

LINKS ¹ LIFE

The Newsletter of the Alagille Syndrome Alliance



The Shea Foundation

The Alliance has \$12,625 more to dedicate to programs and services, including research initiatives, thanks to the generosity of The Shea Foundation and the thoughtfulness of one person in particular – Lessie Ann Shea, a Trustee of the Foundation and grandmother to Rainy Reimer.

Lessie Ann Shea's great grandfather, John Francis Shea, opened a modest, one man plumbing shop called the J.F. Shea Plumbing Company in Portland, Oregon, in 1881. From this beginning, the company expanded, the name was changed to the J.F. Shea Company, and in 1933 its headquarters was moved to Los Angeles, California. Eventually the company expanded and evolved into one of the largest and oldest privately owned construction companies in the United States. Today, the company

legacy of family management has remained unbroken for over 130 years and the J.F. Shea Company remains one of only a handful of 3rd and 4th generation, family owned businesses in the United States.

The Shea Foundation is the philanthropic arm of the J.F. Shea Company and Lessie Ann Shea is a member of its Board of Trustees. Ms. Shea also happens to be the mother of Windy Morrissey-Reimer whose daughter Rainy Reimer has AGS. Ms. Shea wanted to do something to help the Alliance, because her granddaughter has AGS, so she coordinated the \$12,625 donation from The Shea Foundation.

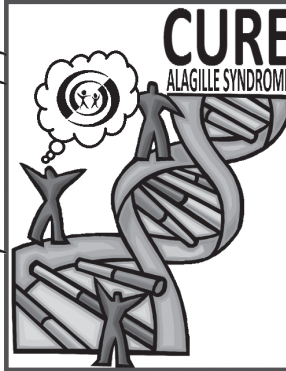


Rainy Reimer just turned two years old and is doing well with height and weight, according to her mother Windy. But, she is struggling with her liver numbers and may be facing the possibility of listing for a liver transplant. Rainy also has heart issues, but they are not too severe right now. Windy says that Rainy couldn't be a happier child!

On an added note, Windy's employer Luxury Link generously hosted an online auction of a travel package last September that resulted in a \$916 donation to the Alliance. And Windy just raised \$290 with her Birthday Wish through Causes on Facebook. This family's generosity and thoughtfulness know no bounds!

SHARING THE JOURNEY

JUNE 24-26, 2011 CHICAGO, IL, USA



AGS2011

The 5th International Symposium on AGS is just around the corner. Now is the time to mark your calendar for June 24-26 and make your travel plans to join the Alliance at the Hilton Orrington/Evanston in North Chicago, Illinois!

At the Alliance we're Sharing the Journey of life with AGS and working toward a cure for this rare genetic condition. We invite you to join us for this once-every-three-years opportunity to learn and play with other AGS families, and to find your place in Sharing the Journey that is AGS.

The registration packet contains all the information you need to register and prepare for AGS2011. We're pretty sure all your questions will be answered in its pages, but if not, we've also provided useful resources to help you. You may download the registration packet from our website at www.alagille.org.

Our past four Symposiums were terrific successes. We expect the same of AGS2011 and plan to make it happen in a huge way!

Whether this is your first Symposium or your fifth, come geared to learn, eager to make new friends, and ready to have a great time. Our growing AGS family is waiting to welcome you!

It's energizing, emotionally charged, enlightening, overwhelming, and exhausting, all at the same time. We wouldn't miss it for the world and know you'll feel the same way!

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President's Page

It's already April and spring has sprung! The weather is improving, my blueberry bushes are budding and the rhubarb has sprouted. Soon it will be time to build some raised beds and plant my vegetable garden. But first, this column needs to be written...

Planning for AGS2011 is in full swing. We are tweeking the program and filling speaker slots, talking about offering discussions for kids based on the Sib Shop model (see related article in this issue), having T-shirts printed, hiring entertainment, and coordinating numerous other details. Registrations have started coming in and I'm getting more and more energized with each passing day! Symposium years are exhilarating and exhausting at the same time, but I wouldn't have it any other way. I hope you plan on joining us – I can't emphasize how worthwhile and unforgettable an event this is. It literally will change your life and that of your AGS family member(s).

