Volume 8, Issue 6

November-December 2001

LiverLink

The Newsletter of the Alagille Syndrome Alliance

From all of us to all of you:

We hope you all had a very safe and joyous Holiday Season.

Your Alliance Board

Biliary Diversion for Severe Itching and Xanthomas in Alagille Syndrome by Karan Emerick MD

Cholestasis is a principal feature of Alagille Syndrome (AGS) and results in several distressing symptoms. The term cholestasis is used to describe conditions in which bile is retained in the liver at high levels and results in an "overflow" of bile contents into the blood (such as cholesterol and bile acids). Patients with AGS are known to have limited bile flow from the liver which can result in blood cholesterol levels that are 5 to 10x normal and bile salt levels that are 100x normal. There is evidence that blood cholesterol level is related to the development of cholesterol deposits in the skin (xanthomas) and also that the levels of other bile-derived substances in the blood, such as bile salts, correlate to degree of "itchiness" in cholestatic patients. Disfiguring xanthomas and "unstoppable" itching due to cholestasis often markedly reduce the quality of life of children with AGS.

Itching, or pruritus, is usually the **most** debilitating symptom, leading to mutilation of the skin, loss of sleep, poor attention and impaired school performance. As discussed in the past few editions of *LiverLink*, many different medical therapies have been tried with varying success. These include bile acids binding resins (cholestyramine), antihistamines (benadryl, atarax), phenobarbital, rifampicin, and ursodeoxycholic acid, singly or in various combinations. Some patients are unresponsive to any medical therapy. Likewise, hypercholesterolemia and xanthomatosis often do not respond to medical therapy. Failure of medical therapy to control these symptoms and therefore permit an acceptable quality of life is a major indication for liver transplantation in AGS.

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We Need to Know

We have enclosed a "Family Survey" in this issue of *LiverLink*. We want to know what services are important to you and how we can serve you to the best of our abilities. This survey will give direction to our efforts and provide a basis for our future actions.

We thank you in advance for your input and guidance. We are here to support and serve our AGS family!

President's Page

At this time of year, I try extra hard to think about the things for which I am thankful, to give loved ones an extra hug, to say "I love you" more often, and to reach out to those less fortunate than our family. I find myself thinking more intently about my blessings this year in light of the September 11 attacks and, much closer to home, the sudden death of Julie Kelin, a loved and appreciated member of the Alliance Board of Directors.

Julie's mother, Judy Swaggerty, called me early on the morning of November 3rd, two days after Julie's tragic and senseless murder. At first I couldn't believe the news, then I cried. I walked around in a daze. I called the other members of our Board of Directors, who reacted in the same way as I. It seems like yesterday that Julie and Justine, her daughter, were in Portland for the Alliance planning meeting we had in May. We joked, we talked, we made plans for the future. It's still hard to believe that Julie won't be a part of those plans when they become a reality, that she won't be at Symposium 2002 with Justine, that I'll never hug her or laugh with her again. I'm thankful that the police were at Julie's apartment before Justine came home from school and that Justine was not the one to find her. That would have been too much to bear. And I'm thankful that I knew Julie for four years, that she was so dedicated to the Alliance and our cause, and that I hugged her hard and long in May.

We've posted a memorial to Julie on the Alliance web site, and I've talked with Jim and Tracy Sawaya, Justine's dad and stepmom, to offer my support. Alaina and I will attend Julie's memorial service in Tacoma, WA, when it is held, when Justine is ready. Eventually we will fill Julie's place on the Board of Directors, most likely at Symposium 2002. In the meantime we'll grieve and we'll remember Julie for who she was – a warm-hearted, loving person who looked on the bright side and didn't give up. She'll never be replaced in our hearts.

