



2004 Issue 1

# C.L.A.S.S. Notes

NEWSLETTER OF THE CHILDREN'S LIVER ASSOCIATION FOR SUPPORT SERVICES

## New Life For Ian

By Michael Fallon, Ian's Living Donor

In August of 1993 I donated 40% of my liver to a 9-year-old boy who had Cystic Fibrosis. His name was Ian Young. Cystic Fibrosis tends to attack the liver and/or lungs. It is a fatal disease and most youth struggle to survive into their 20's. For Ian, it was the liver that was deteriorating fast. At the age of 9 it was apparent his liver would not sustain him. In 1993, the majority of all liver transplants were done with cadaver donor livers. The waiting list was long though, and people often died waiting. Ian's health was progressing from bad to very bad. He would not be able to wait. By the summer of 1993 there had been a number of live liver transplants done in the U.S. This procedure takes a portion of a living donor's liver and transplants it into the sick patient. It looked like this was the only option for Ian. Donat-

ing a liver is not like a bone marrow transplant. With a bone marrow transplant you must match some incredible number of variables and it is all very complicated.

*"I was a perfect match. We would be the first non-related live liver transplant to occur in the United States."*

That is why people across the nation get on the bone marrow transplant list and sick people still never find a match. With a liver transplant there are some variables but it really comes down to blood type, the health of the donor, and the liver itself. Apparently the liver has to have the veins and arteries orchestrated in such a way

that they can cut a big piece out and not disrupt the rest. Ian's Dad Jeff volunteered. But when he was tested it was determined that he was not a viable donor candidate. Four other members of his family were tested and none were a match. Somewhere in the midst of that, I knew I was to be the one. I volunteered but Deb said the hospital would only use a family member as a donor. But they were running out of time. Though the hospital was hesitant at first, they finally allowed me to be tested. I was a perfect match. We would be the first non-related live liver transplant to occur in the United States. The liver is an amazing organ. It has the ability to regenerate tissue. What that means is that when a portion is taken from a donor and inserted into the recipient,

*Continued on page 8...*

**April is National Donate Life Month... stories continue on page 8.**

## Get Ready for the Games!

The 2004 U.S. Transplant Games are July 27-August 1

The U.S. Transplant Games are an Olympic-style event held every other year for recipients of life-saving organ transplants including kidney, heart, liver, lung, pancreas, and allogenic bone marrow; and is presented by the National Kidney Foundation. In addition to the competition, recipients, families, friends, living donors, donor family members, physicians, and allied professionals come together to participate in educational programs, workshops, recognition ceremonies, and other scheduled activities. This year the Games will be held July 27 - August 1 at the University of Minnesota in Minneapolis, Minnesota. The aim of the Games is to call attention to the critical need for



more organ donors in the U.S. while showcasing the success of transplantation. The Games are also a tribute to the 4,000+ donor families who make the decision to give the *Gift of Life* each year. C.L.A.S.S. Kid Marisa McFate., 27-year-old liver recipient who will be competing in her 5th U.S. Transplant Games, writes: *"Donor families come to the Transplant Games after losing a loved one. They cheer us on despite the fact we may not be the recipient of their loved one's organs. But, to them, we are ALL their recipients and the embodiment of their gift, and that is the true meaning of the Games. Without donor families there would be no Transplant Games."* The 2004 U.S. Transplant Games will mark the world's largest-ever gathering of transplant



recipients, with more than 2,000 athletes representing 50 state teams. This year the Games will be celebrating the 50th anniversary of transplantation. The primary sponsor of the 2004 U.S. Transplant Games is Novartis Pharmaceuticals Corporation. Everything is available for recipients who are children, and parents should register their child for events the child wants to participate in! Transplant recipients of all ages participate in the Games and events are staged for young children. In addition, Kids' Time is scheduled on all 3 days of competition so there is something for children to participate in every day.



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### Special Interest in this Issue:

- National Donate Life Month
- 2004 US Transplant Games
- Meet Our "C.L.A.S.S.y" Kids & C.L.A.S.S. Volunteers!
- National Children's Dental Health Month
- West Nile Virus
- Kids Korner

## What is C.L.A.S.S.?

C.L.A.S.S. is an all-volunteer, nonprofit organization dedicated to serving the emotional, educational, and financial needs of families coping with childhood liver disease and transplantation. Our goal is to be both a service to families and a valuable resource for the medical community.

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**Disclaimer:** C.L.A.S.S. does not guarantee the accuracy of the information in this newsletter—it is intended only to keep you informed. Check all items with your physician.

## President's Message

Dear Friends:

You may notice a bit of a different look to our newsletter. With this issue we debut our new editor of C.L.A.S.S. Notes, Amy Bruemmer. Following in the footsteps of Dorothy Bourdon and Mika Denny, Amy has become our newest "super" volunteer to take on this important task. It takes a tremendous amount of effort to produce one of these publications, so a big "thank you" to Amy.



*Diane Sumner*

Please join me in also offering sincere thanks to outgoing editor Mika Denny for the many informative issues to which she gave birth. Through the dedicated efforts of Dorothy, Mika, and Amy, C.L.A.S.S. Notes has and will continue to bring timely information and resources those of us touched by pediatric liver disease.

Although the hustle and bustle of the holiday season is now behind us, we are as busy as ever planning our next two events. On May 1st we will again hold our annual Ladies High Tea fundraiser. For those that have attended previously, you know what an elegant and fun afternoon it is (even if it's raining!). If you will be in the Southern California area on the first of May, please plan on attending. I guarantee you will have a great time, and the proceeds help keep C.L.A.S.S. support programs up and running. In lieu of a holiday party this year, we are planning a C.L.A.S.S. summer picnic in Clearwater, Florida. Watch for information on what promises to be a great picnic! I always look forward to seeing all the kids, and being able to put faces to the many names that are part of the C.L.A.S.S. family.

Enjoy the new newsletter, and I hope to see all of you soon!



*Diane Sumner*

Diane Sumner  
 President • SupportSrv@aol.com

# C.L.A.S.S. 2003 Financial Report

<u>Income</u>	
<b>Ordinary Income</b>	
Bequests	9,066.00
Foundation/Gift/Grants	6,877.18
I Give	266.72
Individual Gifts	1,990.00
Matching Gifts	1,300.00
Miscellaneous Income	267.91
Restricted Funds	
Holiday Party	27.60
<b>Special Events</b>	
C.L.A.S.S. Tea	194.50
C.L.A.S.S. Kids T-Shirts	174.95
C.L.A.S.S. Coffee Mugs	183.25
C.L.A.S.S. Gift of Life Bear	143.25
C.L.A.S.S. Mythical Ball	2,324.00
C.L.A.S.S. Women's Tea	7,666.00
<b>Tributes</b>	
Honors	625.00
Memorials	2,600.00
<b>United Way Designations</b>	824.00
<b>Total Income:</b>	<b>34,530.80</b>

