

LINKS LIFE

The Newsletter of the Alagille
Syndrome Alliance



2010 AGS Virtual Walk Raises \$39,000+

Year three of the AGS Virtual Walk for A Better Life was a foot-stomping success! Seven teams put in countless hours of planning, organizing, emailing, asking – you name it – to educate people about AGS and raise funds for the Alliance and research. Their amazing efforts over two months – August 15th through October 15th – brought in over \$39,000! An awesome accomplishment!

Following are reports from the teams about their events and the experiences they had as part of this phenomenal fundraising effort...

Team Sophie, Team Captain: Ann “Re” Fernald, Amount Raised: \$19,167.

The central event for Team Sophie was a walk along the Cape Cod Canal in Massachusetts starting at 1 pm on September 19th. Everyone met at the Bourne Scenic



Park tent area, which was decorated with banners and balloons. It looked like one big party! About 150-200 people, including family, friends, recruits from all over - people who donated outside of stores, friends of friends, complete strangers – showed up for the event! Some came with bikes and roller blades. Many of the Bourne Scenic Park campers came by to check out what was going on, and many donated and stayed for the day’s festivities. A few people went the whole walk distance, which was about 14 miles, while others walked shorter distances and then stayed at

the tent area listening to music played by a DJ, enjoying a huge raffle of over 40 items (all donated), getting massages from a massage therapist who donated tips to the cause, and watching many, many boats, yachts and barges going through the canal. Groups of Girl Scouts painted faces and made jewelry to keep the young ones amused. Some of the older folks even got their faces painted, too. There was a FULL sheet cake with Sophie’s picture on it, thanking all the sponsors and walkers. Beautiful baskets donated by some very generous people were given away as door prizes. The weather couldn’t have been any better.

Planning for this event started months earlier with printing flyers, and talking to people about AGS

and collecting donations outside of stores and wherever Ann and her friends were allowed to stand. Ann’s sister Gail Topham held candy and cookbook sales. The cookbooks featured recipes of campers at the Bourne Scenic Park and were donated by a woman at the park who had assembled the book. Ann mailed a flyer and letter to everyone who walked last year (this was the second year of the Cape Cod Canal walk), telling them about this year’s event. They called or wrote to numerous companies and stores about a possible donation of raffle items or gift cards to purchase food for the cookout. Ann and her sister Kris started making homemade cookies and froze them until the day of the walk. They put up flyers in every store in town about two months before the walk.

Ann’s team included her two sisters Gail Topham and Kris Loomer, and her daughter-in-law Heather Fernald. They all worked together as one big team. Many other people helped as well. The Boston Red Sox donated a signed baseball for the raffle. Kayem Franks donated 250 hot dogs. Cirelli Foods helped with a donation of hamburgers. Other stores provided munchies and drinks. Sophie’s



Grampa, a Matco Tool Distributor, held a raffle on his truck. Rob Reera, the Matco Tools District Manager in charge of the drivers from Massachusetts and New Hampshire, got

many of the guys on board holding raffles in their trucks as well. Matco Tools brought in over \$2,000 towards

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President's Page

It's hard to believe I'm already writing the fourth and final issue of 2010. The year breezed by and, as always, was full of ups and downs, much to be thankful for peppered with sad and somber news from our AGS family.

We said goodbye to Michael J. Bozek, Daniel Brenchley, Blake K. Postlewate, Owen F. Siranni, Margo Pattison Menger, Colton R. Huss, Regan N. Altman, and Clara P. Sexton. They all earned their angel wings and are now bright shining stars in the sky above. Many of our AGS family experienced health challenges as well – broken femurs, open heart surgeries, biliary diversions, and extended hospitalizations. It's difficult not to get knocked down by these events and, believe me, I have my "I hate AGS!" moments. But once I've fumed, sighed and breathed deeply for however long it takes to find a silver lining, I manage to rally and then – watch out! I'm more energized than ever to do whatever it takes to find better treatments and a cure for this disease. Our children, from infants to adults, should not have to battle for their lives the way they do with AGS. Life is difficult enough when you're "healthy". I'm setting my sights on the day when we no longer will have an "In Memory" column in Links4Life, or if we do the only people listed in it won't earn their wings until they're at least 100 years old ☺

When it comes to being thankful, my plate is overflowing this year! We received some large matching donations, our families were adventurous and creative with fundraising events, and the 3rd Annual AGS Virtual Walk was wildly

successful thanks to the efforts of dedicated and enthusiastic individuals around the country who believe in our cause. In a year when the national economy is still faltering, a preliminary estimate of Alliance total donations for 2010 is an amazing \$70,000+ - wow! And our year-end campaign is still in full swing. I am humbled by the generosity of all our supporters and grateful for their thoughtfulness and caring.

Anna Chow has become the newest member of the Alliance Board of Directors. Anna, whose son Gabriel has AGS, was featured in "Making a Difference" in the April-June 2010 issue of Links4Life. I first met her at the AGS Family Day we hosted in Placerville, California, in 2006. She brought all these cool toys, favors, and decorations with a fireman theme to brighten the room and give to the kids, and it was so much fun! Anna coordinated the silent auction at the 2008 Symposium in San Mateo, California, which was awesome. And she and her extended family in Hawaii and Colorado joined the Virtual Walk this year, raising over \$7,800. She and her husband Dexter own and operate Cheeky Monkey Toys, a single location specialty toy store, and Anna is the special person who chooses the contents and sends out Kid Kare packages on the Alliance's behalf to AGS kids who need a boost. Anna is a terrific addition to our Board and I hope you will join me in welcoming her to her new position ☺

We are adding more members to our Medical Advisory Board (MAB) to expand the breadth of specialties, as well as the disciplines and occupations represented by

its members. Specialties include cardiology, biliary diversion / ostomy, growth and development, nutrition, nephrology, vascular issues / intracranial bleeding, osteology / skeleton, endocrinology, itching, and patient registry and biorepositories. Some of the ways the MAB assists us include:

- ▶ Advising the Alliance of new advances in research, diagnosis or treatment of AGS.
- ▶ Notifying the Alliance of new medical or scientific articles published on AGS.
- ▶ Participating in planning for the AGS Symposium
- ▶ Attending the AGS Symposium,

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We Value Your Opinion!

