and coordinating fundraising activities;
- ❖ Cultivating new donors and nurturing existing ones;
- ❖ Designing and implementing our AGS Kids web site;
- ❖ Translating education materials into Spanish and other languages;
- ❖ Organizing and growing an AGS youth ambassador program or speakers bureau; or
- ❖ Establishing a summer camp for AGS kids.

Even if you have a different idea of what you'd like to work on, we want to hear from you!

If you're energized and ready to roll up your sleeves and get down to work, please let us know! Send an email or letter to us telling about yourself and what you'd like to accomplish as a Board member, and a resume (if you don't have one, that's okay), to [alagille@alagille.org](mailto:alagille@alagille.org) or by mail to Alagille Syndrome Alliance, 10500 SW Starr Drive, Tualatin, OR 97062. We can't wait to hear from you!

## 2008 Donors

Thank you so much to all our donors and friends in 2008. Without you we would not be able to accomplish the important work of building a better life for everyone with AGS.

A special Thank You to Digestive Care, Inc., who provided \$13,000 in educational grants in support of Links4Life and AGS2008, as well as The Blowitz-Ridgeway Foundation for a \$10,000 grant in support of AGS2008 and Southern Union Company for a very generous \$10,000 donation in support of Alliance programs and services!

Individuals and organizations that gave \$200 or more in 2008 are highlighted below. You've gone above and beyond, and your generosity and support are invaluable!

We appreciate all of our donors and hope that you will continue supporting our programs and services in the years to come.

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Thank you!

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It was not Alagille Syndrome like my own daughter has, but another syndrome just as rare. I bonded with this mother of three faster in those 15 minutes then I have ever bonded with anyone. When her son was born, she said, the doctors didn't believe he would live to be one year old. Now, at 8, he's starting to sleep more and play less. His body is getting tired and worn down. We talked about the experience of being a parent with a child who is ill, the ups and the downs and the joys and the sorrows. She spoke about how her marriage failed after the birth of her second son and about having medical bills so high that she lost her car, her home, and her financial stability. Here this woman was trying to take care of her own medical needs for 30 minutes and yet every thought in her selfless mind was with her dying son. So much on her shoulders yet so much more to come. Like all of us, the parents, living our lives day by day coping with whatever comes our way anyway we know how. Looking in on someone else's world for just a moment has had me thanking God I wasn't in her shoes at that moment in time. Not because her life was so much different than mine but because she was currently living the moments I have dreaded since the day my daughter was born. I don't know if Alagille Syndrome will take my daughter's life early. She is doing so great these days. But I know that it has taken many lives early and for those of you still hanging on to hope keep hanging on, because you are not hanging on to hope alone. All of the people that you know and for those you meet for just a few moments in time...we are holding on with you.

**Moving?**

...or changing your email address?  
Don't forget to let the Alliance know. We want to make sure you get your newsletter!

Email [alagille@alagille.org](mailto:alagille@alagille.org) and let us know what your new address is. You don't want to miss another issue!



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age. There are several actions that each of us can take to promote organ donor awareness and help increase the odds that our loved one will receive a transplant in the event that one is vitally needed. Here are some ideas from the United Network for Organ Sharing (UNOS):

- Talk about organ donation with your family, friends and members of your community. By giving just a few moments of your time, you can help increase organ and tissue donation.
- Contact your local Donate Life America chapter to see what you can do to help in your area.
- Find articles to publish in newsletters produced by your community, religious, civic or service organization. If you have a personal connection to donation, add your story to the article.
- Order Donate Life items, such as bumper stickers, T-shirts, hats, buttons and more.
- Request a brochure from UNOS or send an e-postcard to your family and friends.
- Discuss organ donation and transplantation in social situations.
- Post a tribute and photo on the National Donor Memorial Web site.
- If you are a transplant patient, recipient, family member or friend and your life has been touched by transplantation, you can tell your story and spread the word about the vital importance of becoming an organ donor:
  - Visit youth groups and civic organizations
  - Speak at schools and centers of worship
  - Write letters to local newspapers and magazines
  - Participate in the National Kidney Foundation U.S. Transplant Games or the World Transplant Games (for information go to <http://www.kidney.org/news/tgames/>).

Celebrate National Donate Life Month this April and make a difference for someone you love!

## Special Needs Care at Care.com

Waltham, MA—December 16, 2008—Care.com (www.care.com) has added caregiving for children and adults who have special needs to its current offerings. The new service provides families in search of special needs care and respite care with a convenient way to find qualified caregivers in their area.

With Care.com's special needs offering, families of children or adults who have special needs can find caregivers that meet their specific requirements. Care.com features detailed caregiver profiles that outline experience level and availability and; services provided— such as feeding, bathing, and transportation—helping families to find the right match for their unique needs. Additionally, profiles outline conditions that the caregiver is experienced in supporting, such as: autism, Down syndrome, developmental disorder and other physical, mental and behavioral conditions.