<u>Expenses</u>	
<b>Fund Raising</b>	
C.L.A.S.S. Tea	120.81
C.L.A.S.S. Mythical Ball	226.05
C.L.A.S.S. Women's Tea	2,488.16
Other	30.00
<b>Management/General</b>	
Bank Service Charges	23.74
Insurance	1,496.00
Misc.	276.21
Office Supplies	595.76
Permits	150.00
Postage & Delivery	300.00
Printing & Reproduction	45.21
Rent	765.00
Software, Computer Supplies	194.75
Taxes & Licenses	0.00
Telephone	60.57
<b>Patient Services</b>	
Direct Assistance	11,250.24
Holiday Party	35.17
Hotline	2,301.41
Postage & Delivery	1,855.13
Printing & Publications	4,677.00
Prof Fees & Services	332.90
<b>Total Expense:</b>	<b>27,102.97</b>

**Net Ordinary Income:** 7,427.83  
**Other Income:**  
 Interest Income 88.38  
**Net Income for 2003:** 7,516.21

## Letter to C.L.A.S.S.



I am writing to express my appreciation for all of your support on behalf of my transplant patients and families. Your agency has provided monies to three of our families who were in need of financial support. All of the families were extremely appreciative of your donations and your generosity has helped to lessen the burdens on our families during their difficult times. Once again, thanks. Your kindness will always be remembered.

Sincerely,  
 Allison Abel, GSW  
 Children's Hospital, New Orleans, LA

## Volunteer Spotlight...Kristy Kelly

I'm Kristy, 28 years old from NY. My husband Kevin and I have 2 children. Alyssa is almost 6 and our baby, Ashlee, is now 3 years old. Ashlee has Biliary Atresia and is listed for a transplant at Pittsburgh Children's Hospital. I get a lot of support and information from C.L.A.S.S. Because people have helped me so much, I wanted to give back in some way. I have been sending out care packages to children who are ill and in the hospital, or who have just been transplanted. People from all over send me items to include in the care packages. It first started out when Mika's son asked for books for his birthday so he could donate them to Drew's liver friends. Then Kari, angel Jayli's Grandma, made beautiful mini quilts to include in the packages. This started the C.L.A.S.S. Care Packages - books, a quilt, and a C.L.A.S.S. bear. It has grown to things like books, bears, crayons, stamps, cameras, mini photo albums, pens, coloring books, hand sanitizer, quarters, snacks. Items for both parents and children are included. It is a wonderful thing. I love sending them out. It is great knowing you're doing something special for all the people who have helped you. If you would like to donate anything please send to: Kristy Kelly, 7H Baybrook Dr., Queensbury, NY 12804. We need small items now. Crayons, stamps, disposable cameras, hand sanitizer, snacks, socks, slippers, etc. Whatever you want to send is appreciated by all who receive. We have plenty of books at the moment. Thanks!!! • *Thank you, Kristy, for all you do for C.L.A.S.S.!*

Want to see something featured in C.L.A.S.S. Notes? Send in your ideas, comments, stories, or pictures to: ATTN: C.L.A.S.S. Notes Editor, C.L.A.S.S., 27023 McBean Parkway # 126, Valencia, CA 91355. You may also email: CLASSNotesNews@aol.com. Images sent via email must be in .JPG or .BMP format. C.L.A.S.S. reserves the right to edit all items as needed.



# 2004 Family Information Form



**C · L · A · S · S**  
CHILDREN'S LIVER ASSOCIATION FOR SUPPORT SERVICES

**IMPORTANT!**  
We are updating our database. Even if you have filled out this form before, please fill out and send in a NEW form with your current information. Thank you.

## 1 Parent/Guardian Information

Name(s): \_\_\_\_\_ Relationship: \_\_\_\_\_  
Street: \_\_\_\_\_ Home Phone: \_\_\_\_\_  
City: \_\_\_\_\_ State \_\_\_\_\_ Zip Code \_\_\_\_\_ Country \_\_\_\_\_  
Email: \_\_\_\_\_ Primary Language Spoken in your home: \_\_\_\_\_  
Personal Website Address (URL): \_\_\_\_\_

## 2 Child With Liver Disease/Disorder/Transplant

*(If you have more than one child with liver disease, please copy this form and complete for each child.)*

Child's First and Last Name: \_\_\_\_\_ Gender \_\_\_\_\_  
Liver Diagnosis: \_\_\_\_\_  
Other Diagnosis child has: \_\_\_\_\_

Birth date: \_\_\_\_\_  Single Birth  Multiple Birth: \_\_\_\_\_

➔ May we include your child's name and age in the C.L.A.S.S. Newsletter Birthday List?  Yes  No

## 3 GI Doctor/Hospital Information

GI Doctor: \_\_\_\_\_ Hospital: \_\_\_\_\_  
Has child had Kasai Procedure?  Yes  No  N/A Age at Kasai: \_\_\_\_\_  
Hospital Where Kasai took place: \_\_\_\_\_  
All other surgeries/procedures: \_\_\_\_\_

## 4 Liver Transplant Information

My child has stable liver disease/disorder and does not need a transplant at this time.  
 My child is currently on the UNOS waiting list. Current PELD Score: \_\_\_\_\_ Date Listed: \_\_\_\_\_  
 My child has had a liver transplant.  
Check one:  OLT  Split Liver  LDLT Person who donated: \_\_\_\_\_  
Date of Transplant: \_\_\_\_\_ Transplant Hospital: \_\_\_\_\_  
Other Transplanted Organs: \_\_\_\_\_  
 My child has had a second liver transplant  
Check one:  OLT  Split Liver  LDLT Person who donated: \_\_\_\_\_  
Date of Transplant: \_\_\_\_\_ Transplant Hospital: \_\_\_\_\_  
Other Transplanted Organs: \_\_\_\_\_

➔ May we include your child's name and age in the C.L.A.S.S. Newsletter Transplant Anniversary List?  Yes  No

## 5 Allergy Information

My child has no allergies.  My child has allergies (list): \_\_\_\_\_

## 6 Current Medications my child is taking:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

➔ Don't forget to fill out both sides of the form!

# 2004 Family Information Form

Continued from Previous Side

## 6 Health Complications

(please explain): \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## 7 Parent Matching Program

I would like to request a Parent Match based on (check all that apply):

- Diagnosis     Geographic Location     Hospital/Transplant Center  
 Bereaved Families     Other: \_\_\_\_\_

You may add my name and information to the Parent Matching Database so that others may contact me:  Yes  No

Parent/Guardian Signature: \_\_\_\_\_ Date: \_\_\_\_\_

By signing above, I give my permission for the Children's Liver Association for Support Services (C.L.A.S.S.) to release my name and contact information to another parent asking for support. I understand my name will not be released for any other purpose and that the information contained in this form is strictly confidential.