Speaking of the Symposium program reminds me to thank all of you who participated in the planning survey we posted on Survey Monkey. A total of 67 individuals completed the survey, providing us with very helpful information about potential attendance, program content, childcare, and other logistics. You had some terrific suggestions, which we've incorporated into our planning for AGS2011. It's awesome to get such a fantastic response!

We have quite a pool of speakers to pull from for AGS2011 as a result of the recent expansion of our Medical Advisory Board (MAB). I mentioned this in my last President's Page, but must admit that I was not prepared for

the outpouring of positive response that we received to the invitations we extended to potential new members. I'm extremely pleased to announce that, with only two exceptions and one substitution, every one of the 10 individuals we invited have joined our MAB! With 15 members, our MAB has essentially doubled in size and now includes individuals with expertise in a wide range of specialties from gastroenterology to transplant, patient registries to genetics, cardiology to physiology to nutrition. This is a terrific group and we will be involving them in a variety of capacities in Alliance programs and services in years to come.

One activity in which some MAB members will no doubt be involved is revision of our AGS in the Classroom booklet. It's been several years since we published this helpful resource and time that it be updated and expanded. We've posted a new survey about the booklet on Survey Monkey that we invite all of you to complete. Also, if you have pictures of your AGS children on the first day of school or in a school setting that you would like to submit for inclusion in the revised booklet, we encourage you to send them as an email attachment (jpg, tif, or gif format) to Richard or Beth Caldwell at recaldwe@verizon.net or brcaldwell@alagille.net with AGS in the Classroom in the subject line. Children may be any age from daycare to preschool, K-12, or university. We'll do our best to include as many pictures as possible.

This is an exciting time. Remember to keep in touch. Send me an email, drop Joe Anderson a message on Facebook, tweet one of our other

Board members – we're always here and eager to listen to your suggestions and share your ups and downs. We're all in this together and we're working hard for you!

With good wishes and a smile,



New Medical Advisory Board Members

Dennis D. Black, MD,
University of Tennessee Health
Science Center & Le Bonheur
Children's Medical Center

Haleh C. Heydarian, MD,
Children's Hospital Medical Center,
Cincinnati, OH

James E. Heubi, MD,
Children's Hospital Medical Center,
Cincinnati, OH

**Binita M. Kamath, MBBChir,
MRCP, MTR,** The Hospital for Sick
Children & University of Toronto,
Ontario, Canada

William Pennock Laird II, MD,
Pediatric Heart Specialists,
Dallas, TX

Kathleen M. Loomes, MD,
University of Pennsylvania School
of Medicine & The Children's
Hospital of Philadelphia

Yaffa R. Rubinstein, PhD,
Office of Rare Diseases Research,
National Institutes of Health

Meghana N. Sathe, MD, CNSC,
Children's Medical Center –
Dallas, UT Southwestern Medical
Center at Dallas, TX

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.

Contributions to Links4Life should be sent to: Cindy Hahn, President, Alagille Syndrome Alliance, 10500 SW Starr Drive, Tualatin, Oregon 97062. (503) 885-0455. No faxes please. Copyright © 2011 Alagille Syndrome Alliance. All rights reserved.

Roberta's Ramblings: Life Happens

by Roberta Smith

This year has started with a bang! Here in Michigan we are still fighting the snow and cold temperatures in late March and however dreary it may seem, the sun has been shining ever so brightly. I can't help but to fight to stay positive when I wake up and start my day with the sunlight beaming off of the snow. I have noticed a slight change in myself over the last few months and can attribute this to having been blessed with the opportunity to share in the lives of a few kids with Alagille Syndrome. I am so thankful and lucky to have the honor of meeting AGS families, even if only through email. I hope that this continues so that I can share their stories with you and so that I can enrich the lives of those fighting the good fight whether it be the parents, extended family members, or the AGS kids themselves.

