

LiverLink

The Newsletter of the Alagille Syndrome Alliance



Tell Us Your Story

Megan Lavallee was selected as "Student of the Month" for her kindergarten classroom in October 2001. She was honored at an assembly where the principal shared with everyone what her teacher wrote about her. She was beaming with pride as she received her certificate and ribbon. Her proud parents would like to share what was said about Megan.

"Megan came into the classroom with a bubbling enthusiasm that has not wavered one bit. Her happiness and enthusiasm helps to set a very positive tone for our classroom. Megan always has a smile on her face. Megan is also a very focused worker. When Megan starts an assignment, she does not stop until she has completed it to her satisfaction. This ability to focus and concentrate is an example to everyone in Room 26 of how to set high goals and stick to them. We are very glad Megan is part of Room 26, and Megan is a true Super-star!"

Quick update: Megan turned 6 in January. She joined Daisy's (Girl Scouts) last fall and participates in KidFit (youth exercise class) twice a week. Megan is a happy girl who loves bunnies, Barbie, her doll house, anything hot pink, and playing with her 2 year old brother, Ryan. Her health continues to be stable. Itching remains her biggest battle. She is currently on Actigall, Rifampin, Atarax, a multi-vitamin plus vitamins D,E, and K, zinc acetate, and Tums for extra calcium.



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Inside.....

More AGS Kids

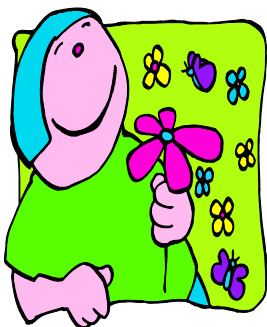
President's Page

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Could It Be You?



President's Page — It's All About Being Connected....

I'm feeling really well connected these days! Not where career or profession is concerned—it's kind of hard being well connected when you're a full-time mom—but with my AGS extended family. Here are some terrific examples...

Anne Pattison in Hanover, New Hampshire, sent me an email after reading the latest *LiverLink* word for word "as usual" to let me know that she finds its contents "invaluable." In response to my comment about Alaina's sore feet (in the President's Page), Anne shared Margo's experience with Rifampin. Within a few weeks of starting Rifampin, Margo could barely walk because her feet were so sore. Her pediatrician read that a side effect of the drug is peripheral neuritis and suggested Margo stop taking it. When she did, her feet were fine. Alaina isn't taking Rifampin, but if she were I'd certainly ask her doctors about a possible reaction similar to Margo's.

Dr. Karan Emerick, whose article on PEBD was featured in the last *LiverLink*, emailed me to say that she's received numerous phone calls from interested families. In her words, "It is amazing what is possible when people are connected." I couldn't agree more!

I received a phone call from Tina Nathan in Grass Val-

ley, California, today. She had some questions about the upcoming Symposium. We got to talking and I mentioned that some AGS kids are having problems with xanthomas. Tina said that her daughter Danielle had terrible xanthomas until she connected with Dr. Chin at Stanford Children's Hospital. Doctors around the hospital call Dr. Chin the "Cholesterol Guru" at the Cardiac Unit because he is so knowledgeable about cholesterol, pesky xanthomas, and a drug called Lipitor. Dr. Chin put Danielle on Lipitor and her xanthomas disappeared, while she was taking high calorie, high protein formula through a g-tube. At least one other AGS family has consulted with Dr. Chin about xanthomas, with the same result as Danielle. If your child is having a similar problem, you might want to call Dr. Chin at 650.723.7913. Just remember to do this in consultation with your child's doctors, so everyone knows what is going on!

One final example of "being connected"—I ran across some interesting news in the latest issue of *SNAP REPORT*, the newsletter of Special Needs Advocate for Parents (SNAP). Seems SNAP is launching a new service called the Medical Insurance Empowerment Program. There will be advisors available to work with

parents to "creatively determine how to approach their health insurance companies" for authorizations or reimbursements for therapies, medical equipment, or other items sometimes not seen by insurance companies to be "medically necessary." The program is designed for families with private medical insurance and is available on a "sliding scale basis." To use this service, contact SNAP at 888.310.9889 or email SNAP through their website at www.snapinfo.org. What a great service for families.

This issue of *LiverLink* is all about being connected, too. Joe Anderson's article on local and regional get-togethers encourages us all to connect with other AGS families near to us and to have a great time doing it. And this newsletter is full of pictures and updates on our wonderful AGS kids. I received so many terrific cards, letters, and pictures during the holidays that I just had to share them with the rest of you!

Let the daffodils bloom and the birds sing—it's almost spring. Have a fantastic next couple months!