The Alliance has four open surveys for you to participate in:

- ▶ 2011 Symposium Planning (<http://www.surveymonkey.com/s/KTJXFFJ>)
- ▶ AGS Research Priorities (<http://www.surveymonkey.com/s/QF55PXF>)
- ▶ AGS and Biliary Diversion Surgery (<http://www.surveymonkey.com/s/MQFFLGD>)
- ▶ Life with AGS (<http://www.surveymonkey.com/s/PJH9X68>)

Logon to the surveys using the web address shown next to each survey above or through the link on our website home page at www.alagille.org. We encourage you to participate and share your comments, opinions, and valuable research information with us!

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 © 2010 Alagille Syndrome Alliance. All rights reserved.

the walk! The Cod Times Newspaper and the Middleboro Gazette ran articles about Sophie and the walk, and two local radio stations mentioned it, too. Ann's mom, Ann Loomer, helped with the door prizes (writing all the names down) and talked to everyone at her place of work.

Sophie had a great time, as did her brother Gavin. Sophie's mom Andrea and dad Matt were very happy that she got to spend the whole day with everyone this year. (Last year Sophie had to leave early to be rushed to the hospital with an intestinal intussusception). Sophie LOVED her cake and helped pass out the door prize baskets. There was so much going on during the day with everyone having a great time for a good cause. The day flew by so fast.

As a result of all Ann's efforts and the success of Team Sophie, more people who had never heard of it before are aware of AGS. That's very important to Ann and all of her team mates - to get the word out. She hopes their walks will get bigger and better as each year goes by, and already has some new leads for next year's walk. At this writing, Ann was in the process of writing thank you cards (which she had a company make with a picture of the cake) to all of the companies, restaurants and stores that made donations. It's important to let these people know just how much they are appreciated and how much they helped in raising money for such a good cause.

Team Gabriel, Team Captain: Anna Chow, Amount Raised: \$7,906
by Anna Chow in California and Kathleen Davis in Colorado

Team Gabriel was a true family affair. Gabriel's paternal grandparents in Hawaii sent out letters to their friends. Gabriel's



maternal grandparents gathered with friends and family in Colorado for a walk around the local lake. In California, we held a Walk 'N Jump, an event conceived by Gabriel. We were fortunate to be joined by two other local AGS families, the Davises and the Brooks. This event once again proved to me the incredible support system we have in our friends and family.

We thought it was important to include Gabriel and his little sister Lia in all aspects of the fundraiser. They wrote a letter asking for donations, they wrote a thank you note, they invited their friends and teachers, but most of all they were present. There are moments in every parent's life when they look at their children in complete and total amazement. I realized that as much as we want to protect our kids from all the things that being an "AGS Family" brings with it, they are willing to rise to the challenge. They are resilient and caring!

I wanted to share an excerpt from an article that Gabriel's grandmother wrote for the local paper. It touched me deeply.

"Gabriel turned eight years old this Fall. Last month when the stomach pain began at a block party, instead of running to his parents or one of the firefighters in attendance, he ran away. Twice.

This is strange behavior unless you know that in those eight years of life our grandson has probably had more shots, blood draws, CT scans, pills, and

specialists than my husband and I in our combined 134 years. Because he doesn't absorb nutrients well, a lot of food gives Gabriel stomach pain, but this time it was bad enough that he didn't want to know the reason.

Gabriel is a smart, imaginative 2nd grader who was diagnosed at 7 weeks with a rare genetic disease identified in the 1970s as Alagille Syndrome. Those first days watching our first grandchild in Neonatal Intensive Care, not knowing why he struggled to breathe at birth or why his jaundice didn't respond to treatment, we all felt as if we had walked into the wrong movie of our lives...

We are grateful for the Alagille Syndrome Alliance, which provides support and information networking to AGS families and collaborates with other liver disease organizations to raise awareness and research funds. Each year the Alliance sponsors a nationwide Virtual Walk month to allow families to raise funds and awareness in their communities.

On Saturday, October 9, our family and friends (Team Gabriel) walked around Evergreen Lake. Our goal was to raise awareness that there are many little known but major health challenges for children."

Team Gabriel Colorado had a beautiful, mild day for their walk. October at 7000 feet elevation isn't always kind! We walked the one-mile loop around Evergreen Lake with our t-shirts and balloons, carrying photos of Gabriel and Lia and handing out brochures on the Walk for Life. Even our dog, Alice, wore a shirt!



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Team Alison, Team Captain: Patty Clemens, Amount Raised: \$1,120
by Patty Clemens

This year for the Virtual Walk we decided to make rubber bracelets that said, "Team Alison" and "Alagille Syndrome Alliance". We sold them for \$2 each, in support of the Alliance and Alison since she is now listed for a transplant. She was listed in June 2010.



We had a "Beef and Beer" event on October 16, 2010, to benefit the Alliance and for our family. The money raised will allow me to take time off of work to be with Alison when she has her transplant and still be able to pay our bills, as I will not get paid while I'm off. I will be using "The Family Leave Act", which allows you 12 weeks off and secures your job position, but does not guarantee pay (you only get pay if you have vacation or holiday time and I have very few hours saved).