## 8 Status Information

My child has passed away. Date of passing: \_\_\_\_\_  
Information you would like to share: \_\_\_\_\_  
\_\_\_\_\_

➔ May we add your child's name, age, and date of passing to a special Memorial Anniversary section of the C.L.A.S.S. Newsletter?  Yes  No

## 9 C.L.A.S.S. Website (www.classkids.org)

You may include my child's information on the C.L.A.S.S. Website.  Yes  No

You may include my child's photo on the C.L.A.S.S. Website.  Yes  No

You may include a link to my email address on the C.L.A.S.S. Website along with my child's story.  Yes  No

➔  I have included my child's story for the website on an additional sheet of paper along with this form.

Note: Only first names are used on the C.L.A.S.S. website. Phone numbers and addresses will not be posted.

C.L.A.S.S. reserves the right to edit your story as needed.

➔  I have included my child's photo for the website along with this form.

Please include any additional information you wish to share with C.L.A.S.S. on a separate sheet of paper.

Signature of Person Filling out this Form: \_\_\_\_\_ Date: \_\_\_\_\_

By signing above, you are stating that all information provided on the form is true and accurate to the best of your knowledge.

### Mail This Form Back Today!

Important! We are updating our database. Even if you have filled out this form before, please fill out and send in a NEW form with your current information. Thank you.

Mail to: C.L.A.S.S., 27023 McBean Parkway #126, Valencia, CA 91355

## C.L.A.S.S. Picnic: Smiles, Sun, & Sand!



Mark your calendars and get ready for some fun, fun, fun! C.L.A.S.S. is having a picnic/seminar weekend for families of children living with liver disease (both pre and post transplant) which is scheduled in Clearwater, Florida for June 25-27, 2004. Most families will be staying at the Red Roof Inn, which is right on Clearwater Beach - make your reservations now! The goal of this year's gathering is to have all activities scheduled within walking distance to the hotel. There will be speakers from Shands Children's Hospital of Gainesville, FL this year speaking on the topics of allergies and immunizations. Tentative plans: arrive on Friday, pizza party Fri. night, Seminar on Saturday (possibly on a boat - plans still in the works), lots of fun free time Sat. afternoon/evening, and on Sunday to take a cruise

on the "Pirate Ship" followed by the picnic on the beach. It's a great time to meet other C.L.A.S.S. families, and is sure to be a fantastic experience! Families are responsible for their own transportation, hotel, and meal costs. There may be additional expenses as plans are finalized. For more information about the C.L.A.S.S. picnic, please contact the C.L.A.S.S. Picnic Coordinator, Katie Purnell, via email: [kpurnell1@tampabay.rr.com](mailto:kpurnell1@tampabay.rr.com), or by phone: (727)796-2376. You are responsible for making your own hotel reservations. \*Please Note!\* You must call directly to the Red Roof Inn in Clearwater and NOT the Red Roof Central Reservations to make your reservations for this event in order to ensure our group rate! Red Roof Inn, 421 S. Gulfview Blvd., Clearwater Beach, FL 33767 Phone: 1-877-905-7663 • **Hope to see you there!**

## Remembering our C.L.A.S.S. Kids



Jayli Doremire

Sunrise December 28, 2000

Sunset April 24, 2003

Jayli was born with Biliary Atresia and had her first transplant when she was 8 months old (living donor). She developed a clot on her portal vein and was retransplanted when she was 16 months old. She experienced a lot of complications from the second transplant. Mainly infections and complications from being too immune suppressed. And chronic rejection. Last of all, PTLD (non ebv related). She passed away while waiting for a third liver. Jayli had a huge bleed and no one knew what caused it. The autopsy showed she had PTLD in her liver, kidneys, and head. She was actually bleeding from her liver. (we thought the ptd was gone). I'm glad we had the autopsy done because I know she never would have survived a third transplant.

By Andrea Doremire,  
Jayli's Mommy



Jayli memories: "Jayli Bug", paci's, Jayli's "baby", rainbows, stinky feet!, the Jayli Balloons, "Oh yea!"

## Time for Tea



It's almost that time of year again. Please hold the date of May 1, 2004. This year we will again hold our annual Women's tea at the home of Dr. and Mrs. Ronald Singer in Canyon Country, California. I have ordered up a wonderful day, no rain we hope. We look forward to seeing all of you again this year.

## Biliary Atresia Research Update and Reception

This conference is scheduled for Sunday, April 25, 2004, and will be held at the Westin Hotel, 99 South 17th Street at Liberty Place, Philadelphia PA 19103, from 12:30-4:00pm. It is open to families, friends, and medical professionals. The purpose of the event is to update parents and providers about developments in biliary atresia (BA) research, share information about the National Institutes of Health's Biliary Atresia Research Consortium (BARC) and



provide information about ALF efforts to raise funds for research via the Biliary Atresia Fund for the Cure. Additionally, there will be an opportunity for parents and families to network and share information about their experiences. Should you have any questions please contact Jessi Erlichman, Coordinator of the Biesecker Pediatric Liver Center at Children's Hospital of Philadelphia, via phone: 215-590-2525 or by email: [erlichman@email.chop.edu](mailto:erlichman@email.chop.edu) •

## April National Donate Life Month

### NEW LIFE FOR IAN (CONT. FROM PAGE 1)

the liver will grow as the recipient grows. Additionally, the portion of the liver that is taken from the donor can be regenerated by itself if it needs to be. The doctor informed me that they would be taking 40% of my liver instead of the normal 20% and he would have to remove the gall bladder to get the larger piece. I remember asking, "What exactly does the gall bladder do?" He told me, "Nothing really, you won't miss it." To this day I don't really know what the gall bladder does. But I think I do miss it. The other thing that we found out was the Ian's body might reject the liver. But if he didn't reject, the CF would no longer be a life threatening issue for Ian. It originated in his liver and when that liver was removed, so would the majority of his CF battle. He could live as long as a normal male life expectancy permitted. We were really thrilled now. The next morning they explained that there were really 2 teams of doctors. One team would be removing the piece of liver out of me. While they worked, the second team would prep Ian but would not be cutting into him until they actually extracted the piece out of me. They wanted to physically hold and look at my liver to be sure

it would be a fit before cutting Ian open. Good for Ian, kind of a downer for the donor. They could take it out of you, find a flaw, and close you up. Fortunately it was exactly what they expected to see and they completed the transplant. When it was complete, the doctors were very pleased with their work. I guess it was a good fit. They felt that everything went as it was supposed to, it seemed to be working, and now it would just be a matter of time to see if Ian's body rejected or sustained the "foreign" body. We received a lot of publicity because we were the first non-related live liver tx in the US. But in the end, our reward was measured by Ian's life & standard of living. He plays music, is a great student, & brings a lot of joy to his parents, teachers, & friends. The event taught us about love, God's peace & His miracles, doctors, hospitals, the media, and the amazing liver. It also taught us about the incredible gift of life we've all been given. We celebrated our 10 yr. anniversary at Ian's high school graduation party last summer. They took a picture of us with our shirts raised and our scars showing. We were both smiling. •