When my twins Cloe and Claudia were born, I had no idea what was about to transpire in my life. The first 3 years after their birth were the toughest times I have ever experienced. The pure emotional roller coaster that comes with having a child with AGS surpasses all other obstacles I have ever endured. Having begun my journey learning about the family struggles and the miraculous strength of the AGS kids outside of my own family, I have reflected back to the earlier days when I did not know what was going to happen each day when I got out of bed. Learning more and more about AGS and the strength we have to have in order to overcome the obstacles it throws our way, I have decided that I need to take more time to smell the roses. However mild or severe our children's AGS symptoms are we have to take some time to find an emotional release and then smell the roses when the opportunity arises. In 2006, three years after the girls were born, I wrote this poem which reflected the emotional tear I felt within myself with every decision

I had to make for Cloe medically and every decision I had to make to continue to move forward in my own life amidst the struggles. Whatever way you find it, I hope you find it well and thank you for allowing me into your lives!

Ourself...me

It seems as though we pass ourselves when life happens.

Yet, we don't have a moment of clarity unless it's forced.

We are parallel worlds inside ourselves, walking inside our own footsteps until one stops and the other continues without discern.

It's as though we are pulled apart unintentionally without control, life happens.

Like an old skin slowly peeled from our being, without mention or concern, we separate. It's not until we need one another that we notice half of ourself is gone. Suddenly, feeling alone and broken and without the strength to take another breath we have a moment of clarity that spews strength and wisdom. Life happens. It happens to all of us unannounced to ourselves, at the worst of times, at the weakest moments, every day, every year, everywhere around us.

It's within ourselves that we find our peace to go it alone when we must and to pick our other half up or drag it behind when we need to keep moving. We are the skin that is slowly peeled back, that protective overlay that keeps us together, we are one in ourselves. We are strength beyond words or motions. We are far above what we ever thought we'd be or ever could have imagined. We are what we choose to portray, we are how we live, we are how we treat another, we are me... and I choose to live. Life happens.

I choose to live while my children teach me, while my lessons mold me, while my will to overcome all obstacles protects me, while I walk with myself soaking it all in observing whatever I see, so that next time myself leaves me I am aware and conscious of my departure and strong enough to be me.

Roberta Smith, February 2006

Sibshop coming to AGS2011

In our effort to continue to provide relevant as well as new activities for you and your families, we will be holding a Sibshop at this year's Symposium. Sibshops are the brainchild of Don Mayer and Dr. Patricia Vadasy and are focused on the brothers and sisters of children with ongoing special health needs. The basic idea behind Sibshops is that healthy siblings need opportunities to share the things that they love about their siblings with special needs, as well as the challenges they face as a well sibling. More information to come on the specifics of this unique

opportunity, so stay tuned! We look forward to seeing you at AGS2011 in Chicago.

Mark Your Calendar

June 24-26 = AGS2011

July 16 = Gehman Annual Picnic

Aug 15-Oct 15 = 4th Annual AGS Virtual Walk for a Better Life

Sept 18 = Ann "Re" Fernald's AGS Walk for a Better Life along Cape Cod Canal

July 30 = AGS Family Gathering at Legoland in the UK; email tariciabrownlie@hotmail.co.uk for details.





Happy Birthday!



January

Hunter Blake Blair	14
Bryston Burson	3
Jayron Chaco.....	5
Carley A. Corbett	20
Tessa J. Derusha.....	19
Levi Dilts	7
Jeffrey Dubrawski.....	24
Luke T. Fasano.....	19
Lauren Gajdosik.....	20
Kayla A. Garland	21
Avery C. Glenn	3
Heather L. Hansen	28
Mihai Alexandru Hogas	7
<i>Liver transplant 2005</i>	
Brianna James-Beckham.....	17
Mitchell Jelley.....	23
<i>Liver transplant 05/28/1996</i>	
Megan Lavallee.....	15
Carter Letterman	7
Hanna Peterson	8
David M. Rader.....	12
Aria Rowley	8
Jiri C. Solka.....	5
Sebastion Wilson Sorrells	2
Cael Stenger.....	8
Zachary Tilger.....	12
Debra Wilson	41
Hannah L. Zinno	15
<i>Liver transplant 01/16/2009</i>	

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<i>Liver transplant 11/13/1991</i>	
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Caroline Hardwick.....	42
Carine Hendriks	15
A.J. Koller.....	7
Sara-beth Martin	9
<i>Liver transplant 06/12/2005</i>	
Jasmine R. Morris	2
Tessa K. Petersen	8
Connor Quillen.....	12
<i>Liver transplant 12/20/2007</i>	
Trevon "Tre" M. Rountree.....	12