We also had friends and family members contribute online.

Alison is very proud of her accomplishment this year for the Virtual Walk, hopefully in the next year or so, we will be able to organize a Real Walk in the Philadelphia area. That is our goal!

Thanks to Cindy, the board and the Alliance for all your support and continued commitment to Alagille Syndrome!

Editor's note: Patty

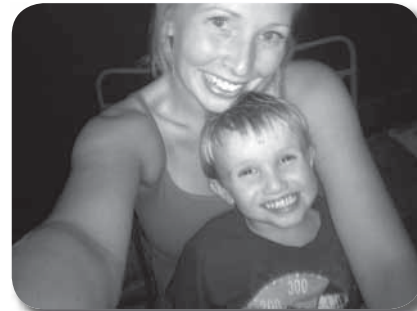


and Alison still have rubber bracelets available. They are two sizes, small and regular. If you are interested in buying one, email or message Patty on Facebook. Money may be sent to: Patty Clemens, 865 Springhill Rd, Secane PA 19018. Anyone wanting to make a donation can do so by sending to the address above. All checks made out to: Alison Kempton.

Team Bryston, Team Captain: Britny Burson, Amount Raised: \$355
by Britny Burson

There's nothing more in this world that I wouldn't do to be able to trade places with my son, Bryston who battles Alagille Syndrome. He has no idea how special he is or the impact he has on everyone who meets him. He truly is an Angel in Disguise.

As a single mom at the age of 27, I am sandwiched between a sick child, a sick mother, and a sick grandmother. It's hard for me to wrap my head around everything going on in my life. My life is like the world spinning on an axle, I wake up every day, get Bryston dressed for school, get myself ready for work, take him



to school, put in at least 8 hours at my job, then head to pick up Bryston from school, get home, get Bryston fed, bathed, and ready for bed. It's the same repeat cycle every day, he is my focus, and he is my world. My life revolves around him. In between our routine days, I make the time to take him to his Cardio, GI, Kidney, ECI, etc. appointments.

I did this fundraiser for Bryston and all other families affected by AGS. I didn't raise a lot of money but I did get the opportunity to raise NATIONAL awareness of Alagille Syndrome, which in my opinion is priceless. I was given the opportunity to speak about AGS on the Ellen Degeneres show. When I originally wrote into Ellen, I wrote about my mom and my son being "ill". I never imagined I would get the chance to be on her stage talking about my son and Alagille Syndrome.

God has given me these things because he knows I can handle it. Life for us has not been easy, and I think any parent can testify that having

a special needs child is not easy. But as my mom always says, "we put on our big girl panties" and we deal with it! I truly believe that in life you have Good and you have Bad. There's always something bad that comes from something good and vice versa. Prime example, my son has Alagille Syndrome (the bad) but he is the most

loving, sweet, free-spirited little boy who teaches you how precious life is and to never take a day for granted (the good).

These Alagille children are truly amazing, and despite how awful this disease is, they are a blessing from God. I know this is only the beginning for us, and I have high hopes to continue supporting the Alagille Syndrome Alliance and raising awareness of AGS.

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

Team CharLET'S FIGHT!, Team Captain: Veronika Byers, Amount Raised: \$6,115

by Veronika Byers (Charlet's aunt)



When we decided to participate in this year's fundraiser, naming the team was so important for us. We wanted to include the disease and of course include Charlet. I was thinking Let's Fight for Charlet but since Let's is already in Charlet's name my mother-in-law blurted out excitedly CharLET'S FIGHT! PERFECT!!!

It was my first time ever participating for a real fundraiser let alone being the team leader. But this fundraiser was different from selling books for school or my cheerleading team. This fundraiser was for the disease that my niece is battling and she is so near and dear to my heart that I wanted to do everything I can to make it a success. My sister, Violeta (Charlet's mommy), was in charge of organizing the park play day fundraising event. I was in charge of doing the fundraiser at my favorite NYC bar, Mug Lounge. The two events were two weeks apart and oh my gosh, was it fun!



Park Play day was held at Van Saun Park in Paramus, NJ. We had food, drinks,

games, in the picnic area and our wonderful local politicians donated free passes to the Zoo, Carousel, and Trolley for all! So many friends and family came and the weather was perfect! It was really a day well spent with family and friends for a great cause!



Two weeks later it was a night out for our friends and family at Mug Lounge. We got there and ahhhhh Keanu Reeves was filming a movie right outside of the bar, so we got to see him – wow is he tall and handsome! We had wonderful prizes to raffle off: Jason Kidd autographed basketball, Yankees autographed baseball, yes Joe we are big Yankees fan! We also got Spirit Cruises Lunch Tickets which is a harbor cruise around Manhattan, US Open Tickets, gift cards to haircuts, supermarkets, Tour of ESPN campus in Bristol, CT, a Mountain Bike and much much more! Plus Mug Lounge was

kind enough to donate 20% of the bar tab to the charity. Thank you Mike!

The events were a major success! CharLET'S FIGHT raised \$6,115 and we couldn't be happier! We had such a wonderful time raising money for Alagille Syndrome Alliance and I look forward to many more years to come! Thanks again to all our friends and family who helped donate and be part of our lives! Thank you, thank you! Be well and God Bless!