### My Son Dan

Dan was born on January 13, 1975 at 11:59 pm the oldest of our 3 children. Dan liked to be outside and around farms and the equipment. Dan would spend time during the summers at his grandparent's small farm. Dan began operating small equipment at 10 years old and loved to do fieldwork. His first job was at a neighbor's farm after school and weekends milking cows; after high school his fulltime job was working on a large farm in Wisconsin. Dan liked to deer hunt, go bowling, and hang out with his friends. On November 10, 1996, Dan spent the evening at a local bar with friends. At closing time he made the unwise choices to drive away from the bar in his car and not wear a seatbelt. Dan missed a curve and rolled his car 3 miles from the bar on his way home. He was partially thrown out of the passenger door of the car and the injuries he sustained left him brain dead. We were asked later that morning at the hospital if we knew anything about or would consider organ and tissue donation for Dan. We told Dan's nurse yes we would be very willing to let Dan become an organ and tissue donor. Our feelings were that maybe something good would come out of this rotten mess. No one could save Dan, but now he had the opportunity to save others. Dan donated his heart, liver, both kidneys, and pancreas. Dan has 4 organ recipients that are alive and doing well 7 years after he became a donor. Dan also donated his eyes, skin, bone, and the tendons from his

*"Dan left a far-reaching legacy that day that affected many individual's lives in a positive way. I am very proud of my 21-year-old son."*

knees. Dan left a far-reaching legacy that day that affected many individual's lives in a positive way. I later learned Dan had signed his driver license indicating he wanted to become a donor if something happened to him. I am very proud of my 21-year-old son. I had no idea how your life is affected by the loss of a child until Dan's death. My life changed forever when the phone rang at 2:30 am Sunday morning and it will never be the same as it was before. Family pictures, gatherings, and everyday of my life, one of my children is missing. Knowing Dan helped others with his donations and saved other families from this terrible loss helped to make it easier to deal with his death. I know some of Dan lives on in his recipients. I began speaking to driver education classes, groups, anyone looking for information about organ and tissue donation 6 months after Dan's death. I needed to try to make a difference. Organ and tissue donation are so very worthwhile and needed that if I educate one person and they are willing to become a donor, then Dan has helped even more. I try to make every month Organ Donor Awareness Month as April is. This message needs to be spread every day of the year so more individuals become donors and less families have to say good-bye to their loved ones too soon. Remember - sign your driver license, but most importantly, speak to your family about your decision! •

*By Sherry Linzmeier, Dan's Mom*

## April National Donate Life Month

### Missy's Gifts

My name is Julie and I'm married to this wonderful guy, John. Together we have three children: Chris (25), Brad (24), and Missy who would have been 22. Missy died of a cerebral A.V.M. (which is somewhat like an aneurysm) at the age of 11.

Our story began on Aug. 20, 1992 when I got a call at work from our son Chris, who was 13 at the time, saying "Mom, Missy is acting funny and she is lying on the floor throwing up." She got a headache at noon and by 12:35 p.m. she was in a coma never to regain consciousness. Chris and Brad (who was 12) were with her a short time, but it must have seemed like forever.

Twenty-nine hours later we made the decision to donate Missy's organs. My husband was very reluctant to mention organ donation to me. You see, 26 years ago when we were dating, I had John take organ donor off of his license. I heard bad rumors and never bothered to ask someone or check things out. We never talked about it again. Then when we realized that Missy was not going to get better, John asked me reluctantly what I thought about organ donation. He had no idea how I would react. All of a sudden, it was like a light shined around, and John couldn't believe how my eyes lit up. I said "yes". I would not want another family to go through this heartache we were feeling if we could help it. The feeling is like something is reaching in your chest and pulling your heart. What better way for Missy's legacy to go on but through others? In my heart I could not imagine Missy's job here being complete. She did so much good in her short life.

There are four people who continue healthy lives because of her gift. We have met Connie from Iowa on several occasions, one of which was a Thanksgiving dinner with her family. She received Missy's kidney. Tiffany, who is now 13 from Colorado, received Missy's heart valve. Anselmo, who is from Italy and is now 12, received her heart valve also.

*"There has not been one moment of regret for our decision to donate... We love you, Missy."*

We have met them on a couple of occasions. Ron, a gentleman from California, received Missy's kidney and liver 13 days after he signed a durable power of attorney that on day 14 all life support would be shut off. Ron was in the U.S. Transplant Games in 1994 and received a silver medal. He later sent it to us saying that without Missy's gift he would not have been able to accomplish this. Oh did we cry. What a difference Missy has made.

Organ donation has been a God send to us. There has been so much support through our organ procurement center (Lifesource), the National Kidney Foundation, and many other donor families and recipients. Without all this we would have been even more devastated. With this support it eased the pain a little.

We have been to the 2000 and 2002 U.S. Transplant Games and this is such a wonderful experience. People who were once wishing they could just die were competing in Olympic style events. It just brings tears to your eyes. They have such a love for life and are so grateful for your loved one's gift of life. We have many new friends who are so kind and wonderful. Recipients are such a great group of people.

There has not been one moment of regret for our decision to donate Missy's organs. I would like to feel that we have helped taking on Missy's legacy in her memory by giving talks to church groups, hospital officials, and schools. We also volunteer to hand out information at games and the state fair. Our goal is to make as many people aware of how precious life is and to share their wishes with their family about donation.

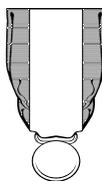
We miss Missy greatly and know we will all be together one day in this great place. Until then we will continue our legacy and hers in her memory.

We love you, Missy. Love Mom, Dad, Chris, Brad, Andrew, and many other family and friends. •

*By Julie Schlueter, Missy's Mom*

### 2004 US Transplant Games (cont. from page 1)

Travis Kitch, father of 2-yr-old C.L.A.S.S. Kid Carson who is a liver recipient and will be competing in his first U.S. Transplant Games this year, shares his thoughts: "As the (U.S.) Transplant Games approach, I think back to the time when Carson was at his sickest and most desperately needed a liver transplant...he would have died in a matter of weeks had our donor family chosen not to donate the organs of their loved one. So as I watch Carson run the 50 meter dash and throw the softball alongside all those other wonderful transplant recipients, I will hold a special thought in my heart for the family that lost so much and gave us everything." Jina McKenna, who has attended the U.S. Transplant Games in the past with her son, C.L.A.S.S. Kid Jackson, explains how emotional the events really are: "What an experience! As the youngest athlete (at the 2002 U.S.



Transplant Games), Jackson had the honor to participate in Opening and Closing Ceremonies. This was a once in a lifetime opportunity that we will never forget. We met so many amazing people and made many new friends. Through it all, we remember our donor and we are thankful to our donor family for giving us the chance to make these memories." The website for registration and for information about this year's Games: <http://www.transplantgames.org>. Registration deadline is May 31, 2004! Individual State Team registration deadlines may be sooner, so please check with your respective State Team Managers. If you are unable to register online or don't have access to the Internet, you can call the National Kidney Foundation to get help in registering or for more information: (800) 622-9010.