Special needs and respite caregivers can post a profile at Care.com to look for jobs and find families in their area in need of care. In addition, Care.com features expert guidance for both caregivers and families in need of care on finding the right type of caregiver.

Care.com helps families to find babysitters, nannies, pet sitters, caregivers, housekeepers and tutors through a national network of trusted caregivers. All caregiver profiles are pre-screened by experienced moms, and members can run background checks, listen to recorded references and view caregiver ratings. These aspects of the service provide users an added layer of confidence and security when making important decisions regarding family care needs.

For more information on how to find special needs care using Care.com, visit <http://www.care.com>.



## Happy Birthday!



### January

Hunter Blake Blair	12
Jayron Chaco	3
Carley A. Corbett	18
Tessa J. Derusha	17
Levi Dilts	5
Jeffrey Dubrawski	22
Luke T. Fasano	17
Lauren Gajdosik	18
Kayla A. Garland	19
Heather L. Hansen	26
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Carter Letterman	5
Hanna Peterson	6
David M. Rader	10
Aria Rowley	6
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Jiri C. Solka	3
Cael Stenger	6
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Hannah L. Zinno	13

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Benjamin Doehling	18
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Caroline Hardwick	40
Carine Hendriks	13
A.J. Koller	5
Trenton LaMadline	4
<i>Liver transplant 11/26/2005</i>	
Sara-beth Martin	7
<i>Liver transplant 06/12/2005</i>	
Tessa K. Petersen	6
Connor Quillen	10
<i>Liver transplant 12/20/2007</i>	
Trevon "Tre" M. Rountree	10
Quinn Scholtes	5
Kendall N. Shepard	10
Kristopher R. Stanley	19
Tara Tchalabi	31
Ryan Wilson	17
Jessica Wood	18

Sheena Wood	23
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Breanne Dunn	15
Patricia Espin-Jurado	11
Ross Garrison	18
Ali Gorham	13
Megan Grote	3
David "Cole" Harden	26
Sophia Hermans	2
Rachel Herschmann	11
Susan Heuser	51
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Amanda Marx	16
Ernest Ouellette	21
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Victor J. Rivero	5
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## In Memory

Sheridan Lysette Wilson  
August 8, 2007 — January 6, 2009

Sheridan Lysette Wilson and her twin sister, Suriana Jordin, were born on August 8, 2007. Even before Sheri was born we knew that God was preparing us for an extremely special gift. We understood that God had entrusted her to our care in order to demonstrate the valuable lessons of endurance and joy regardless of adversities we face in life. We can even say she was a mini missionary of sorts.

From the time she was born she began touching lives with her presence without saying a word. Her smile was therapeutic and her waving inviting. She captivated all who met her with just a point of her little finger. She was gifted with the gentlest touch and the warmest gaze.

On January 6, 2009, our Lord saw it best to call Sheri to His heavenly abode. Her loving memories will always be cherished by her parents, Stephen James and Sharonda Lynette; her sisters and brother, Shayna Lynn, Suriana Jordin, and Saul Jeremiah; grandparents, Phillip and Florence Brooks, Vernon Wilson and Beverly Walker, and a large host of uncles, aunts, cousins and friends.

Sharonda Wilson & Family,  
Irvington, NJ



*Sheridan, my baby,  
You've left an impression  
Deeply engrained in our  
souls.*

*Where, once, two made one,  
Now A pair torn in half;  
No longer a whole.  
You'll be missed my baby,  
But we won't mourn  
We celebrate the life you  
shared with us*

*And rejoice that you are now home.  
Kiss Jesus, put in a good word for us.*

*Ask our Father to continue  
to keep and protect us.  
Like a fingerprint you can be found on  
every life with which  
you came in contact.*

*Most memorable your smile  
Always so wide, bright and beautiful!  
How wonderful for Suriana that her  
other half is now her Angel.*

*We take joy in knowing  
that we will see you again.  
We love you my "Sheri" Amour!*

— Mommy



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this newsletter.

## Ashlee's Virtual Walk Victory

Ashlee Ricci took 1st Place in the 2008 AGS Virtual Walk for a Better Life by raising over \$700. When asked about her secret to success, Ashlee shared the following story:

I model for fashion and glamour, but nothing big yet! I do have 25,000 fans/viewers on my MySpace page, though, and I raised the money through my page. These 25,000 people were asked only for \$1.00 in hopes that we could raise \$25,000. I

posted daily reminders and bulletins in hopes to raise at least \$1000, and while we didn't quite get there, we are so proud to have done what we did. I am also very thankful for David Brewer AKA Bubba! He donated over \$300 and made Justen's dreams come true for Christmas (Justen is Ashlee's 9-year-old son who has AGS). Bubba bought Justen a long-awaited ipod, which we never thought we would win from the



Alliance, and a Wii. I have never met this amazing man. He was a fan on my page until he saw my video on Justen. His only son had a rare disease, and died at 18 years old, just after he graduated from high school! It's soooooo important to Justen and I that Bubba be mentioned in your newsletter.