Team BALAA, Team Captain: Adriana Glenn, Amount Raised: \$4,490

by Bill Glenn

Team BALAA (Bill, Adriana, Liam, Aidan, and Avery) was thrilled to be able to help raise funds for the Alliance this year. Once Avery was diagnosed with AGS, Adriana committed to the effort to raise money to support the cause. Adriana solicited family and friends who contributed generously to provide the bulk of what we raised. We also benefited from unexpected efforts by Bill's mom in California and by the support from several of Bill's colleagues at Virginia Tech. Bill insisted that we actually walk somewhere, so we decided to hike for 2 miles (since Avery is 2 years old) on the Mount Vernon Trail along the Potomac River. We forgot to take pictures on the trail itself, but snapped a shot of Avery and her brothers snacking during a break at Mount Vernon. We look forward to trying again next year and are happy to have been a small part of the efforts to fund one or more research grants.

Donate Online... It's Easy!
Go & click on DONATE 
www.alagille.org

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 and let us know what your new address is. You don't want to miss another issue!
 See you next issue!

Making a Difference: Teena Gehman

by Teena Gehman

Twenty one years ago our family was introduced to the words Alagille Syndrome (AGS). Children's Hospital of Philadelphia (CHOP) diagnosed our 4 month old son Darren with AGS after his skin and eyes turned yellow. We wanted desperately to know there were others who were surviving this disease. We asked for names of other families with AGS children who would be willing to talk to us. At that time CHOP occasionally had meetings which offered information and support for liver disease families. What a blessing it was to find two other families with children just slightly older than Darren who were willing to share their experiences with us. Over the coming years we would meet with these families a few times a year in each other's home for support. I know I called each of these two moms many times with my questions and concerns.

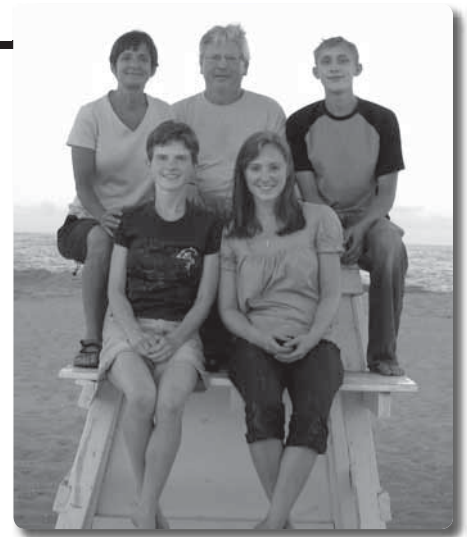
Through church connections we also found two other families each having a child Darren's age with another liver disease called biliary atresia. Our families began socializing together occasionally but the mothers and I formed a friendship which included the children and us meeting at Chuckie Cheese. Our children would play as we discussed what each of our families was facing as a family of a child having a liver disease. We offered each other support and a listening ear to experiences at home as well as at the doctors and hospital. There was a common bond of trials that were unknown to families with healthy children. Sharing and venting our stresses helped us continue on our journey. "Someone got it" even though our individual dealings with our children were not identical. They could identify with frustration due to the lab not finding your child's veins or when you were up all night with an itchy baby or when you were told for the umpteenth time that your child's eyes were yellow.

Families who have listened and shared their journeys with us are the reason we started a yearly Alagille picnic at our home in 1996. Alagille families need to know no matter how rare AGS is there are others out there having similar experiences. Children of this rare disease need to meet other children with AGS. Siblings need to know there are others living with brothers and sisters having AGS. Parents need to feel hope and support by seeing AGS children of all ages growing up to become adults living with this disease. We have found meeting in a relaxed atmosphere with time for fun, fellowship, and food has proved beneficial to other families. Why have the doctor and hospital visits be the only interaction with others connected to this disease?

Every year we are fortunate to have the support of doctors and staff from CHOP at our picnic. With their encouragement and attendance at our picnic families are able to receive new medical updates and information on AGS. They show their support by taking extra time to talk individually with the children and their families. What an addition to the fun for the families.

Our child raising journey had very rough beginnings. Our oldest, Marie, was not quite three when her twin siblings, Darren and Danielle, came into this world prematurely. Lowell and my days and nights became frantic with two babies on different feeding and sleeping schedules. Just when I had made up my mind to enjoy this time no matter how crazy, Darren was diagnosed with AGS. No, I was wrong. Life could become harder.

Twenty-one years later through AGS ups and downs, which included a liver transplant when Darren was nine, we are survivors. Through God's grace Lowell and I are still a happily married couple and our children have lived to become college students. Although liver enzymes and such are



still checked, Darren is stable and living a very healthy life.

"What else can I do to further the AGS cause now that my family is grown and we have survived?" was the question I asked myself several years ago. While talking to another Alagille Syndrome Alliance volunteer I found out the job of sending out welcome packets to new families would be available. Even though I am far from the west coast base of the Alliance this was something I could do to help. The time and effort I spend sending out welcome packets for this organization is definitely worthwhile if it helps other families find information and support for this disease. Support by others who have made a similar journey helped my family pass through many rough years with Alagille Syndrome. It is now my turn to help others.

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 (mm/dd/yyyy), the transplant date, type of organ received, and whether it was a cadaver or live donation. We'll include Transplant Anniversaries in future issues of Links4Life.

speaking at or moderating one or more proposed sessions, and meeting with AGS individuals and family members for consultations.

- ▶ Responding to specific questions about AGS that require medical expertise.
- ▶ Reviewing educational materials prepared by the Board of Directors for medical and scientific accuracy.
- ▶ Advising the Board of Directors in preparation of a Request for Proposals to award at least one \$25,000 research grant in 2011.
- ▶ Reviewing research grant proposals and making funding recommendations to the Board of Directors.