**Carly B.**  
Age 6  
Biliary Atresia  
Liver Tx. Jan. 1999



**Erin B.**  
Age 2  
Prim. Hyperoxaluria Type 1  
Liver Tx. Apr. 2002



**Jamie B.**  
Age 20  
Biliary Atresia, Alagille Synd.  
Liver Tx. Dec. 1988



**Nick B.**  
Age 9  
Biliary Atresia  
Kasai, Stable



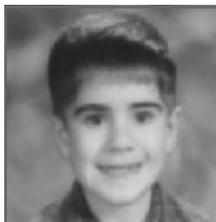
**Wyatt B.**  
Age 1 1/2  
Biliary Atresia  
Kasai, Stable



**Gabriela C.**  
Age 12 months  
PFIC  
Liver Tx. Jan. 2004



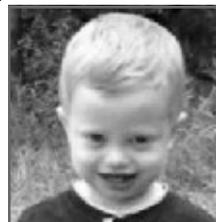
**Gilbert C.**  
Age 4  
PFIC  
Liver Tx. Jun. 2000



**Kyle C.**  
Age 4  
Biliary Atresia  
LD Liver Tx. Dec. 2000



**Drew D.**  
Age 4  
Biliary Atresia  
Waiting for Liver Tx.



**Eric F.**  
Age 3  
Biliary Atresia  
Liver Tx. Aug. 2003



**Kallie Sue F.**  
Age 17 months  
Biliary Atresia  
Waiting for Liver Tx.



**Kyle F.**  
Age 20 months  
Alpha-1 Antitrypsin  
Deficiency  
Liver Tx. Dec. 2003



**Sami F.**  
Age 3  
Alpha-1 Antitrypsin  
Deficiency  
Waiting for Liver Tx.



**Chedaya G.**  
Age 2  
Biliary Atresia  
Kasai, Stable



**Sarah G.**  
Age 7  
Autoimmune Hepatitis  
PSC  
Waiting for Liver Tx.



**Marisa H.**  
Age 11 months  
Biliary Atresia  
Waiting for Liver Tx.



**Jaime I.**  
Age 4  
Biliary Atresia  
Liver Tx. Jan. 2001



**Zashayrah Zoe I.**  
Age 6  
PFIC  
Part. Ex. Biliary Div.  
Stable



**Ali J.**  
Age 12  
Alpha-1 Antitrypsin  
Deficiency  
Liver Tx. Apr. 1992



**Ashley J.**  
Age 5  
Biliary Atresia  
Kasai + revision  
Stable



**Lauren J.**  
Age 10  
Biliary Atresia  
Stable



**Jason J.**  
Age 5  
OTC Deficiency  
2 Liver Tx's. Dec. 1998



**Ashlee K.**  
Age 3  
Biliary Atresia  
Waiting for Liver Tx.



**Carson K.**  
Age 2  
Biliary Atresia  
Liver Transplant Dec. 2001



**Adalyn "BooBoo" L.**  
Age 3  
Choledochal Cyst  
Liver Tx. Dec. 2001



**Jen L.**  
Age 17  
Alpha-1 Antitrypsin Deficiency  
2 Liver Tx's.  
Feb. 1993 & Dec. 2002



**Jon L.**  
Age 13  
Alpha-1 Antitrypsin Deficiency  
Liver Tx. Mar. 1993



**Ayden M.**  
Age 2  
Biliary Atresia  
Kasai, Stable



**Jackson M.**  
Age 3  
Biliary Atresia  
Liver Tx. Feb. 2001



**Marisa M.**  
Age 27  
Biliary Atresia  
Liver Transplant May 1988



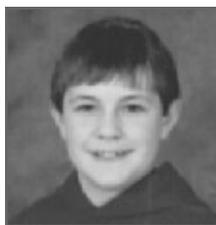
**Shelby M.**  
Age 21 months  
Biliary Atresia  
Waiting for Liver Tx.



**Gabriel Anthony "Munchie" P-P.**  
Age 2  
Biliary Atresia  
Liver Transplant Nov. 2001



**Shyam P.**  
Age 3  
Biliary Atresia  
Stable



**Derek R.**  
Age 11  
Biliary Atresia  
Liver Tx. Mar. 1993



**Willis R.**  
Age 9  
Biliary Atresia  
Kasai, Stable



**Zachary R.**  
Age 4  
Biliary Atresia  
Liver Tx. Aug. 2001



**Zachary R.**  
Age 2  
Biliary Atresia  
Kasai, Stable



**Connor S.**  
Age 5 months  
Biliary Atresia  
Kasai, Stable



**Othello S.**  
Age  
Gastroschisis  
5 Organ Tx. Apr. 2003



**Rylie S.**  
Age 7  
Undefined Liver Disease  
Stable



**Annika T.**  
Age 3  
Biliary Atresia  
Liver Tx. x2  
Oct. 2001 and Jan. 2002



**Claire T.**  
Age 4  
Biliary Atresia  
Kasai, Stable



**Haley V.**  
Age 10  
Autoimmune Hepatitis  
Lupus Complications



**Alec W.**  
Age 2  
Biliary Atresia  
Kasai, Stable



**Kayla W.**  
Age 6  
OTC Deficiency  
Liver Tx. Aug. 2000



**Lucy W.**  
Age 5  
Biliary Atresia  
Liver Tx. Mar. 1999



**Sean W.**  
Age 7  
Alpha-1 Antitrypsin Def.  
Liver Tx. Mar. 2000



**Madison "Smoochie" Y.**  
Age 2  
Biliary Atresia  
Kasai, Stable

## Don't Forget to Brush!

By Michael P. Healey, D.D.S. P.C., Dental and Orthodontic Care for Children

Children who are organ transplant candidates present with some unique challenges when it comes to receiving good dental care. Prevention is one of the keys to preventing complications, and the children who continue with an aggressive preventive program usually have healthy dentitions. This can be key in maintaining good nutrition during all your child has to endure. Unfortunately, some children are in crisis so often that the dental care is placed on the back burner and then they present with problems that take unique solutions to solve.

Dental decay is caused by streptococcus bacteria. When these bacteria enter the innermost layer of a tooth, the pulp chamber, they are then spread throughout the body.

Tagged bacteria introduced to a pulp chamber in controlled experiments has been harvested from the hand in 15 minutes. Obviously, the damaged organ is eventually reached and can cause complications. Prophylactic antibiotics are required for invasive dental treatment. Many of the medications used in dentistry are metabolized in the liver. Lidocaine and epinephrine are two such medicines. Sedatives such as valium and versed are also metabolized there so lower amounts should be used for your child if a pre-transplant condition is present. Immunosuppressive medications for post transplant children will suppress the infection fighting ability so prophylactic antibiotics are also required. Some of the medicines used to retain the transplanted organ have

February is  
National Children's Dental Health Month!



oral side effects. Cyclosporin will exacerbate the gum tissue response to the bacteria laden plaque on the teeth. This gum tissue may overgrow and actually move the teeth. This gum tissue bleeds easily and becomes a source of infection. We generally remove it surgically in a hospital setting. Fortunately, transplant teams have access to specialists in pediatric dentistry who have had formal training to treat these problems. I often coordinate care with general dentists for children living in outlying areas. If any questions arise, either ask the transplant team or other parents who they recommend. Children who have had transplants can safely receive most care dentistry has to offer including orthodontics when the appropriate care is taken. •

## West Nile Virus

The Health Resources and Services Administration, Special Programs Bureau, Division of Transplantation is issuing this notice to the transplant community to provide clarification about available West Nile virus (WNV) diagnostic and screening tests, and to provide guidance for the use of these tests in the setting of organ donation and transplantation.