Thinking of loved ones, Alaina is having a particularly tough time with itching these days. Her feet are sore, her ankles and calves are scratched and bleeding, she's having a hard time sleeping and wakes up several times during the night. Her meds don't seem to be as effective, or maybe it's because of all the rain and a dismal lack of sun. Whatever the cause, she's frustrated and itchy and sore. I've told her about the study Karan Emerick is proposing on Partial External Biliary Diversion (PEBD) and Alaina wants to participate. Even if the surgery isn't 100% effective, she says she'll take any reduction in itching that she can get, and if that means she'll have a stoma that's okay. I have to give her an A+ for courage, that's for sure! With Dr. Emerick's study strarting in early 2002, I guess that means we'll be in Chicago sometime soon. It will be quite a way to blast into the new year! Future issues of *LiverLink* will, no doubt, include updates on Alaina's condition as well as that of other AGS children who undergo the PEBD surgery. Stay tuned!

On a final note, the Alliance Bulletin Board appears to be a popular spot for AGS families to share information. Since it got started, thanks to the gargantuan efforts of our Webmaster Erik Luxhoj, the BB has grown by leaps and bounds. Families are asking all sorts of questions, and sharing experiences and ideas – exactly what the BB is intended for. When you have a moment, definitely check it out! It's a great place to visit!

Thank you all for believing in and supporting the Alliance, for being a part of our growing AGS family, and for sharing your experiences with us. May you all find bright beginnings in 2002.

Until next time,
with hope and in
peace,

Cindy L. Hahn
President

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.

Biliary Diversion (continued)

There is clearly a need for a therapy that is more effective than current medical treatment, yet less invasive and life threatening than liver transplantation.

Surgical diversion of bile from the body, or Partial External Biliary Diversion (PEBD), is another option for the treatment of "unstoppable itching" and severely elevated cholesterol levels causing xanthomas. PEBD was first reported in 1988 by Dr. Peter Whitington as a way to achieve control of itching in children with cholestasis. Dr. Whitington reported that 6 patients with cholestasis, 2 with AGS, had experienced improvement in their itching and drastic decreases in their serum bile salt concentrations after PEBD.

In the PEBD procedure a connection is created between the gallbladder and the skin so that a portion of the patient's bile may be drained through a small stoma to the outside of the body and removed from recirculation. As the patient's bile is drained to the outside of the body there is a net loss of bile salts and cholesterol and the levels in the blood decrease in parallel. This treatment essentially accomplishes the same goal as cholestyramine by removing bile salts and cholesterol from the body but it does so approximately 2 to 3x more effectively. This treatment has become relatively standard for the management of progressive familial intrahepatic cholestasis (PFIC), another familial cholestatic disease, in which it eliminates symptoms and arrests the progression of disease in the majority of patients.

We recently described the results of PEBD in 9 AGS patients to demonstrate the effectiveness of this procedure for relief of pruritus and xanthomas in AGS patients who fail medical therapy. Between the years of 1985 and 2001, 9 AGS patients underwent PEBD. The average age at PEBD was 4.8 years (youngest patient was 1.4 years old and the oldest was 10 years old). The average duration of follow-up was 7.5 years (shortest was 0.5 years and longest was 16.0 years). Patients with cirrhosis on liver biopsy or evidence of a failing liver (fluid accumulated in the abdomen (ascites), blood that won't clot despite vitamin K, or enlarged blood vessels in the gastrointestinal system (called varices) were not considered candidates for the procedure.

Pruritus was measured on a 0 to 4 scale where:

0 = none
1 = mild scratching when undistracted
2 = active scratching without skin injury
3 = scratching until skin injury
4 = mutilation of skin with bleeding and scarring due to scratching.

All 9 AGS patients had severe, mutilating pruritus (grade 4 itching) prior to diversion. One year after PEBD the average pruritus score was 1.1; 8 patients had only mild scratching when undistracted. Three patients with extensive xanthomas prior to PEBD had complete resolution within one year. Mean serum bile salt levels in 5 patients decreased from 136.5 to 37.1 μM/L (normal is less than 10 μM/L) and mean cholesterol in 7 patients from 724 to 367 mg/dl (normal is less than 200 mg/dl) 1 year after PEBD. A single 21-year-old patient with PEBD for 14 years experienced an increase in pruritus from grade 1 to grade 4 within 2 months of choosing to reverse the PEBD.

(Continued on page 4)

Corporate Contributions

Did you know that many corporations and small businesses will match donations to non-profit organizations? Some will even allow employees to donate time to a non-profit organization and then match that time with dollars sent to the non-profit organization. Others choose to do it through the United Way.

