



A Success Story: *Amanda Watermeier*

Today Amanda Watermeier is a healthy teenage girl who has just completed her senior year of high school. She is an honor student at Carlinville High School and a member of the softball and volleyball team. Many of her family and peers find it hard to believe that she is back to her active lifestyle after having a liver transplant in December 2004.



Amanda Watermeier

In early December, Amanda started having severe stomach pains and fatigue. Her family doctor said that it might be indigestion, but wanted to do more lab work. She had to get more tests done when she became jaundice. The tests showed that she had high liver enzyme readings. Amanda was admitted to Barnes-Jewish Hospital where they diagnosed her with Wilson's disease, a genetic disorder that causes excessive copper accumulation in the liver or brain. Although the accumulation of copper begins at birth, symptoms of the disorder appear later in life, between the ages of 6 and 40. It affects about one in 30,000 people worldwide.

Without proper treatment, Wilson's disease is generally fatal, usually by age 30. If the disease was detected and treated early enough, recovery is usually complete and the individual can lead a normal, healthy life. The doctors told Amanda and her family that her liver was scarred and she would need a transplant. Amanda's condition was serious enough to place her at the top of the transplant list. Her kidneys shut down and she was put on dialysis to help her kidneys function.

That same night they found a liver and had planned to do the transplant at 6 a.m. on Wednesday, December 16, 2004. Her liver did not arrive on time and her condition was getting worse. Her parents made the decision to take out her liver before the new liver got there at 8:30 a.m. Amanda was told that she could live 24 to 48 hours without a liver. The doctors had put her on life support while she was in surgery. They completed the surgery at 12:30 that afternoon. Amanda was sedated and on a ventilator for three days. Three weeks later she was able to leave the hospital. Amanda remained on dialysis for four days a week because her kidneys had not started yet.

Amanda remained at home until February 18, 2004. She was home tutored until she went back to school part-time. Three weeks later she was able to go back full-time. In March, with the consent of her doctors, Amanda decided to play softball for her high school team. Amanda was the third baseman a year ago, but her coach moved her to first base for the season. Amanda is co-valedictorian of her high school with a 4.0 grade-point average, and an article about her accomplishment was recently published in the St. Louis Post-Dispatch.

Today, Amanda is doing well. She is living her life to the fullest. She wants to help others who have Wilson's disease and other liver diseases, by helping the Missouri Chapter of the American Liver Foundation raise money at the 8th Annual American Liver Walk & Run. The event will take place Saturday, July 9, 2005 in the Upper Muny Parking Lot at Forest Park. Please see page 10 for more details.

For more information about the event, please contact Richard Mattler at (314) 352-7377. You may also visit www.liverfoundation.org/missouri for more information and/or register online.

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Dear Members:

In the world of not-for-profit management, I am frequently in awe of the power of a volunteer's spirit. I have worked with so many wonderful people who volunteer their time to further the mission and goals of the American Liver Foundation. As a national, voluntary health organization, volunteers are instrumental to our success. The staff and the board of directors of the American Liver Foundation are grateful for all of our volunteers. You make a difference! Recently, I met a new volunteer who inspired and me personally and professionally.

Kathie Bryson recently contacted the American Liver Foundation to register for the 8th Annual American Liver Foundation's Run/Walk, scheduled for Saturday, July 9. Kathie is a team captain helping coordinate team leaders and team walkers to raise awareness of liver disease, and in her case, liver cancer. Kathie has liver cancer caused by an unknown case of hepatitis C (HCV). The only risk factor Kathie can think of is her job where she worked with chemically dependent teenagers at St. Anthony's Medical Center for 27 years. While she cannot prove where she contracted the virus, she is concerned that thousands of nurses like her, are at risk for contracting this most common blood borne virus. "In nursing school during the 1970's, I was taught to never put on gloves unless you were doing a sterile procedure. We were told to have comforting hands," says Kathie.