### **Background:**

WNV is a flavivirus transmitted to humans from birds through the bite of infected mosquitoes. In immunocompetent individuals, the incubation period ranges from about 2-14 days, but may be longer in immunocompromised individuals. Although the majority of infected individuals are asymptomatic, WNV produces flu-like symptoms such as fever, headache, malaise, and body aches in approximately 20% of infected individuals. Less than 1% of infected individuals develop severe disease such as encephalitis or meningitis. However, immunocompromised individuals may be at greater risk for severe disease.

WNV IgM tests are available for diagnostic use in individuals with clinical symptoms suggestive of WNV infection. Detectable levels of IgM antibody to WNV may not be present during the first week of illness; antibody production in an immunocompromised individual may be delayed or absent. By the time antibody is detectable, the viremia may be at a very low level or resolved. Testing with WNV IgM antibody-capture enzyme-linked immunosorbent assay is available through the Centers for Disease Control and Prevention (CDC), many state and local health departments, and a few commercial laboratories. The Food and Drug Administration (FDA) recently approved a WNV IgM test kit manufactured by Pan-Bio; any accredited laboratory may purchase this kit. Because there may be cross-reactivity with other closely related flaviviruses, a positive WNV IgM test should be confirmed by more specific testing (e.g. plaque reduction neutralization test available only at CDC and a few State public health laboratories). Also, IgM antibodies to WNV may persist for 6 months or longer; a positive test for IgM therefore is not suggestive of an acute infection by WNV unless it is associated with a recent compatible illness. In general, IgM tests should not be used for screening asymptomatic individuals.

WNV polymerase chain reaction (PCR) assays, which detect nucleic acid sequences, also are available through a few commercial laboratories for diagnosing WNV infection. WNV nucleic acid amplification tests (WNV-NAT) can detect viremia

early in the course of infection before antibodies are produced. Because viremia may peak before the onset of symptoms and because the majority of infected individuals do not develop symptoms, WNV-NAT may be effective for screening of asymptomatic individuals. Nucleic acid tests manufactured by Roche and Gen-Probe currently are in use under Investigational New Drug applications (IND) for screening blood donors. False positive and false negative results may occur. The investigational protocols include confirmatory testing of initially reactive samples. All civilian blood donations in the U.S. have been screened with WNV-NAT since July 14, 2003.

No specific therapy has been found and the treatment of WNV illness is supportive. Omr-IgG-am,™ an Israeli source intravenous immunoglobulin containing high titers of WNV neutralizing antibodies, is currently under Phase I/II study to assess its safety and efficacy in treating patients with, or at high risk for progression to WNV encephalomyelitis. Further information about this randomized, placebo-control trial sponsored by the National Institutes of Health is available on the Internet at [www.clinicaltrials.gov](http://www.clinicaltrials.gov).

### **Screening of Organ Donors and Recipients:**

The nucleic acid tests manufactured by Roche and Gen-Probe are now available for investigational use in screening organ and tissue donors; the specimen must be obtained while the donor's heart is still beating. There still are some factors that may make WNV-NAT screening impractical for use in decision-making about organ acceptance and counseling of potential recipients:

Under the current INDs, WNV-NAT is performed at a limited number of testing sites. In addition, only a limited number of these sites have expressed interest in testing samples from organ donors.

Many of the testing sites use a mini-pool format to perform the initial screening. If the mini-pool is reactive, the component samples then are tested individually to identify the reactive sample(s). A single donor format is preferable for screening organ donors.

Although it may take as little as 4-6 hours to actually perform the WNV-NAT, the turn-around from the time that the donor blood sample is drawn until the result is reported back to the hospital may be 24 hours or longer. This delay is due to factors such as transport of the sample to a distant site, validation steps in the investigational protocol, and procedures for reporting results. Some testing sites may be able to provide faster turn-around. For non-urgent living

donor transplants, the long turn-around should not pose a problem. However, for deceased donors, it is likely that some or all of the organs will have been transplanted prior to availability of the screening test result. Despite these possible delays, a reactive test result reported after the organs have been transplanted has some value for counseling and monitoring the recipients, and potentially for the administration of a particular therapy (e.g. Omr-IgG-am™) should one be available.

Given the practical limitations of using these screening tests and given that they are still investigational, HRSA does not maintain that screening of all organ donors with WNV-NAT should be required at this time. Once a WNV-NAT is licensed and more widely available, the appropriateness of required screening should be reassessed. An OPO that desires to pursue use of one of the investigational tests to screen organ donors should contact a testing site and negotiate with the investigator at that site the cost, logistics of sample delivery and result reporting, and turn-around time.

### **Recommendations:**

#### **HRSA encourages the following measures:**

Defer potential donors with encephalitis, meningitis, or flaccid paralysis of undetermined etiology who resided in geographic areas with known human WNV activity (Consult the State or local health department for up-to-date information on human WNV activity in the particular geographic area.)

Exercise a high index of suspicion of WNV infection if an organ transplant recipient develops a febrile illness. Perform a WNV IgM test and a WNV-NAT if WNV infection is clinically suspected.

Consider screening of living donors with WNV-NAT as close to the time of donation as possible. If WNV-NAT is performed on potential donors, HRSA recommends the following measures in response to reactive WNV-NAT results:

#### **For Deceased Donors**

1. *If the donor WNV-NAT is reactive, and the organs have not been transplanted:*

Consider transplanting the organs only if the potential recipient has an emergent, life-threatening illness requiring transplantation when no other organs are available and no other lifesaving therapies exist.

Inform the potential recipient of the risk and potential consequences of acquiring WNV infection.

Consider enrolling the recipient in a clinical trial of Omr-IgG-am™ if the recipient develops symptoms suggestive of WNV infection and the recipient meets trial eligibility criteria.

2. *If the donor WNV-NAT is reactive, and the organs already have been transplanted:*

Inform the recipient of the risk and potential

*Continued on page 13...*

**West Nile Virus (cont.)**

consequences of acquiring WNV infection. Monitor the recipient closely for development of fever, headache, meningitis or encephalitis of unexplained etiology, and perform a WNV IgM test and a WNV-NAT if WNV is clinically suspected. Consider enrolling the recipient in a clinical trial of Omr-IgG-am<sup>TM</sup> if the recipient develops symptoms suggestive of WNV infection and the recipient meets trial eligibility criteria.