Every employer and state agency handles this differently, and we encourage you to talk to your human resources department to discover ways in which they can help the Alliance.

Biliary Diversion (continued)

This data supports that PEBD is effective for treating severe pruritus and hypercholesterolemia in AGS patients without cirrhosis who did not respond to medical therapy. PEBD should be considered as a therapeutic option for these patients prior to referral for liver transplantation.

Who should consider PEBD?

Alagille patients with mutilating pruritus (Grade 4) and/or patients with excessively elevated cholesterol levels (cholesterol >600 mg/dl) and disfiguring xanthomas who have not had relief from medical therapy. The effect on cholesterol is most marked in patients with highest levels.

How difficult is the stoma to care for?

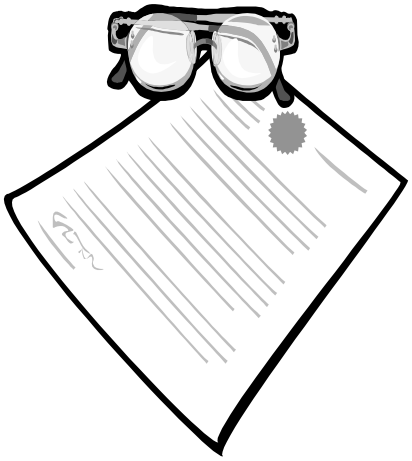
The stoma is about the size of a quarter and sits on the right side above the waist line. A child would drain about 60-120 ccs per day (over a 24-hour period) of bile which would be collected in a flat small bag (about 4" wide by 5" long) adhered to the child's skin. The bag is usually emptied once per day, is not visible under even a cotton t-shirt and never smells or makes noises. The bile looks like cooking oil and is odorless. Children with diversions can live a normal life and participate in whatever they would like to do including swimming (a small patch is placed over the ostomy with a water-proof dressing). Parents find the ostomy easy to deal with compared to not having slept for years and having watched their child scratch constantly.

How do children feel about the stoma?

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

How exactly is a PEBD done?

PEBD is performed by making a small incision in the skin of the upper right of the abdomen through which a 10cm segment of small bowel is separated from the



rest of the bowel. The rest of the small bowel is reconnected together and continues to function normally, minus 10cm of length. The separated segment is then connected to the gallbladder at one end and to the skin as an ostomy (just below the surgical incision) at the other end. Preoperative planning of the location of the stoma is important to avoid interference with the belt line, which is a problem in small children who have a protuberant abdomen.

What complications have there been?

One patient had minor bleeding at her stoma which resolved in 2 days, one patient developed a small scar from a stitch at the operative site, and one patient developed a bowel obstruction due to scar tissue (common surgical complication) 1 year after the PEBD and required a second surgery to remove the scar tissue.

Why does PEBD work?

By disposing of bile the procedure allows the body to waste bile salts and cholesterol which are being retained by the sick liver. It is possible that the PEBD also wastes "other" unnamed products retained from bile that cause the itching. The levels of the "other" products in the blood likely fall in parallel to the bile acids and promote relief. The decrease in bile acid levels seen after PEBD in our patients correlated with improvement in pruritus. We think of the mechanism of action of the PEBD as "Super Cholestryamine".

"One 10 year old patient when asked if he would like to get rid of his stoma 6 months after its placement declared "Don't even think about it!".

(Continued on page 6)

Special Thanks—to *all* the people who have made donations to the *Alliance* during the past 6 months:

In Honor of…

Jayson Wallasky's wonderful recovery
The Wallasky Family
Mary-Genevieve Moisan
Meg Osterhaus McNaught
Ann & Bob Osterhaus
Jane Osterhaus & Ray Townsend
Hannah Zinno
Sandy & Jim Hardin
Margo Pattison's Birthday
Anne & Brian Pattison
Their son with AGS
Nelson & Ruth Johnson
Justine Sawaya's Birthday
Julie Kelin
Christian Druckhammer
Judy Hoffman
Julia Hope Schiff's recovery
Merna & Steve Schiff
Ashley Meyers' Birthday & being a Sophomore in High School
Mr. & Mrs. Robert Pistorius
Justen Angel Giron's 2nd Birthday
Lorrie Ricci
Justen Ange Giron & just to help
Lee Bandh
Anthony Strukel
Matthew & Christine Strukel
Michael Blais' 8th Grade Graduation
Brenda & Dean Blais
Kevin Clark's 22nd Birthday
Darlene Clark
Alexis Baldwin's Bravery
Aurora & Brad Baldwin
Clara Sexton's Birthday
Karen McDonald
Connor Quillen's 3rd Birthday
Adair & Marie Hoskins
Nicole Rippentrop
Jeff & Karla Rippentrop
Taylor Maria Soule
Leonard & Patricia Roecker
Megan Lavallee's 6th Birthday
Marie Dolen
Ben Doehling's Birthday & Transplant Anniversary
Ted & Marian Doehling

In Memory of…

Walker Cannon
Bill, Evelyn & William Cannon
Carly Rosendal's Birthday & Passing
Jill Rosendal
Todd Laughlin
Mary Laughlin
Sammy Johnston's 7th Birthday
Patty Johnston
Matthew David Newman
Cody Leger
Shirley Christensen
Lynne E. Castle
Dorothy M. Chevalier
Thelma Lawson
Mr. & Mrs. Douglas Gremillion
Evelyn & Bill Cannon
David & Lynn Labrot
Brian Clifford
Dan & Debra Clifford

Symposium 2002 Friends…

John & Amy Moisan, In Honor of Mary-Genevieve Moisan
Walther & Caecilia Hahn, In Honor of Alaina Hahn
Barbara Bisgorve, In Honor of Patricia Nicole Espin Jurado
John & Mary Pat Osterhaus, In Honor of Mary-Genevieve Moisan
Anton & Sonja Luxhoj, In Honor of "A Special Grand daughter" Alaina Hahn
Anne & Brian Pattison, In Honor of Margo Pattison
Pat & Patti Everett, In Honor of Alex Everett
Paul & Rita Everett, In Honor of Alex Everett
Kent & Linda Anderson, In Honor of Joe Anderson

Julie Kelin
Jill Smith, your loving twin
Debbie Kelin Smith
Alisha Rovner
Daniel & Ruth Kelin
John W. Kelly
Mateo Gregory Marchel
Jean & Greg Marchel

General Donations…

Walther & Caecilia Hahn
Early Connections, Carol Sepowitz
Tibor Sipos, PhD, Digestive Care Inc.
Paul & Jane Fuglevand
Debby & Barry Meyers
Kimberly-Clark Foundation, Community Partners Matching Fund, for Volunteer Work by Erik K. Luxhoj
Sue Murbach
Keith Lin & Linda Tseng

Dan & Carol Kline, In Honor of Ryan Daniel Kline
Eric & Debra Herschmann, In Honor of Rachel Herschmann
Richard & Moonyeen Anderson, In Honor of Joe Anderson
Evelyn & Bill Cannon, In Memory of Walker Cannon & Matthew Newman
Steve & Stacy Parker, In Memory of Alyssa Parker
Madeline & Ernst Hurlimann, In Honor of Alex Everett

Remember…

The *Alliance* on special occasions for loved ones with AGS – birthdays, graduations, transplant anniversaries, or just because…With your help, the *Alliance* will continue to grow in members and services!

Biliary Diversion (continued)

Does it affect liver transplantation in the future?

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

Do children need any itching medicines after the Diversion?

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

What should I do if I would like to have my child considered for a PEBD?

You should seek consultation at a center experienced specifically in this surgery. You should also consider participating in a prospective study being done at our institution. The PEBD would be performed in the usual fashion by the surgeon who performed the PEBD in many of the patients from our previous study. The patient's blood levels, height, weight and degree of pruritus would be followed before and after the procedure. The advantages of participation would be that the procedure would be performed by a surgeon who is very experienced in this operation and your child will be followed closely. By participating you will also contribute to our understanding of how this procedure serves as effective therapy for children with AGS.