With joy and in peace,

Cindy L. Hahn, President

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LiverLink is published six times per year for members of the Alagille Syndrome Alliance, a national support network for people with Alagille Syndrome (AGS), a rare inherited liver disorder. The primary purpose of *LiverLink* is to provide general information. *LiverLink* 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 *LiverLink* should be sent to: Cindy Hahn, President, Alagille Syndrome Alliance, 10630 S.W. Garden Park Place, Tigard, OR 97223. 503-639-6217. No faxes please. Copyright©2002 Alagille Syndrome Alliance. All rights reserved.

Getting (It) Together!!!!!!!!!!!!!!

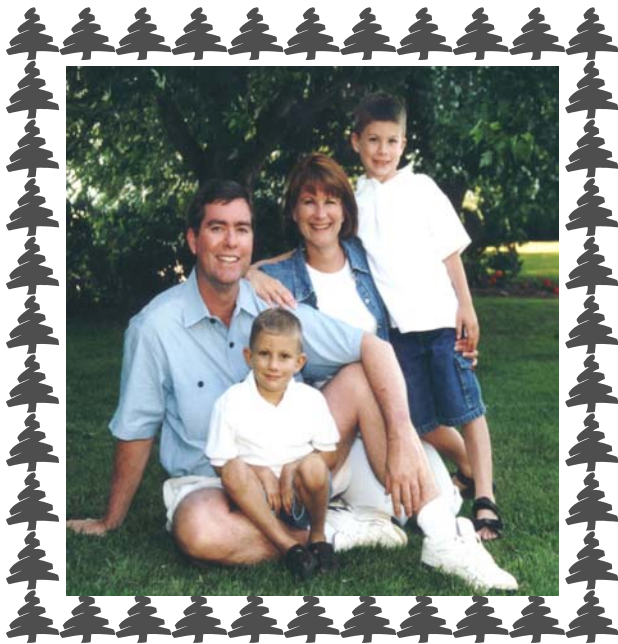
Joe Anderson says.... Last summer I had the opportunity to attend the Annual AGS Family Picnic held at the Gehman residence near Philadelphia, PA. It was a great event with about a dozen or so families from all around Pennsylvania, New Jersey, and even as far as Manhattan, New York. A Norwegian family visiting relatives in NJ came by after seeing information about the picnic on the Alliance website (www.alagille.org).

I bring this up because I can envision events like this being held all across the country. All that is needed is some initiative and planning on the part of our AGS families. I know we are spread rather thinly across this continent but I feel that many will find it rewarding enough to drive several hours to meet and mingle with others who are in their shoes. This is a great way to meet other families in your state or region and helps the Alliance work towards its goal of becoming a close, tight-knit community.

It doesn't need to be overly complex or costly. For example, the Gehman picnic was a BAR-B-Q and potluck with plenty of good eats. If your residence is too small to host a large number of people you may be able to reserve a spot at your local municipal or state park. That way you would have plenty of space for games or even water warfare, which is customary at the Gehmans. If you are more ambitious, plan an overnight camp, which would be really good for those traveling a long distance. If your group is large enough, take in a sporting event or amusement park at a group discount. These are just a few ideas and I'm sure there are many other ways a group can spend time together.

The Alliance will gladly help put out word of your event by announcing it in *Liverlink*, and on our website (www.alagille.org). Right now is probably the best time to plan an event for this summer, but keep in mind the 2nd International Symposium on Alagille Syndrome is August 8-11. Still, that leaves plenty of time in the year for other activities. Make the effort and I'm sure you'll make some new friends.

If you have an event you would like to tell us about, email us at alagille@earthlink.net, or call us at 503-639-6217.



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HANNAH

Hannah Zinno with her big brother Ben make quite the football team! Hannah celebrated her 6th birthday in January 2002 and is doing fairly well with her AGS. Yeah, Hannah!!!



Pat and Patti Everett with their sons Alex (in Pat's lap) and Ethan enjoying a quiet moment at a family reunion in June 2001. Alex, who has AGS, started Kindergarten last September and celebrated his 6th birthday in November. Unfortunately Alex broke his leg in December and was in a half-body cast until it healed. An in-home tutor made sure that he didn't get behind his classmates at school. Alex couldn't wait to start riding the school bus again with his big brother Ethan.

SAMMY



Patty Johnston, whose son Sammy passed away from AGS in 1996 when he was 1 yr old, poses for a picture with her boyfriend. Sammy's death was so hard on Patty that she lost the use of her kidneys and went on dialysis. She is now waiting for a transplant. Patty says that her family and boyfriend are very good to her and she is looking forward to getting better.



Jordan



Olivia, Hunter and Jordan Sihle enjoying the holidays. Jordan, who will be 9 years old in May, has AGS and received a liver transplant in 1995 when he was one and one-half years old. He's doing great!