Quinn Scholtes.....	7
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Tara Tchalabi.....	33
Ryan Wilson.....	19
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Anna M. Laurent.....	16
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Amanda Marx	18
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Victor J. Rivero.....	7
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Anthony Strukel.....	13
Raya Tashchieva	5
Abigail Weissmann	11
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Emma J. Burgamy.....	6
Benjamin T. Earnshaw	13
Taeghan Holder.....	7
Olivia A. Huelsbergen.....	2
Jesse L. Isabelle	19
Trenton LaMadline	6
<i>Liver transplant 11/26/2005</i>	
Mateo Marchel.....	19
Christopher McCoy.....	36
Alyssa M. Parker.....	16
Clara P. Sexton.....	10

In Memory

Larsen Grace Purvis

August 17, 2007 - January 25, 2011

Larsen is survived by her parents, Frank Purvis and Tamar Gremillion, and her sister, Courtlyn Faith Purvis, all of Murfreesboro; her maternal grandparents, Stan and Janene Gremillion of Covington, LA; her paternal grandfather, Frank Purvis, Sr of Bethesda, TN; her paternal grandmother, Diniah Butler of Seminole, FL; her great grandmothers, Dorothy Jones of Bartlett, TN, and Marjorie Purvis of Franklin, TN; her aunts, Cindy Gremillion of New Orleans, LA, and Dawn Belair of St. Petersburg, FL, and her great aunt, Judy Miranda of Murfreesboro, TN.



Terri Ann Jacobson Dragony

August 21, 1961 – December 3, 2010

Terri Dragony's son Jacob has TAGS and Terri's family has been a member of the Alliance for several

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years. Terri passed away on December 3, 2010, in Tucson, AZ, after a short illness. She was the daughter of Carol D. Moran of Old Saybrook, CT and Richard C. Jacobson of Newberg, OR. Terri attended Cromwell Schools and served in the US Marine Corps as a drill instructor and an air traffic controller during the Persian Gulf War. Along with her parents, Terri is survived by a son Jacob R. Dragony; and three brothers: Richard Jacobson of Tarrytown, NY, Jeffrey Jacobson of Middletown, CT and Peter Jacobson of Old Lyme, CT. Also by a stepfather, Daniel Moran of Old Saybrook, CT, a stepmother, Leann Jacobson of Newberg, OR and two stepbrothers, Matthew Moran and James Moran, both of Simsbury, CT. Also nieces and a nephew as well as a most special friend, Tina Valente who was with her until the end.

Lauralyn Danielle "Dani" Yonce

December 19, 2007 - March 19, 2011

Dani Yonce, 3, daughter of John Preston Yonce, Jr. and Stephanie Timmerman Yonce of Spring, SC, died Saturday March 19, 2011 at the Children's Hospital of Pittsburgh.

Dani was a native of Edgefield County and was a member of Johnston United Methodist Church. She was the 2010 ambassador for the March of Dimes for the Edgefield Area.



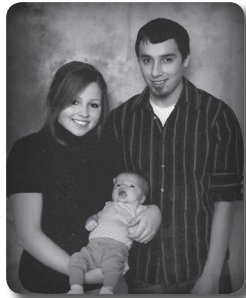
Survivors include her mother and father; her brother Tre's Yonce; her paternal grandfather, John Preston Yonce Sr., Ridge Spring; her maternal grandmother, Joyce Montgomery Timmerman, Edgefield; and her uncle, Jamey (Mollie) Timmerman, Edgefield. Dani was predeceased by her maternal grandmother, Virginia Prescott Yonce, and her paternal grandfather, Jim Timmerman.



Maddox David Rodriguez

September 14, 2010–January 14, 2011

Maddox was born two weeks late on September 14, 2010. We had no idea anything was wrong with him at all. We spent the first month in the NICU where we made lots of memories and got to know our sweet baby boy! The doctors told us he had a heart murmur that should heal on its own and that he probably had Alagille syndrome, due to the facial features, liver, heart and kidney problems. We were devastated but thought everything was going to be just fine. The doctors sent us home for 6 weeks before our next hospital stay, only for Max's heart to work harder and get weaker. What they didn't know, was that his heart valves were way too small, but they failed to see that on the numerous echoes they did.