It's particularly important that we expand the MAB as this time so that we will have the necessary expertise to review grant proposals in 2011 and future years. Response to our invitation to MAB candidates has been very positive, and new members will start their initial three-year term of service on January 1, 2011.

Enjoy the holiday season and rest up for 2011. It's shaping up to be quite a year for AGS and the Alliance! Rare Disease Day® 2011 in February, Get Liver Smart! at SickKids in Toronto in March, the 5th International Symposium on AGS in June, our 4th Annual AGS Virtual Walk for a Better Life in August-October... We might even throw in an AGS Family Day somewhere, you never know. And we have research grants, newsletters, Kid Kare packages, welcome packets, and all the usual programs and services to juggle as well. But we always have time for your emails, letters, and phone calls, your comments and suggestions. We're here, we're listening, we're working hard for you!

With joy and good wishes,

Tell Us Your Story for Rare Disease Day® 2011

February 28, 2011, is the fourth International Rare Disease Day®. On that day hundreds of patient organizations from more than 40 countries worldwide will be organizing awareness-raising activities around the theme "Rare but Equal".

For Rare Disease Day® 2011 the Alliance is inviting you, our readers, to send in a photo, slideshow, or video you've created that will Tell Us Your Story about AGS and reflect the theme "Rare but Equal".

What does "Rare but Equal" mean? Everyone with AGS, or every parent of a child with AGS has their unique story of injustice to tell. For some of you, it might be about obtaining life-saving treatments or being reimbursed for medical expenses, about gaining access to specialized services or being considered eligible for disability compensation. Perhaps it's about finding a job after a difficult search, getting a scholarship based on academics rather than disability, or finally gaining access to lifetime insurance.

The Alliance wants to see and hear your stories of AGS health inequalities, instances where you've felt "Rare but Equal", times when having this rare disease didn't put you at a disadvantage but instead helped you gain access to something you very much needed to live a better life with AGS.

Send your submissions to alagille@alagille.org by February 14, 2011, so there will be time to display everyone's entries on www.alagille.org. If you have questions about the theme or Rare Disease Day®, contact Cindy Hahn at

alagille@alagille.org or (503) 885-0455. If you have questions about composing slideshows, filming video, or uploading, contact AGS Webmaster Erik Luxhoj at agswebmaster@alagille.org. Have fun being creative!

Roberta's Ramblings

Recently, my daughter Cloe fell on the playground at school. She didn't fall off of anything but rather slipped in water at the metal base of some playground equipment. As was told to me by the playground aid, Cloe laid on the ground screaming in pain. I got the call to come and get her while I was at work with the warning "I think it's very serious". I arrived at the school and headed down the hallway realizing out of the corner of my eye that Cloe's entire class was sitting there near the front doors listening to the teacher read a book. Panic started to set in. I thought, if the teacher makes the children leave the classroom, it must really be serious! So I power walked to her classroom where she was laid out on the floor with one of her classmates winter coats underneath her head like a pillow. The aids had carried her in from outside until I could get there. When I saw her, I knew she was in terrible pain. For Cloe, when there is an overabundance of pain after a period of time she tends to quiet down and zone out. I knelt down to her and said "honey, are you doing OK?" Obviously I knew she wasn't but I didn't really know what else to say at that moment. I knew that her femur was broken just by the way her leg was upwardly rounded. No bone sticking out of the skin. I told her I needed to pick her up and get her to the van so I could take her to the hospital, and I scooped her up and headed out the door wondering why no one had called an ambulance after

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Got Storage Space? Let's Fill It Up!

Lana O'Shea has generously offered to store silent auction items for the 2011 Symposium in an office in downtown Chicago with extra storage room! If you have an auction item or two that you would like to donate, or you are asking vendors to donate to the auction, items may be sent to the following address:

Lana O'Shea
Abalta Technologies, Inc.
325 West Huron Street, Suite 508
Chicago, IL 60654

Please indicate on the package or packing slip that the item is for the Alagille Syndrome Alliance 2011 Symposium. It would be helpful to give Lana advance notice of any shipments, so that she'll know when an item is being delivered. Her email is svetlanaoshea@gmail.com and her phone is (310) 507-3880.

Thank you in advance for your generosity! And thank you to Lana for answering our call for storage space!



Director Spotlight: Beth Caldwell



Elizabeth (Beth) Caldwell first contacted Cindy Hahn in 1995 through the physicians at the Children's Hospital of Philadelphia (CHOP). She was looking for support for her infant twins, Christopher and Timothy, who have AGS. Today Chris and Tim are amazing 16 year old high school sophomores who enjoy speaking to new families about their challenges and triumphs. Beth has written several articles for the Alliance newsletter, but really enjoys meeting families face-to-face and helping them connect with other families.

An ASCP certified Medical Lab Technician, Beth works for two hospital systems in the Columbus, Ohio area, and is taking pre-requisites to obtain a Nursing degree. She is a former Scout leader, and helped to organize a Liver Disease Support group thru Columbus Children's Hospital in the late 1990s. She serves on the Cardiology Clinic Redesign Committee for Cincinnati



Children's Hospital, focusing on making the clinic more accessible for families and patients. Beth helped organize and run the first AGS Walk for a Better Life in Marion, Ohio, in 2007. She has a strong interest in customer service that lends itself to wanting to serve the AGS community in any way possible.

Alliance Symposium sessions on education would not be the same without Beth in the lead sharing her insight and experience. She has been involved in all forms of instruction as she has led her four boys through homeschooling and public school online, as well as attendance at public school both part- and full-time. She feels education should meet the students' needs, not force the student to meet its structure.