THANK YOU  
**DAVID BREWER**  
AKA BUBBA!!!!!!

## We've Got Mail

Chuck and Nancy Soule report that their daughter Taylor, who received a liver transplant in March 2001, celebrated her 9th birthday in October 2008. Taylor is doing awesome! She is in 3rd grade and doing girl scouts and tap dance and loving life. Chuck and Nancy feel very blessed and thankful to the family who chose to donate a liver.

Billy Couvall, who is 3 years old, had a partial external biliary diversion at Children's Memorial Hospital in Chicago, IL, in January. His dad George reports that Billy is doing great and he sure looks happy in this picture!



## Alliance is Rare Disease Day Partner

On February 28, 2009, millions of people around the world observed the 2nd International Rare Disease Day. The Alliance joined NORD, EURORDIS (in Europe), and over 200 organizations and companies to support this effort. Oregon Governor Ted Kulongoski even granted our request, on behalf of AGS families and the rare disease community, to proclaim this important date Rare Disease Day in Oregon!



# LINKS <sup>1</sup> LIFE

The Newsletter of the Alagille Syndrome Alliance

## Alagille Syndrome Alliance

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WE'RE ON THE WEB

WWW.ALAGILLE.ORG

## Welcome to New AGS Families

A warm welcome to the new families and relatives who have joined the Alliance in the past few months:

Mae Dove, Gentry, AR

Krista Going & daughter Katey,  
Warwick, Queensland, Australia

Tiffany Jensen & daughter Malee,  
Wilmington, NC

Jane Potiez, South Windsor, CT

Katie Vlies, Luxemburg, WI



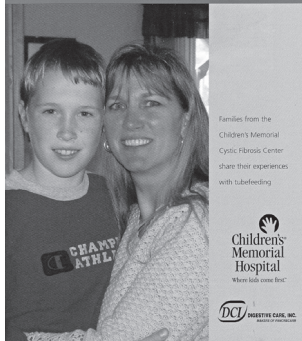
... and an equally warm welcome back to:

Deborah Brown & son Logan Foster, Atherstone, Warwickshire, England

## Tube Feeding Resources

A couple years ago, the Children's Memorial Cystic Fibrosis Center at Children's Memorial Hospital in Chicago, IL, and Digestive Care, Inc., published Supporting Nutrition: Understanding Tube Feeding. This helpful booklet contains personal

### Supporting Nutrition: Understanding Tube Feeding



perspectives from parents and patients who know a b o u t tube feeding firsthand, as well as frequently a s k e d questions, and specific tips to make

tube feeding easier. If you are interested in obtaining a copy of this publication, the Alliance has a limited supply or you can download a copy in pdf format at [www.cff.org](http://www.cff.org) (search on "tube feeding" and click on the document in the search results).

Another useful resource is the Parent-2-Parent.com and RefluxInChildren.com web site at [www.parent-2-parent.com](http://www.parent-2-parent.com). Its section on tube feeding addresses frequently asked questions and includes additional site links. To go directly to the tube feeding section, enter <http://www.parent-2-parent.com/tubefeeding/index.htm> in your browser.

## AGSers In the News



Sixteen-month-old Dylan Pannuto, Sa Harwinton, CT, resident, has been the subject of several news stories lately. He needs a double transplant – liver and kidney – because his kidneys are small and underdeveloped and his liver is severely affected by AGS. Doctors also are testing the strength of Dylan's heart to support major transplant surgery. Fundraisers are being held to help pay Dylan's medical expenses and to help cover the cost of the upcoming transplants. If you would like to help Dylan's parents, David and Vanessa, with their medical expenses, please send your donation to: Webster Bank, 150 Main Street, Bristol, CT 06010. Account Name: Dylan Pannuto Fundraiser. Account Number: 10103019680.

Horatiu and Irina Slavescu live in Romania. Their son Sebi, who was born in 2004, has AGS. In 2006 his condition worsened to the point where he needed a liver transplant and it turned out that his father was compatible as a living related donor. The family went to Cliniques Universitaires Saint-Luc in Brussels, Belgium, for the transplant, which was successful. Today both Sebi and Horatiu are doing well. You can follow Sebi's progress on his blog at [www.alagille.ro](http://www.alagille.ro) (To translate the web site from Romanian to English, use Google Translate at [www.google.com/translate](http://www.google.com/translate).)

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