For more information or questions please contact Dr. Karan Emerick at Children's Memorial Hospital, email: KEmerick@childrensmemorial.org or call 773-975-8837. Arrangements for transportation and accommodations can be made through the

Other articles on PEBD:

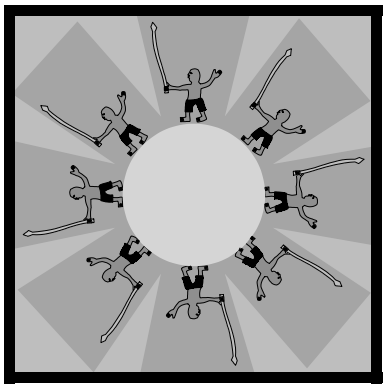
Partial External Diversion of Bile for the Treatment of Intractable Pruritus Associated with Intrahepatic Cholestasis
PF Whitington and GL Whitington, Department of Pediatrics, University of Chicago Pritzker School of Medicine, Wyler Children's Hospital, Chicago, IL, USA.
[*Gastroenterology*, Vol 95, 1988: pp 130-136]

Cholecystoappendicostomy in a Child with Alagille Syndrome
*Michael WL Gauderer and #John T Boyle
*Division of Pediatric Gastroenterology, Department of Pediatrics, Rainbow Babies & Children's Hospital, Cleveland, OH, USA; #Department of Pediatric Surgery, Children's Hospital, Greenville Hospital System, Greenville, SC, USA.
[*Journal of Pediatric Surgery*, Vol 32, No 2 (February), 1997: pp 166-167]

Long-tern Outcome after Partial External Biliary Diversion for Intractable Pruritus in Patients with Intrahepatic Cholestatis
Vicky Lee Ng, *Frederick C Ryckman, #Gilda Porta, #Irene K. Miura, +Elisa de Carvalho, ^Maria F Servidoni, Jorge A Bezerra, and William F Balistreri
Pediatric Liver Care Center and Divisions of Gastroenterology and Nutrition and *Pediatric Surgery, Children's Hospital Medical Center, University of Cincinnati, Cincinnati, OH, USA; #Universidade de São Paulo, São Paulo, Brazil; +Hospital de Base do Distrito Federal, São Paulo, Brazil; and ^Universidade de Campinas, São Paulo, Brazil.
[*Journal of Pediatric Gastroenterology and Nutrition*, Vol 30, (February) 2001: pp 152-156]

Quilts and Raffle Items Sought for Symposium 2002

The Silent Auction and Raffle was such a hit at Symposium 1999 that we want to do it all again, only bigger and better, at Symposium 2002! We need quilts, afghans, and other handcrafted items for the Silent Auction, and items or theme baskets for the Raffle.



Need some ideas for the Raffle? How about pecans from Georgia? Disney World passes from Florida? A Pendleton wool blanket from Oregon? Olympics memorabilia from Utah? Know any recording artists who would autograph a picture or CD? What about a sports legend who would sign a ball or bat? If every family that attends Symposium 2002 brings one or two items for the Raffle, just think of all the fun we'll have!!! Don't forget the kids, either—Beanie Babies were real popular last time...

Would you like to be Coordinator for the Silent Auction or Coordinator for the Raffle? Are you terrific with handcrafts or a fantastic quilter? Are you particularly adept at soliciting raffle items? We'd love to hear from you!!!!!

Contact Cindy Hahn at 503-639-6217 or email to alagille@earthlink.net. We need lots of help and if several people do something, one person won't have to do everything!

Symposium 1999 Scrapbook Needs Photos

Patti Everett is putting together a scrapbook for the Alliance of Symposium 1999 pictures. She'd like to include at least one picture of everyone that attended—that's a lot of photos!! In particular, she needs:

- pictures from the first evening's activities—Remember Mr. Bob, the parachute, and balls flying everywhere?,
- pictures of the children and their families and friends,
- pictures of the speakers—somehow, we missed getting any photos of our faithful medical and scientific folks, and
- pictures of the final morning raffle and closing.

Patti will be happy to make copies of your photos and return the originals to you. She promises to get them back to you in a very timely manner. If you have pictures to share, please send them to her at 550 West Magnolia Circle, Alpharetta, GA 30005 or email them to pattieverett@mindspring.com.

Thanks a million!!