Maddox was the sweetest little boy! He was so content. He had just learned how to smile before going into cardiac arrest. We miss every little detail about him. He loved watching football with his daddy and bath time was his favorite! He would always flirt and flash a huge smile at all the nurses! He was such a joy to us and we felt so connected to him. We knew he had a purpose but we wanted him here longer. We miss our little boy every day. We are so angry that they neglected his heart and did not do surgery soon enough, yet we are so relieved that he is **SAVED** from the

struggles of Alagille syndrome and congenital heart disease (CHD).

We miss our little man so much, life doesn't seem to get much easier but we take comfort in knowing he is in the best hands and that we will be reunited again one day...

Editor's note: Brooke has a beautiful video tribute to Maddox on her Facebook page. To view it go to: <http://www.facebook.com/?ref=home#!/video/video.php?v=10150182245849009>.

Research Scope

Update from Spinner Lab

at CHOP by Dr. Henry C. Lin

The Spinner Lab at the Children's Hospital of Philadelphia (CHOP) continues to work on trying to understand how genetic changes contribute to the clinical features of Alagille Syndrome (AGS).

Currently, our main focus is on trying to understand the variability of the liver disease. In other words, understanding why some patients have very severe disease, requiring a liver transplant, while others have such mild disease that they have no clinical symptoms. There is no direct correlation between the specific mutation and the severity of liver disease, so we hypothesize that there is something else in a person's genes that modifies the effect of the primary mutation in Jagged1 or Notch2, and we are looking for those factors. For this work, we are collecting patient samples to analyze the DNA while also obtaining clinical data to help classify the severity of liver disease. This study needs as many participants as possible, so we would love to hear from anyone who has not already submitted a blood sample who might be interested. So far, we have over 400 people with AGS enrolled in our database and we need about 800 before we can complete our analysis!

We also have several other AGS



Joey Valente was on KGUN 9-TV in Tucson, AZ, late last year talking about training to earn his blue belt in karate. That's amazing, considering that just two years ago at age 11 he was so sick from his AGS that he wasn't able to travel to California for a liver transplant, but instead received his surgery at University Medical Center in Tucson. Now instead of being focused on survival, he's eating whatever he wants, exercising and training, and celebrating his newly found freedom in life.

Two-year-old Rosie Gill was featured in a story in the Manchester Evening News (by Katehrine Vine) in January. Rosie's father Chris said that she wasn't diagnosed with AGS until she first became sick in the summer of 2010 around the time she turned two years old. According to her father, "... despite operations and ongoing treatment, Rosie takes it all in her stride, and remains cheerful and upbeat."

Patricia Enright turned 18 in October 2010 and is doing quite well with her AGS, according to a story in the Lac du Bonnet Leader (by Lory Mitton). That wasn't the case when she was born, however, and a huge fundraising effort to pay for a liver transplant should Patricia need one began in her hometown and surrounding communities. The effort raised over \$77,000 (Canadian), which was kept in an account called the Patricia Fund for the Enright family to use to pay for the transplant and other medical expenses. Now, because Patricia is unlikely to need the surgery, the Enright family would like to see the money in the Patricia Fund designated to another cause. The family wants to stay true to the initial purpose for raising the money, and the mandate of the Patricia Fund states that, "if for some reason the total or partial amount of the funds raised are not used, then these funds shall

be used for another unwell child(ren) for the same purpose as originally set up for Patricia." The committee that manages the fund has not made a formal decision about distribution of the funds, but is moving to disband in the near future.

The Payne family recently participated in the 6th annual Knightwalk for Babies event at the University of Central Florida (UCF Student Newspaper, Emon Reiser). Their daughter Madalyn, who has AGS, was born eight weeks early and weighing only three pounds. The March of Dimes paid for the genetic test that confirmed Madalyn's AGS diagnosis when the Payne's insurance would not cover the cost of the test. The Knightwalk raised \$5,000 for the March of Dimes. The March of Dimes encourages future volunteers to invite family and friends to walk together to raise more money and share a meaningful experience.