**For Living Donors**

1. If the donor WNV-NAT is reactive, and the transplant is non-urgent:

Defer the donor for 28 days

2. If the donor WNV-NAT is reactive, and the potential recipient has an emergent, life-threatening illness requiring transplantation when no other organs are available and no other lifesaving therapies exist:

Inform the recipient of the risk and potential consequences of acquiring WNV infection. Monitor the recipient closely for development of fever, headache, meningitis or encephalitis of unexplained etiology, and perform a WNV IgM test and a WNV-NAT if WNV is clinically suspected.

Consider enrolling the recipient in a clinical trial of Omr-IgG-am<sup>TM</sup> if the recipient develops symptoms suggestive of WNV infection and the recipient meets trial eligibility criteria.

**Additional Resources**

A map of WNV activity and human cases, clinical guidance, news releases, and publications can be found on the CDC web site at [www.cdc.gov/ncidod/dvbid/westnile/index.htm](http://www.cdc.gov/ncidod/dvbid/westnile/index.htm).

The FDA Guidance for Industry: Revised Recommendations for the Assessment of Donor Suitability and Blood and Blood Product Safety in Cases of Known or Suspected West Nile Virus Infection can be found on the FDA web site at [www.fda.gov/cber/gdlns/wnvguid.htm](http://www.fda.gov/cber/gdlns/wnvguid.htm).

Published article: Martha Iwamoto, M.D., M.P.H., Daniel B. Jernigan, M.D., M.P.H., Antonio Guasch, M.D., et al. Transmission of West Nile Virus from an Organ Donor to Four Transplant Recipients. The New England Journal of Medicine. 2003;348:2196-2203.

Information about WNV clinical studies at [www.clinicaltrials.gov](http://www.clinicaltrials.gov).

**Answers to Crossword on page 14:**

ACROSS: 2.life 4.bandaid 6.barf 8.yellow 10.ascites 12.IV 14.diet 16.virus 18.stethoscope 20.cure 22.ultrasound 24.bile 26.nurse 28.hope 30.yawn DOWN:1.itch 3.fever 5.xray 4.blood 9.pulse 18.scrubs 13.medicine 15.saline 17.IV 2.liver 21.donor 23.fib 25.ouch 27.transplant

**Meet some C.L.A.S.S. Volunteers!**



**Mika Denny**

C.L.A.S.S. Board Member since 2001. Volunteer designer for past newsletters, brochures and a variety of printed materials. Produces fundraiser ideas, T-shirts, and coffee mugs. Serves as a back up for the Correspondence Secretary. C.L.A.S.S. Annual Tea fundraiser Speaker for the past 3 years. "I became involved with C.L.A.S.S. because I was so grateful to receive help and information and I wanted to return the favor to other parents like myself. C.L.A.S.S. has been a huge source of support for me over the past four years since my daughter was diagnosed with biliary atresia. I read the C.L.A.S.S. forum daily which helps me cope and learn." ~Mika

C.L.A.S.S. Advisory Committee Member since 2000. Volunteer Parent Matching Coordinator, maintains the database for the Parent Matching Files which enables C.L.A.S.S. to quickly match C.L.A.S.S. families in over 50 categories (age, diagnosis, hospital, # of transplants, state, etc.). "I thoroughly enjoy meeting and talking to other C.L.A.S.S. families. One of my main hobbies is meeting families online and traveling. I have been very privileged to have met many of our C.L.A.S.S. friends in person. I am also active in organ donor awareness events, and I look forward to meeting more of you this next year." ~Shawn



**Shawn Curry**

**Mary Wallace**

*Photo Unavailable*

Member of C.L.A.S.S.

Advisory Committee since 2001. Email Correspondence Secretary for website, including membership inquiries, requests for financial information/links for transplants, requests for general information on medical conditions, and medications. Forward questions to doctors on Scientific Advisory Board for their reply to C.L.A.S.S. Q & A column. Assist webmaster as needed. Participate regularly in online discussion forum and occasionally in C.L.A.S.S. online chats. Represent C.L.A.S.S. at annual Camp Chihopi Family Brunch with display table at Children's Hospital of Pittsburgh. "I first contacted C.L.A.S.S. 7 years ago when my son was an infant, looking for information. I found the C.L.A.S.S. Notes so informative and so parent-friendly, I requested copies of all of the back-issues since the start of the newsletter! The internet has allowed C.L.A.S.S. to reach so many more parents. It's really exciting. I believe the information sharing and support facilitated by this organization are priceless! I am a former administrative assistant, now a stay-at-home Mom, enjoying my son's activities, traveling, scrap booking, and decorating my home. I also have three grown "kids" and three grandchildren (already!). I am on the Board of Directors for Alpha 1 Advocacy Alliance, a member and participant in several Alpha 1 organizations, and support the activities of the American Liver Foundation." ~Mary

**Liver Waiting List**

(As of January 30, 2004)

Age	Number Waiting
< 1 year	59
1-5 years	385
6-10 years	167
11-17 years	287
18 years & up	16,367
<b>Total Children:</b>	<b>898</b>
<b>Total Liver Waiting List:</b>	<b>17,259</b>

**Number of Children Waiting**

**by Blood Type:**

Type O	976
Type A	269
Type B	118
Type AB	23

Source: United Network for Organ Sharing. Totals may be less than the sum due to patients included in multiple categories.

# Kids Korner

If you're a C.L.A.S.S. Kid, this place is for you! This section is for your stories, letters, drawings, poems, pictures, games...anything you'd like to share. Let us hear from you! (Moms and Dads, please be sure to include your permission for your child's submission in C.L.A.S.S. Notes.) All submissions become property of C.L.A.S.S. and may or may not be published depending on content. Mail to: Attn: C.L.A.S.S. Notes Editor, C.L.A.S.S., 27023 McBean Parkway # 126, Valencia, CA 91355.



February 14th:



A	X	D	A	I	Z	D	F	L	O	U	R	I	D	E
H	T	E	E	T	U	J	E	S	M	H	E	M	G	O
D	C	A	V	I	T	Y	I	N	V	C	T	O	T	F
E	T	S	A	P	H	T	O	O	T	A	X	L	O	L
B	H	B	R	A	C	E	S	M	W	I	J	A	O	O
G	I	N	G	I	V	I	T	I	S	B	S	R	T	S
V	A	Q	S	U	B	A	D	B	R	E	A	T	H	S
C	R	O	W	N	R	F	J	C	S	G	T	L	B	I
R	P	L	A	Q	U	E	P	E	G	I	M	I	R	N
G	E	O	K	Z	S	Y	O	N	U	T	J	D	U	G
U	K	W	R	S	H	B	G	A	Z	L	K	N	S	R
M	E	N	K	A	E	V	O	M	O	R	L	N	H	L
S	P	L	B	Q	L	F	H	E	H	C	P	I	X	W
L	F	I	L	L	I	N	G	L	R	F	J	Z	R	M
Y	F	Q	D	R	C	E	S	N	I	R	P	Y	W	D

Since February is National Dental Health Month, here's a Word Find with things you might hear when going for a visit with your dentist! Can you find them all?