Remember the AGS Quality of Life Surveys?..... PLEASE, Keep 'em Coming!!!

The return rate on AGS Quality of Life Survey that Dr. Karan Emerick sent to Alliance families last fall has been terrific—about 50% as of January 15, 2002. Dr. Emerick sends her thanks to all the families who have completed and returned the survey. Your input will be invaluable in understanding quality of life issues that affect the daily lives of AGS children.

If you haven't yet completed your survey, please consider doing so as soon as possible. Dr. Emerick would like to increase the return rate to 65% or more and this can only be accomplished if more surveys are returned!

If you have questions, or need more information, please contact Dr. Karan Emerick at Children's Memorial Hospital, email: KEmerick@childrensmemorial.org or call 773-975-8837.

Happy Birthday to You!

Congratulations to all who celebrated their birthday in the second half of 2001!

June

Iain A. Barr	7
Michael Blais	15
Gregory Bryant-Bruce	8
Claudia Jane Chung	6
Krista Doornenbal	8
Ryan Duncan	14
Neema Khazaie	5
Angeline Rae Macias	1
Jean K. Marchel	43
Justine Sawaya	14

July

Hayden "Link" Bryant	5
Dara Ann Dargatz	6
Jacob Reece Dragony	7
Christian Druckhammer	2
Drew Flores	3
Luke Harbur	6
Michael Hogan	6
Dylan Micallef	9
Jacob Neff	7
Michael Nichols	9
Adam Nietling	8
Celina Ouellette	5
Cara Siegel	32
Lauren Thornton	40
Carlie Hope Tomlin	Newborn

August

Grace Victoria Adams	6
Whitney Michelle Ballard	7
Cassandra "Caitlin" Clark	10
Zachary A. Damir	4
Tanner A.M. Faught	7
Hazel Fletcher	6
Alison Kempton	4
Claragh O'Keeffe	8
Margo Pattison	22
Nancy Ann Rodgers	27
Edward B. Rodgers	62
Nathan Smith	16

September

Marantha Lynn Beathard	7
Matthew Carrao	10
Alaina K. Hahn	11
Carl Hanson	9
Janice Kruger	39
Maria Jean Marchel	12
Camryn Belle Newby	1
Charlie Rader	31
Elizabeth Lee Ribal	15
Zachary D. Schrader	7
Jennifer Shafer	4
Serena Venturini	8
Myles Walsh	3
Grace Welden	3
Dwayne Page Wood	12
William Bryan Wood	14

October

Lillian "Lilly" Blackmon	2
Abigail F. Blankenship	4
Christopher M. Caldwell	7
Timothy D. Caldwell	7
Jason Doornenbal	11
Ivan F. Fernandez	4
Michelle Long	29
Justin Savage	19

November

Kaitlyn R. Bossler	7
Michael E. Capozzi	7
Alex Matthew Everett	6
Heather N. Fauth	4
Marquise Dobre Flowers	7
Emily Veronica Kruger	7
Erick Murbach	23
Jessica Needham	23
Luman A.J. Pinto Rodriquez	4
Devon Ramachandran	5
Nicole Rippentrop	8
Michael Shane Smith	10
Spencer Taylor	16

December

Joe Anderson	24
Katelyn Gajdosik	7
Frank D. Gerome	7
Ryan Johnson	1
Joseph Valente	5

In Memory

Jenica Ashley Bryant	4
Walker Cannon	9
Joshua David Garland	15
Hayden Gibson	10
Samual R. Johnston	7
Matthew D. Newman	12
Carly Rosendal	6
Crystal Wilson	11

In Loving Memory: Julie Kelin November 1, 1961—November 1, 2001

On November 1, 2001, Julie Kelin, an Alliance Board member since 1999 and loving mother of Justine Sawaya, was suddenly and tragically murdered in her home in El Cajon, California. It was Julie's 40th birthday. We are still trying to understand why this happened to such a sweet, kind-hearted, loving person.

The Alliance has posted a memorial to Julie on our website at www.alagille.org. A memorial service was held for Julie on November 26, in Spring Valley, CA, and another service will be held in December in Tacoma, WA. Here we include an excerpt from the memorial service held for Julie in Dallas, TX, in early November.