NICOLE

Nicole Rippentrop is doing terrific! She turned 8 in November and is in the 2nd grade. Nicole breezed through her annual checkup and her doctor thinks her AGS is stable. Yeah!

Financial Report 2001 for AGS Alliance

Category	Total	
<u>Income Categories</u>		
Contributions	\$ 11,790.00	*1
Investment Income	81.91	
Other Income	127.00	*2
Total Income Categories	\$ 11,998.91	
<u>Expense Categories</u>		
Affiliations	\$ 215.00	
Bank Charges	81.90	
Charitable Donations	60.00	
Copies	261.77	
Corporate Fees	20.00	
Education	1,652.96	*3
Fax	3.21	
Food	120.50	
Furnishings	99.98	
Mailing	2,208.02	
Miscellaneous	2,598.71	*4
Postage	396.96	
Promotional	267.31	
Supplies	1,272.29	*5
Transportation	1,882.58	*6
Utilities	326.09	
Total Expense Categories	\$ 11,467.28	
Grand Total	531.63	

Notes:

- *1 Includes \$6,150 in Symposium 2002 Friend donations from families.
- *2 Sale of T-shirts and videos from Symposium 1999.
- *3 Primarily lodging in Portland, OR, for Board members attending the May 2001 long-range planning meeting. Also includes lodging for Cindy Hahn to attend the AGS Family Picnic in July 2001, and a Grant Makers & Grant Seekers conference in January 2001.
- *4 This is the first deposit made to Eastern College on the contract for Symposium 2002. A second deposit is due February 1, 2002, and the third deposit is due May 1, 2002.
- *5 Major expenses in this category include two packets of computer software (Event Planner Plus and Acrobat Reader 5.0), and mailing and remittance envelopes for *LiverLink*.
- *6 Primarily air transportation for Board of Directors members to attend the long-range planning meeting in Portland, OR, in May 2001, and for Cindy Hahn to attend the AGS Family Picnic in Philadelphia, PA, in July 2001.



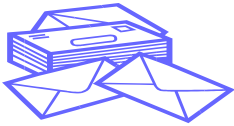
“At School” Pictures Needed

...for Booklet on “AGS In The Classroom”

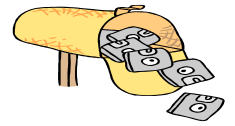
With the assistance of Digestive Care, Inc., the manufacturers of PANCRECARB® (delayed-release enzymes), the Alliance is assembling a booklet about AGS for pre-school, K-12, and other educators, health-care staff, and administrators. The booklet will discuss what AGS is, how it is treated, and how it can affect

school behavior and performance. It also will include a pull-out section on web and other information resources about AGS.

We need pictures of AGS kids to go in this full-color booklet! Children in the classroom, taking medications, using a g-tube, in a wheelchair or wearing a cast, doing school work, or posing with their teacher are some of the types of photos we could use. If you have pictures you are willing to share, please send them to Cindy Hahn at the Alagille Syndrome Alliance, 10630 SW Garden Park Place, Tigard, OR 97223. We will scan them and return them, if you request. Photos in .jpeg format also can be emailed to Cindy at alagille@earthlink.net. We appreciate your help with this booklet. It will be a terrific resource for parents and school staff.



Letter Box



Maggie Litton writes that her sister Lauren, who has AGS, (Corbin KY) is going through some tough times right now. In mid-January, Lauren received a living donor kidney transplant from her mother and she is on the waiting list for a liver transplant. Anyone wishing to send notes of support to Lauren can do so at email bleu-frog@msn.com or mailing address 419 4th Street, Corbin KY 40701. I'm sure Lauren would appreciate your words of encouragement.

Marien Doehling (Larsen WI) writes that her grandson Ben Doehling, who has AGS, will celebrate his 11th birthday on February 19, 2002. Ben received a liver transplant when he was less than one year old and celebrated his 10th transplant anniversary on November 13, 2001. Marien says that Ben is doing great and has not had any problems since his transplant.

Jean Marchel (Junction City WI), who has AGS, writes that she greatly appreciated the series of articles on itching in *LiverLink*. When Jean was a baby her mother used to pin cotton gloves on her hands so that she wouldn't itch herself raw. As an adult, the itching has attacked Jean "full force" during each of her pregnancies. Consequently, she lost much needed sleep at those times. Jean didn't realize she had AGS until she became pregnant the first time and started to itch—the midwife thought she must be "allergic to male or female hormones from the baby." Jean and her husband Greg have three children: Maria, who is 12 years old, and Christina, who is 5, both with AGS; and Teresita, who is 7 years old and has not shown signs of AGS. A fourth child, Mateo, who had AGS and would have been 10 years old in January 2002, died during heart surgery when he was one year old. Jean writes that she and Greg hope for more children in the future.