Ann Rea promotes organ donor awareness every year at the Sungold Field Days in Allansford, Victoria, Australia, in honor of her granddaughter Chloe Britton. Chloe, who lives in Perth, received a liver transplant in 1997 at the age of six when she was very sick from her AGS. She is now studying for a Bachelor of Science in exercise physiology and eventually hopes to work with rehabilitation patients. According to the article in The Warrnambool Standard (by Mary Alexander), Chloe did not know how her donor, a middle-aged woman, died, but her parents Ian and Eleanor Britton, had written to the family thinking them for their gift of life. Chloe said, "We usually have a cake to celebrate the liver's birthday each year so I have two birthdays."

Ayden Soong, who first made the news in Singapore when he was born with AGS two and a half years ago, died from complications of a fever in late March. Ayden's father, Shaun Soong, said in an article on Asiaone.

com (by Rae Tan) that Ayden's initial diagnosis was an infection causing the fever, but then his son started coughing violently and vomited blood. His heart stopped beating and Ayden died from internal bleeding shortly after. Doctors thought Ayden's heart and liver condition were stable, so his death was totally unexpected. His mother, Tee Bee Ling, called Ayden her "baby of hope" when he was born because he was not expected to live past delivery. Both parents are shocked and greatly saddened by their loss.

Livers – For Kids

The Children's Hospital of Pittsburgh of UPMC website has some awesome resources for explaining livers to kids. Called Helping Your Child Understand, the website is at <http://www.chp.edu/CHP/dr+lizzie+livertrans> and includes:

- "Dr. Lizzie" Learns about Alagille Syndrome
- Hector's Liver Transplant Story (Narrative & Cartoon Animation)
- Interview with a 15-Year-Old Liver Transplant Patient
- Life Gets Busy for Cody and Nate: Returning to Life after Liver Transplant
- Taylor's Liver Biopsy
- 3D Animation : Digestive System

"Dr. Lizzie" starts like this: "Lizzie wants to be a doctor when she grows up. She sees her doctor more often than most kids, because she has a problem called Alagille's syndrome. This is a disease that can make a person sick. Lizzie is okay, though." The story goes on to tell all about AGS, the liver's job, how bile breaks down the food you eat, and how AGS hurts your bile ducts, as well as provides tips on learning to live with AGS.

This is a terrific resource and we encourage you to check it out!

We've Got Mail

Sari Ost wrote to us about her son Yoav who has AGS, her family,



and Israel where they live. They live about 15 minutes from Tel Aviv. Yoav had his liver transplant at Sent Luc Hospital in Brussels, Belgium, in 2003, and they usually go for follow-up every two years. Yoav's father was his living donor. Routine medical visits are at Tel Hashomer (Safra) Hospital in Israel, near Tel Aviv. Sari knows of only one other family in



Israel with AGS, and they are not seen at the same hospital as Yoav. This

is why she feels "it is so important for me to communicate with AGS families all over the world." Sari reports that "Yoav is doing great." He is almost 8 years old and in the second class of school. Yoav's brother Nadav is 15 and his sister Ella is 11. Sari writes that Yoav "is a very optimistic guy, always with a smile, has lots of friends...Where ever he comes.... everybody likes him: doctors, nurses, teachers, family....It is very hard to be angry of him...."

Shannon Price bought an AGS Awareness bracelet and shared her brother's story with us: "My little brother, Gregory E. Toland, passed away due to complications from heart surgery... His passing happened May 16, 2009... He was diagnosed in the late 1970s with AGS and at that time, no one knew anything about this horrible disease... Since his passing, I have made friends on-line with others who either have AGS or someone in their family... Greg, who lived 32 years beyond what the doctors gave him, lived a normal life... One day, he was walking home from the

bus stop and he passed out... After awakening, 911 was called... It was his heart... The entire next year, he was sent to one doctor after another trying to find someone who knew something about his condition... Finally, Greg was set for surgery... Upon the day of the surgery, they said it would take a few hours... Five hours into it, they came down to tell us that they had to repair something else and all was going well... Around 8pm, we got a call from the hospital telling us that he had gone back into surgery... The next morning, his liver and kidneys started failing... My little brother was living on a machine and there was nothing anyone of us could do to help him... My father had to make the hardest decision in his life and that was to turn the machines off... Since his death, I have found out more about AGS and felt a need to support others who have been touched by this disease... I thank you for having an alliance group for people and families of ones with AGS... God bless all who have AGS and their families..."