The lives that Julie touched are countless, her accomplishments many. Julie's number one passion was her daughter, Justine. From the day she found out about Justine's liver disease she dedicated the remainder of her life to raising awareness, fundraising, and education for the Alagille Syndrome Alliance. The love she had for her nieces was indescribable, as family was always a very important part of her life. Her other passions included softball, which she still played regularly, the theater, the San Diego Padres, amusement parks and roller coasters just to name a few. She was an avid Dallas Cowboys fan. She had recently decided on a career as an English teacher and was attending college to reach that goal. She will be missed more than any words can possibly say. We all draw comfort in knowing that God is now cradling Julie in his arms and enveloping her with His almighty love. With never ending love, Your Family

Julie is survived by her daughter, Justine Sawaya; her mother, Judy Swaggerty; her father, Kenneth Kelin; her twin sister, Jill Smith; and her brothers, Scott Kelin (Scooter) and Ken Kelin (Kenny).

Contributions can be made at any Bank of America location to the Julie Kelin Memorial Fund, or in Julie's memory directly to the Alagille Syndrome Alliance at 10630 SW Garden Park Place, Tigard, OR 97223. Anyone making a donation is asked to email Judy Swaggerty at jswagg5825@aol.com so that the family may express its gratitude.

LiverLink

The Newsletter of the Alagille Syndrome Alliance

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WE'RE ON THE WEB
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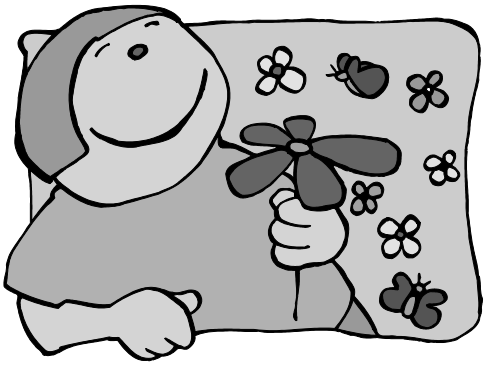


PSSSST!...

Symposium 2002 Update

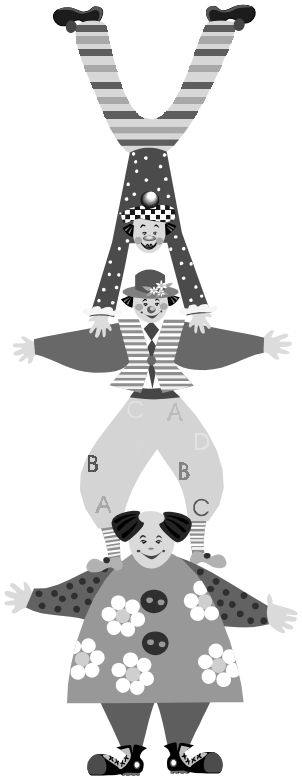
August 8-11, 2002! Don't forget those dates!

Many, many thanks to all the families who are supporting Symposium 2002 through their donations as "Symposium 2002 Friends"—the total is now $6,150!!! We're thrilled there is so much positive energy behind our second symposium. It's fantastic!

We're extremely pleased to announce that The Blowitz-Ridgeway Foundation in Chicago, IL, has provided a major educational grant for Symposium 2002. The grant will help reduce costs for families attending the symposium, pay for the child care and youth programs, provide funding for three speakers, and help defray the costs of registration and evaluation materials. We're on our way and working very hard to ensure that Symposium 2002 will be a positive, rewarding, and affordable experience for all the families who attend.

If you're wondering about air travel discounts to attend Symposium 2002, just wait until you here what we've arranged! For families traveling less than 1,000 from their home to Eastern College, free travel can be arranged with private pilots through Mercy Medical Airlift! For those traveling more than 1,000 miles, and those who prefer to travel on commercial airlines, super saver discounts are available through Rich Worldwide Travel in cooperation with Mercy Medical Airlift's National Patient Travel Center. Details about these discounts will be included in the Symposium 2002 Registration Materials, which will be ready for distribution in the next couple months.

We're psyched and hope you are, too, for a terrific symposium! Look for more information in the next *LiverLink*.



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