Ashley Cheyenne Boyce has AGS and will be 3 years old in March. According to her mother Sandy King, who also has AGS, Ashley's experience has been "a long haul". Ashley still has a g-tube and isn't eating solid foods yet. A speech therapist visits her once a week and she itches quite a bit. She only weighs 21 lbs. Sandy would like to hear from other parents with AGS kids on g-tubes who aren't interested in eating solid foods. She's frustrated and could use some advice. You can email Sandy at SKing10044@aol.com or write to her at 9707 King-

ASH-



ANJA

Anja Raab has AGS and is 2.5 years old. She lives in Austria with her parents Rüdiger and Christine. In September 2001, doctors found two tumors on her liver, but they were not malignant and Anja is growing well. Her mom says that she "speaks like a waterfall" and is a very happy little girl.



?????????????COULD IT BE YOU????????????????

The Alliance Board of Directors currently includes six people: Cindy and Chris Hahn, Erik Luxhoj, Patti Everett, Beth Caldwell, and Joe Anderson. Julie Kelin’s seat is vacant. We would like to add three new members to the Board, for a total of nine Directors. In particular, we are looking for parents of AGS kids or people with AGS who are interested in:

Education—spreading the word about AGS to the public and health care providers through print and broadcast media (TV, news shows, newspapers, etc.). This was Julie Kelin’s passion and we need someone to pick up where she left off.

Marketing and Public Relations—building awareness of the Alliance and our mission, with the public and health care providers, as well as with other organizations such as NORD, the American Liver Foundation, and the Genetic Alliance. This could also involve developing partnerships with these organizations, producing booklets like “AGS In The Classroom,” and generally promoting the Alliance’s activities to anyone who will listen.

Regional or Local Group Coordination—concentrating on helping people with AGS and their families get together in different parts of

the U.S., Canada, and abroad, on an informal basis to enjoy each other’s company and share experiences. Eventually, we’d like to divide the U.S. up into regional groups that would hold some type of annual event for families in their region, but we’re starting small. The Gehman’s annual AGS picnic is a great example of what we have in mind.

If you are the parent of an AGS child or have AGS yourself, and are interested in serving on the Board of Directors in any of the above capacities, please let us know! We don’t have a formal application process, but would like to receive a letter of interest from you along with a resume, if you have one. Tell us why you’d like to serve on the Board of Directors and share your special loves and talents. Please send materials to Cindy Hahn at the Alagille Syndrome Alliance, 10630 SW Garden Park Place, Tigard OR 97223, or email to alagille@earthlink.net.

We will be announcing our new Board members at Symposium 2002 in August. As a new Board member, you would attend our Board meeting on Monday, August 12, 2002, at Eastern College. Thanks for your interest!

If you are the parent of an AGS child or have AGS yourself, and are interested in serving on the Board of Directors ... please let us know!



PEGGY

Linda Tseng, Keith Lin, and their daughter Peggy Lin have joined the Alliance from Taiwan! Peggy has AGS and is 2.5 years old. Her older brother Ray is 9 years old and doesn’t have AGS. Keith found the Alliance through the web and doesn’t know of any other AGS families in Taiwan.



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WE'RE ON THE WEB
WWW.ALAGILLE.ORG



CHRIS AND TIM

My name is Beth Caldwell, and these are my twins, Chris and Tim. They are featured here because I need your help. Yes, you! I edit *LiverLink*, and I desperately need YOUR stories about YOUR children and yourselves, itching strategies that work for you, sleep strategies.....if it deals with AGS and could help others, send it in! If you or your child have a neat story to share.... this is the place! Children's artwork, sibling stories, we need them all. *LiverLink* is for YOU! Adults with AGS "survivor stories" are in DEMAND! Share what works for you! Please feel free to share here, and join us in our chat room on Sundays at 7 pm, EST. (Just follow the prompts on the AGS website!) Speak out on our Bulletin Board! We want to hear from YOU! Send stories, etc., to me or to Cindy at the Alliance office (see emails and addresses below).

Now, for an update on Chris and Tim. They are seven years old, and doing fairly well. Chris has a currently inoperable heart condition and his future is in serious doubt at this point. He doesn't realize this, and other than an extreme exercise intolerance, he is doing well in Kindergarten and youth group, and recently won a speaking part in a children's theatre production of "The Three Little Pigs". Tim is a little over a year post liver transplant, and he is also doing well in Kindergarten, youth group, and children's theatre. He is gaining weight and looks healthy for the first time in his life! He is even doing karate! He and Chris look out for and take care of each other on a daily basis. They are both feeling well enough to drive their siblings crazy!

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