Britny Burson emailed to let us know that she had purchased an engraved brick in the Walkway to the Stars at the Space Center Houston's Grand Plaza! The Walkway to the Stars is located at the entrance to the official visitor center of NASA's Johnson Space Center. Bricks in the walkway commemorate a loved one or family memory and support Space Center Houston's ongoing mission to educate and inspire the next generation of explorers. Britny's brick reads: Angels Among Us Cure Alagille's B.A.M. Moms Hero. It is located immediately to the right of a brick dedicated to Gene Krantz, Flight Director of NASA from 1960-1994.

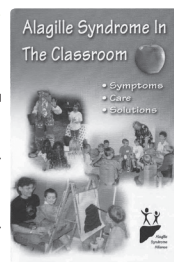


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related projects, including searching for mutations in patients with AGS but no Jagged1 or Notch2 mutation. Our most recent project is to better understand how bile duct paucity develops in patients with AGS. To this end, we are creating cell lines from skin cells of patients with AGS to create cell culture models of bile duct development.

We hope that our current projects will help us to better understand the etiology (cause or origin) of liver disease associated with AGS and to develop more effective treatment methods. If you are interested in learning more about any of the research studies pertaining to AGS, please contact Annie Hutchinson at (215) 590-3316 or via email at hutchinsona@email.chop.edu. We thank you for all of your support.

Share Your Opinion!



The Alliance has a new survey for you to participate in. We are revising our AGS in the Classroom booklet and we need your help! We want to know what information in this popular booklet you've found helpful, looked for but didn't find, or perhaps thought needed some more explanation. To gather your opinions and insights, we've put together a short survey, which you can access by clicking on the link below. Thank you for your time and assistance!

- AGS in the Classroom (<http://www.surveymonkey.com/s/YXRQ8BT>)

If you sell on eBay, donate a % of your proceeds to the Alliance through Mission Fish.
www.missionfish.org

Cameron's Class Goes Green!

by Jennifer Wilkerson, mom to Cameron, Troy, OH

Go Green!! Yes, it's everywhere and my son's school went "Green" on St. Patrick's Day. Cameron is in the 3rd grade at Concord Elementary School. A few months ago his class was discussing kids with disabilities. Cameron decided to talk about his liver disease, how it affects him, and answered some questions. It was amazing for a 9-year-old to be so brave to share it with the class. Well, it didn't end there. His class and teacher decided to raise money on St. Patrick's Day for the Alagille Syndrome Alliance. The students made posters and spoke every morning on the announcements about the sale and about Cameron. On the day before the sale, Cameron spoke himself stating "no matter what syndrome I have, it doesn't stop me from being myself."

On St. Patrick's Day the class sold green and flower leis, green beads and green cause ribbons (Cameron's favorite color). There was such overwhelming support that we sold out!!! A total of \$704.69 was raised for the Alliance to aid in research, education and support of other AGS

kids. Next year I hope to have a bigger turnout and make over \$1000.

Cameron was diagnosed when he was 3 months old and has been under the care of several specialists at Cincinnati Children's Hospital. When he was 18 months old, he had an internal biliary diversion to help reduce his itching and lower his cholesterol. At one point, his total cholesterol was over 2500. His cholesterol numbers are normal now and after several years, his xanthomas have finally disappeared. We are grateful to this day we had the surgery. Right now Cameron is just another kid on the playground, which is the way we have always treated him. He is anticipating Opening Day for his baseball league this April. Unfortunately, he fractured his femur in early March so he will be in the dugout for a few weeks.

I guess the thing to always remember is that it only takes one voice, one great kid, one event to raise awareness and make a difference. I'm proud to say that I am the Mom of one awesome kid!!