Beth loves spending time with her family, including her husband Richard, four boys Zachary (a college freshman), Chris, Tim and Matthew (a 5th grader), and two medium-sized dogs! Recently, Beth walked a 5K with Richard and Rhonda, her brother's widow. She also keeps a close eye on Chris, who is doing okay at the moment, and Tim, who is recovering from his 4th major open heart surgery.

We've Got Mail

Andrea McGuinness wrote us a thank you for the Kid Kare package we sent her daughter Sophie when she broke her femur in October and had to be in a hip spica cast for six weeks: "Thank you so much for the care package! Your generosity put a smile on my beautiful girl's face, and those smiles were not coming very often at that point. Sophie loves the frog game with the "googly eyes" (as she calls them), and she already made a book from the pictures she's created using the crayon rubbing set.

She and Gavin have been doing the mosaic pictures together. Sophie is doing much better now. She finally started eating and sleeping after the first three weeks. She's accustomed to her cast, and has figured out how to roll over and pull herself across the room. We go for x-rays on the 17th [of November], and are hoping that the bone has healed and the cast can come off. Then maybe we can return to our "normal" lives!"

Ashlee Ricci, whose son Justen Angel Giron has AGS, sent us

a copy of her Facebook Birthday Wish – to raise \$300 for a cause she really cares about, Alagille Syndrome Alliance. Ashlee did a fantastic job and raised a total of \$325. Congratulations, Ashlee, and a very Happy Birthday!

Carol Burgess wrote us a note about her son Thomas: "He is 18 months and very active, not walking unaided yet but can climb on everything He is still very jaundiced and itches on and off. He doesn't eat

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a lot and is topped up with formula via a NG tube, but it seems to be working and he is gaining weight. We are taking part in a research project over here [in the United Kingdom] to see why the severity of the symptoms [of AGS] differ from child to child so dramatically." Carol is thinking about holding a cake bake as a fundraiser for the Alliance. Sounds like fun!

Kassandra Ross, whose 12-year-old daughter has a partial external biliary diversion (PEBD), recently completed our online biliary diversion survey. She wrote us an email asking if anyone else has a child with a PEBD that uses a Bard button as the closure. If you have any experience with this and would like to correspond with Kassandra, you may reach her at spkpross@gmail.com.

Nicholas Zenhenko from Sudbury, Ontario, Canada, emailed to let us know that he and Nicholas Jr. had moved and that they're doing great! Nicholas Jr. turned 4 on December 11th and his dad included a great picture of him. It sounds like they've been busy with work, appointments, and getting ready for the holidays.



Stephanie Yonce wrote to us about her daughter Lauralyn Danielle "Dani" Yonce, who turned 3 on December 19th: "Dani served as the Ambassador for the area chapter of the March of Dimes last year. In March, she had an EGD to see if there was presence of esophageal varices. None were found but we were referred back to the transplant team at MUSC [Medical University of South Carolina]. It was agreed that her heart needed to be repaired before a liver transplant would be possible. In



order to make sure we understood all of the treatment possibilities, the doctors recommended getting second opinions. After evaluations in Atlanta and at Duke, we were referred to the Children's Hospital at Pittsburgh. Thinking we were coming up for diagnostics, we ventured out. There was a planned cardiac catheterization on October 26th. Dani had a Tetralogy [of Fallot] repair on October 28th. Today, she is still in CICU at Children's in Pittsburgh. She will likely be spending her birthday and Christmas there. Dani is making small strides toward recovery, but there have been many setbacks. The staff here at Children's has been awesome. However, we still need a lot of prayers for recovery. ... We read our Links4Life newsletter from cover to cover. The story about Colton Huss really touched us but encouraged us at the same time that anything is possible! Please keep Dani in your

prayers as she recovers this holiday season. For her to get out of CICU and show some forward progress would be the best Christmas of all. You can follow Dani's progress at www.carepages.com; her page is Pray4Dani."

Pat & Len Roecker included this note with a recent donation: "This check is in honor of our granddaughter Taylor Soule who turned 11 on October 23, 2010. We are so proud of her and all she has accomplished. She is a joy to all our family and to all who know her. We pray daily for an answer to this syndrome. Keep up the good work."

Beth Ann & David Newman included this note with a recent donation: "We were excited to receive the most recent newsletter

and marvel at the breakthroughs and accomplishments over the years. Little did we know when the Alliance first started that we would be considered one of the pioneer families. We are sorry we have not kept up better over the years but, amazingly life has gone on since Matthew's passing 9 years ago. It is never easy but, time does dull the ache. Our Katie is 22 and in college while working full time and running for local office in her new hometown. We are lucky to be only an hour away and can help her campaign even if she is with a "different" party. We are so proud of her! David and I keep busy with house renovations, camping, work, the Labrador retrievers and I am back in school for completion of my degree. Enclosed find our Christmas donation and best wishes for a wonderful 2011."

it happened considering the obvious break and the fact that it was going to take me quite a while to get there. The principal maneuvered my passenger side seat back so that it was lying down and I placed Cloe there to get her the few miles to the local ER. When I got there I couldn't help but to be upset with myself and the local medical professionals I was supposed to be able to count on.

Nearly 2 months before, I had taken Cloe into the ER after a slip and fall in our kitchen. I thought for sure her leg was broken at that time because of the amount of sheer pain she was in. I told the doctors she was prone to having greenstick breaks or hairline fractures associated with her Alagille Syndrome and suspected such because she did have some minor limping for a few weeks in the same leg prior to the slip and fall in the kitchen. At that time they had a portable x-ray taken and saw nothing. They ordered further x-rays of the hip down to the knee and saw nothing. I followed up with her pediatrician two days later where another x-ray was ordered; yet again, nothing was noticeable on the films.