bad breath  
braces  
brush  
cavity  
drill

crown  
dentist  
enamel  
filling  
flossing  
fluoride  
gingivitis  
gums  
molar  
oral

plaque  
rinse  
teeth  
toothbrush  
toothpaste

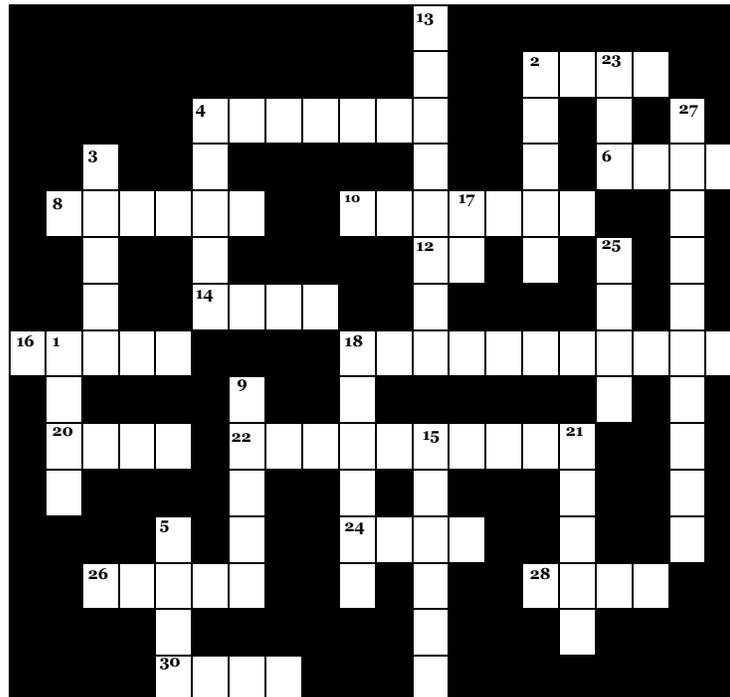


## A Liver Crossword

Puzzle just for you!

**Across:**

- 2. "The gift of \_\_\_\_\_"
- 4. helps cover "owies"
- 6. if you don't feel good, you might do this!
- 8. color of your skin when your liver is sick
- 10. fluid on your tummy
- 12. tube that gives liquids in your vein
- 14. eat a healthy \_\_\_\_\_
- 16. illness your computer gets!
- 18. doctor listens to your heart with it
- 20. to make better
- 22. you can see pictures of your liver with this
- 24. too much of this makes you yellow
- 26. press your call button and this person will come
- 28. "\_\_\_\_\_ you feel better soon."
- 30. when you're tired you do this



**Down:**

- 1. to scratch
- 3. when you feel hot, you might have one
- 5. a picture of your bones
- 4. red and runs through your arteries and veins
- 9. tells how fast your heart is beating
- 18. outfit your nurse wears
- 13. "It's time to take your \_\_\_\_\_"
- 15. nurse flushes your IV with this
- 17. tube that gives liquids in your vein
- 2. biggest organ in your body
- 21. the person that gives you your new liver
- 23. when you don't tell the truth
- 25. what you say when something hurts
- 27. when they take your liver out and put a new liver in

Answers on Page 13

Crossword words and clues submitted by Marisa M.

### National Doctor's Day

National Doctor's Day is **March 30th**. The resolution was signed by then-President George Bush in 1991. Hallmark now offers Doctor's Day cards as a more formal way to thank your physician. Let's not forget to remember and thank our doctors for the commitment and compassion that is required of them every day.

### National Nurse's Day

Just as a reminder... National Nurse's Day is also coming up soon. It is on **May 6**.

## Nickels for Notes

If you are currently receiving and enjoying C.L.A.S.S. Notes, this is your chance to help us keep future newsletters free! "Nickels for Notes" is our campaign to help defray costs of our newsletter production. If you are able, please consider helping C.L.A.S.S. with whatever amount you can, and specify "Nickels for Notes" along with your donation. Mail to: C.L.A.S.S. 27023 McBean Parkway #126 Valencia, CA 91355. Every nickel counts and we need your help!

**Thank you!**



## WANTED!

C.L.A.S.S. is looking for a new webmaster for our website. If you are computer savvy and would like to volunteer, please contact C.L.A.S.S. for more info!



## Extended-Release Prograf

Fujisawa is committed to developing products that improve or simplify the complicated medication regimens transplant patients must take to maintain a healthy organ. Fujisawa is working on a modified release formulation of their product Prograf. Currently, they are enrolling patients in Phase III clinical trials both in the US and in Europe.

## IN THE NEWS

### Organ Donation Recovery and Improvement Act

November 26, 2003

I congratulate the Senate for unanimously approving the "Organ Donation and Recovery Improvement Act" sponsored by Senators Frist and Dodd. I thank the House for their work in passing an organ donation bill earlier this year and anticipate a speedy conference. This bill authorizes \$25 million for fiscal year 2004 for a variety of efforts to increase donation including providing reimbursement of the travel and subsistence costs associated with living donation; providing greater resources to states to expand their public education and outreach efforts; and awarding grants to establish programs to coordinate organ donation activities of eligible hospitals and organ procurement organizations. These authorizations compliment and strengthen the Gift of Life Initiative I launched in 2001.

The list of those needing an organ has grown to over 83,000. The need for organs continues to grow faster than the supply. I am passionate about continuing to increase organ donation in this country to save and enhance thousands of lives. I encourage Congress to continue their efforts on this bill to give the Department of Health and Human Services additional tools to encourage more people to give the gift of life.

Tommy G. Thompson  
Secretary of Health and Human Services

## Symphony of Life

The 115th Rose Parade took place on Thursday, January 1, 2004. This year's theme was *Music, Music, Music*. The Coalition on Donation was invited by the Pasadena Tournament of Roses to enter a float in the parade, and this was the first-ever Rose Parade float for the Coalition on Donation. The float was spearheaded by Coalition on Donation member OneLegacy, a not-for-profit federally designated transplant donor network serving Southern California. The float was supported by 35 partners from across the nation, including 22 organ procurement organizations, 9 industry partners, and 3 Southern California transplant centers. The Deputy Surgeon General of the U.S., RADM Kenneth P. Moritsugu, MD, MPH, and Olympic bronze medalist snowboarder Chris Klug were among the 22 donor family members and transplant recipients chosen to ride the float. The float's theme was *A Symphony of Life*. It featured 2 gardens connected by a 50-foot bridge, symbolizing the living bridge between organ and tissue donors and recipients. Riders were nominated by organ and tissue recovery organizations, research foundations, and transplant centers nationwide.

### Website Statistics

[www.classkids.org](http://www.classkids.org)

**January 2004: 42,412 visits, average visitor examined 10.21 documents before exiting the site, visitors came from 12,688 distinct internet addresses, the web server delivered 8,653 unique documents >1 time each.**



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A sturdy white mug printed with a colorful design of the C.L.A.S.S. logo and an organ donation awareness message. **\$10.00**



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Newsletters mailed under our nonprofit bulk mail permit are not forwarded if you move. Please help us keep costs down and our mailing list up-to-date by notifying us of any changes to your address. Thank you!



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