Welcome to New AGS Families

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

Arsov Blazhe & son Andrej, Republic of Macedonia

Melanie Bolle-Banks & daughter Kayla, Whitby, Ontario, Canada

Jessica & Chad Brower & son Bryce, Huntingdon, PA

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Bernardo Gonzalez Virgen & daughter, Zapopan, Jalisco, Mexico

Ryan Hall & daughter Malia, Lafayette, IN

Neesha Knox & son Julian Trower, Bronx, NY

Tim & Sabrina Lane, & twin sons Nicholas & Nolan, Marlborough, MA

Susie Lloyd & son Austin, Urbandale, IA

Tyesha Lyon & daughter Kayla Warren, Bronx, NY

Our YouTube Channel Needs YOU!

We know you're creative! Do you have some fun videos of your AGS friends and family to share? Did you happen to capture awesome clips of a memorable event featuring AGS kids, sibs or family members? We would love to see those precious shorts uploaded to the Alliance YouTube channel!

We have tons of ideas, but need YOU to film them...

- Having a fundraiser to benefit the Alliance? Film it!
- Film an interview with your AGS child. You never know what kind of interesting answers you might get!
- Were you or your child on a news spot or talk show? Let us know so we can link to the video from our YouTube channel.
- Set up the camera and film yourself talking about what it's like to be an AGS parent, grandparent, sibling, or other relative.
- Write a song about AGS and film your kids singing it!

Contact AGS Webmaster Erik Luxhoj at agswebmaster@alagille.org with questions or if you need help with filming or uploading your video. He's waiting to be wowed by your creativity!

Charlet Villanueva

Monique Navarro, Baldwin Park, CA

Sheila Postlewate & son Blake (who passed away in June 2010), Shalimar, FL

Kassandra & Simon Ross & daughter, North Rockhampton, Queensland, Australia

Amanda Smith & son Logan DesJarlais, Antigo, WI

Violeta Pavliski Villanueva & daughter Charlet, Hackensack, NJ



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Thank you so much to all our donors and friends in 2010. 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 goes to The Shea Foundation and Lessie Ann Shea, who provided \$12,625 in support of our programs. Several individuals – Deb & Jay Marusich, Tara Moore, Maggie Litton, Patti & Pat Everett – companies and foundations – Southern Union Company, Motorola Foundation, Granite Telecommunications, Matco Tools – and Trinity Episcopal Church each donated over \$1,000 in support. Numerous individuals contributed to our 2010 AGS Virtual Walk, which raised over \$39,000 due to the awesome efforts of Ann Fernald and Team Sophie, Anna Chow with Team Gabriel, Veronika Byers' Team CharLET's FIGHT!, Adriana Glenn and Team BALAA, Patricia Clemens with Team Alison, Joe Anderson's Team Dragonfly, and Britny Burson and Team Bryston. Those of you who remembered to apply for matching gifts from your employers also are deserving of recognition – these requests resulted in an additional \$4,415 in donations in 2010.

Individuals and organizations who gave \$200 or more in 2010 are highlighted below (\$200-499 with "\$", \$500-999 with "\$\$", \$1,000-4,999 with "\$\$\$", \$5,000-9,999 with "\$\$\$\$)", and \$10,000 and above with "\$\$\$\$\$"). You've gone above and beyond, and your generosity and support are invaluable!

We have done our best to compile a comprehensive list of everyone who donated in 2010; but, since we are only human, we may have missed someone. Please be assured that we appreciate all of our donors and acknowledge your generosity whether or not your name appears below. We are sincerely thankful for

your thoughtfulness and hope that you will continue supporting our programs and services in the years to come.

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Do you sit on the Board of Directors of a company or foundation that makes grants to non-profits like the Alliance? Does your employer have a community or charitable grant program that is by invitation only?

The Alliance is always looking for new sources of funding for our programs and services. High priority funding needs are for the 2011 Symposium, AGS Family Days, the Links4Life newsletter, and research, including an AGS Patient Registry and Biorepository.

If you are aware of a source of grant or other monies that you think may offer a funding opportunity for the Alliance and you are willing to help us explore the opportunity, please contact Cindy Hahn at alagille@alagille.org or (503) 885-0455.