Happy Birthday!



October

Lillian "Lily" Blackmon	11
Abigail F. Blankenship.....	13
Matthew Calabro.....	19
Christopher M. Caldwell.....	16
Timothy D. Caldwell.....	16
<i>Liver Transplant 07/19/2000</i>	
Jyotiraditya Chauhan	4
Gabriel Chow	8
Victoria Damikolas	5
Jason Doornenbal.....	20
Brendon Ednie	15
<i>Liver, Heart, 2 Lung Transplant 08/21/1998</i>	
Emma Ellefson.....	9
Ivan F. Fernandez.....	13
O'Desa Gentry	11
Nicholas Lane	2 mos
Nolan Lane.....	2 mos
Michelle K. Long	38
Christina Marchel.....	14
Aaron McCoy.....	17
Cody Moldenhauer.....	8
James "Joshua" Samson.....	9
Justin Savage.....	28
Taylor M. Soule	11
<i>Liver Transplant 03/22/2001</i>	
Manato Yoshida.....	6

November

Bayli Paterson Bird.....	11
Kaitlyn R. Bossler.....	16
Michael E. Capozzi.....	16
Regina Echeverria Ornelas	5
Alex M. Everett.....	15
<i>Liver Transplant 12/19/2003</i>	
Heather N. Fauth.....	13
Marquise D. Flowers.....	16
Logan Foster	8
Caroline E. Gallagher.....	8
Zoe Hagarman.....	6
Adam Herrera.....	6
Cloe Hunt	7
Malachi Johnson	4
Austin Lloyd	6
Tyler McGee	13
Eric Murbach	32

Jessica Needham	32
Giana Pasquell	3
Bayli Paterson-Bird.....	11
Luman A.J. Pinto Rodriguez.....	13
Nicole Rippentrop.....	17
Devon Ramachandran.....	14
Veronica A. Sanchez Montano.....	22
Spencer Taylor	25
Andrew Wecker.....	13

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Joe Anderson.....	33
Sam Ayre	9
Nataleigh Cobb	10
Chloe Alyssa Finger.....	1
Katelyn Gajdosik	16
Frank D. Gerome	16
<i>Liver Transplant 08/06/1996</i>	
Samantha Hewitt.....	4
Kiera Inman	11
Ryan E. Johnson.....	10
Mattie Joyner	5
<i>Liver Transplant 01/09/2008</i>	
Will Lackey	5
Chloe-Lila J. Loadsman.....	6
Austin A. Loyd.....	18
Matthew Magninat.....	7
Sam Melbourne.....	1
Yoav Ost.....	8
<i>Liver Transplant 11/05/2003</i>	
Raphael Ramirez.....	11
Antonio A. Sandim.....	7
Joseph Valente.....	14
Mark van Berghem.....	7
Adam Wall	15
Lauralyn Danielle "Dani" Yonce ...	3
Nicholas Zenhenko, Jr.....	4

In Memory

Michael J. Bozek.....	2
Kevin Clark.....	31
Michela Fischer.....	28
Hazel Fletcher	15
Maddox Hatfield	4
Samuel R. Johnston.....	16

Christopher Minard.....	16
Camryn B. Newby	10

In Memory

Regan Nicole Altman

August 13, 2007 - November 12, 2010

Regan Nicole Altman, 3, passed away at Levine Children's Hospital in Charlotte, NC. Born in Rock Hill, she was the daughter of Matthew Cody Altman and Erin Williams Altman. Survivors include her sister, Madison Altman;



maternal grandparents, Kim Williams and Hank Williams; paternal grandparents, Betty Altman and Ronald Altman; maternal great-grandparents, Phyllis Eubanks, Sue Williams and Clayton Williams; paternal great-grandparents, Waitus Altman, Rosalie Altman, LaRue Baker and Ruth Baker; one aunt,



Katie Williams; two uncles, Jeremy Williams and Brice Altman; and numerous great aunts, uncles and cousins. Funeral services were held on November 16, 2010, at Herbert Memorial United Methodist Church, with the Rev. Michael Leonhardt officiating. Burial followed in the Souls Chapel Cemetery. (Source: www.legacy.com/obituaries.)

Clara Pauline Sexton

January 19, 2001 - November 11, 2010

Clara Pauline Sexton, of Melrose, MA, only 9 years old, passed away at the Children's Hospital of Boston. She was born in Cambridge and moved to Melrose when she was 18 months old. Clara was a fourth grade student at St. Mary's Grammar School in Melrose where she was very artistic,

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enjoyed writing, and drawing. She was also a member of Miss Janice's dance class at the Melrose Dance Academy. She loved all animals, the outdoors, and nature.



Clara was the cherished and loving daughter of Daniel J. Sexton and Karen Anne G. MacDonald. Cherished granddaughter of Archie and Theresa MacDonald and Pat and Marguerite Sexton, and the late Pauline Sexton. Niece of Paul and Kathleen MacDonald, Jen Sexton, Mike Lynch, Bob Sexton, and Norine Williamson, and Mike Sexton. Special cousin of Big Molly, Gabe, Aiden, Little Molly, and Breanna. Also survived by her dog Lauchie and puppy Huey. (Source: www.findagrave.com.)

Does Your Employer Make Grants?

Does your employer have a community or charitable grant program? Many employer grant programs require their employees to start the grant application process for a nonprofit organization they are involved with or want to see funded. The organization is not allowed to apply for the grant on its own, even if it qualifies.

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

If your employer has a grant program that you think may offer funding and you are willing to help us explore the opportunity, please contact Cindy Hahn at alagille@alagille.org or (503) 885-0455.

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I was sent home with the suggestion that perhaps she had strained a muscle and if she didn't seem to be improving within one week then a neurology visit would be the next course of action. I felt frustrated that none of the doctors had taken me seriously enough regarding her condition and the likelihood that she could have a break that is hard to see on an x-ray. I also felt upset and insulted that even humoring me by treating her leg as having a possible greenstick break was beneath them. As well as the fact that they would send us to neurology without even a more thorough exam to absolutely rule out a greenstick break. When I took Cloe into the ER for the fall on the playground I tried to tell the doctor there that we had just been in less than two months ago and I had suspected a break in her leg at that time and asked if it was possibly related. He looked at me and said "are you trying to tell me we didn't do our job the last time?" I had to explain that that wasn't at all what I was getting at and that I was just trying to tell him that obviously there was something going on with her leg making it weak in that area all along.



So, now I'm standing with that same doctor looking at the current x-ray with a femur that looks like a broken branch and underneath that break is an older break covered by a healing callus. The doctor turns and says to me "there was a break the last time you were in, seems as though your suspicions were correct. We just couldn't see it in the x-ray because it was too new of a fracture at that time." Instead of saying anything to him, I went back into the emergency room Cloe was lying in and broke down into tears thinking "my little girl will have so much to endure and will always have to trust her instincts and I have to always trust mine". Even if they hadn't believed me when I said I felt it was a greenstick

break or hairline fracture the first time I took her into the ER they could have done something for her. Maybe putting a leg wrap on her leg or something to let me know they were acknowledging that she was in pain and that she was having problems walking. Whether this is a completely rational thought process on my part, I don't know. But, it feels right!

Once the femur break was diagnosed and proven through x-ray, we were taken to University of Michigan hospital 2 hours away by ambulance. This is the trusted medical safe haven for our family regarding Cloe's medical issues. She has a much loved liver transplant clinic doctor and team, kidney specialist, dietician, orthodontist, ophthalmologist, cardiac specialist, and GI team that we wouldn't trade for the world! Cloe did end up having surgery where two flex pins were placed into the femur. It is 2 weeks post trauma and she is doing wonderfully. I have also had a few weeks to reflect on my thoughts and feelings throughout the whole ordeal. I understand that for us, the AGS families, visiting local medical offices may be difficult due to the rarity of Alagille Syndrome alone. It is not a medical issue most doctors are aware of nor is it one that they will completely understand in a matter of a few hours when we visit the ER with our children. It is a complex and difficult syndrome with many twists and turns. I have learned through this experience that I need to be better prepared so that I can quickly prepare the medical professionals treating her with valuable information that they may need in order to assess the situation. Perhaps printing off a full description of AGS and having an already prepared list of every symptom associated to it of Cloe's would also be extremely helpful. I also

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Alagille Syndrome Alliance

10500 SW Starr Drive, Tualatin, OR 97062

WE'RE ON THE WEB

WWW.ALAGILLE.ORG

Board of Directors

Cindy L. Hahn, President

10500 SW Starr Drive
Tualatin, OR 97062
(503) 885-0455
alagille@alagille.org

Christopher J. Hahn

10500 SW Starr Drive
Tualatin, OR 97062
(503) 885-0455
alagille@alagille.org

Erik K. Luxhoj

7295 Old Mission Dr. NE
Rockford, MI 49341
(616) 884 - 0694
agswebmaster@alagille.org

Joseph M. Anderson

120 S. 400 W.
Brigham City, UT 84302
(303) 241-6303
janderson@alagille.net

Elizabeth A. Caldwell

100 Union Street
Cardington, OH 43315
(419) 864-3486
brcaldwell@alagille.net

Richard E. Caldwell

100 Union Street
Cardington, OH 43315
(419) 864-3486
brcaldwell@alagille.net

Anna Chow

135 Hedge Road
Menlo Park, CA 94025
(650) 353-5250
achow@alagille.net

Patricia H. Everett

550 West Magnolia Circle
Alpharetta, GA 30005
(770) 740-1910
peverett@alagille.net

Wanda L. Sheppard

3029 Granada Place
Plano, Texas 75023
(469) 767-4357
wsheppard@alagille.net

Return Service Requested

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know as it is reinforced every time we go, that I am my daughters' best line of defense. I know her better than anyone and have to be able to convey my knowledge without expressing frustration when I come face to face with someone who just assumes I am not knowledgeable enough to give valuable input.

One thing is for sure, being prepared for a medical emergency with your child is something all AGS parents should think about. Being prepared can help decrease the time it takes for your child to receive the proper care and can help you think more clearly during an emergency. Here are a few things to consider doing/having in order to be more prepared in those scary times:

- 1) Do know your child's current weight.
- 2) Have a medication list including all doses and strengths.
- 3) Have a description or print out detailing your child's illness, especially if it is very rare.

- 4) Have a complete list of all symptoms your child has related or unrelated to the illness.
- 5) Have your child's medical history documented, pertinent surgeries or instances and the dates they occurred.
- 6) Have a list of all doctors/specialists that see your child including addresses and phone numbers.
- 7) Have your pharmacy name and phone number.
- 8) Have current medical insurance and identification information ready.
- 9) If your child was recently seen by a pediatrician and was given a diagnosis, have this info ready for the doctor.
- 10) Do bring comfortable clothes, if possible.
- 11) Do bring change for snacks and drinks.
- 12) Do bring your cell phone charger, if needed.
- 13) Do bring your child's most loved toy or blanket, if possible.

Roberta Smith, maxiine@hotmail.com