In between doctor's visits, chemotherapy and thoughts of life and death, Kathie is making an impact in raising awareness of liver disease. State Representative Jim Lembke, sponsored Senate Bill 74, MO Sec 191-645, "Kathie's Law" in the 2005 Missouri State Legislature. The bill proposed voluntary testing for healthcare workers. While the bill did not pass, Representative Jim Lembke plans to reintroduce the bill in 2006. Kathie is volunteering to help organize a free hepatitis C screening for frontline healthcare workers at St. Anthony's Hospital sponsored by the American Liver Foundation. "This is a gift to my employer of 27 years, and I hope it will save lives," says Kathie.

Katherine "Kit" Auble

Executive Director

American Liver Foundation – Missouri Chapter



Mission Statement

The American Liver Foundation is the nation's leading nonprofit organization for liver health promotion and disease prevention. ALF provides research, education and advocacy for those affected by hepatitis and other liver-related diseases.

American Liver Foundation Missouri Chapter

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Missouri Chapter Liver Bulletin

Volume VI, Issue 2

Irene Agustin, Editor

The information contained in this newsletter is provided for information only. Such information does not constitute medical advice, and should not be relied upon as such. The American Liver Foundation (ALF) does not engage in the practice of medicine. ALF, under no circumstances, recommends, particular treatments for specific individuals, and in all cases recommends that you consult with your physician before pursuing any course of treatment.

Legislative Update: Illinois House of Representatives Approves First-Person Consent Organ and Tissue Donor Bill

The Illinois House of Representatives approved Secretary of State, Jesse White's, initiative to create a First-Person Consent Organ and Tissue Donor Registry in Illinois that would make a person's decision to donate organs and tissue following their death a binding decision.

Currently, more than 6 million participants may donate if the registrant's next of kin gives consent. According to Gift of Hope, an organ and tissue procurement organization covering much of Illinois, 40% of families say "no" to organ donation when approached for permission. Families also say "no" 19% of the time even when notified their loved ones had joined the state's donor registry. Gift of Hope estimates that a first person consent law could save at least 100 additional lives each year. One donor can save or enhance the lives of more than 25 people.

Although Illinois has the largest donor registry in the country, approximately 300 people in the state die each year waiting for a transplant. Nationally, there are 87,000 people waiting for transplant operation – nearly 5,000 of them in Illinois. Every 13 minutes a new person is added to the national waiting list and 17 people across the country die each day waiting for a transplant.

The General Assembly in Illinois created a legislative task force last year to serve under the direction of White's office to study the issue of first-person consent. State Rep. Kathy Ryg (D – Vernon Hills) is the chief sponsor of White's measure (HB 1077) to create the new first-person consent registry. Similar legislation has been approved in other states. Pennsylvania was the first state to pass the legislation. Missouri and Kansas do not have the first-person consent law. The legislation now moves to the Illinois Senate for consideration.



Welcome New Board Member

Samuel Hamacher is the newest board member to join the American Liver Foundation. He is the Executive Vice President of Harbour Group and has been with this company since 1988. He is married to Jill and they have four children (three daughters and a son). He is actively involved with the United Way, St. Louis Variety Club, Alzheimer's Association and Family Support Network. Mr. Hamacher served as honorary chair of the 2005 Bid for Life.

Thanks Dr. Todd Howard

The Missouri Chapter of the American Liver Foundation would like to take this opportunity to thank Dr. Todd Howard of Suburban Surgical Associates, Inc. Dr. Howard resigned from the American Liver Foundation Board of Directors in February of 2005 after serving for six years. He is a very dedicated physician and we are grateful for his service and generosity.

Partnership for Prescription Assistance

The Partnership for Prescription Assistance helps individuals who do not have prescription coverage and cannot afford their medicines, help to get the medications they need. They may even get their medication free or nearly free. Many people may qualify for assistance. For example:

- Working people • People without jobs • Seniors and retired people •
- Students • Families • Single people •

What they need to do:

Know the names of the medicines they take. Call toll-free: 1-888-4PPA-NOW (1-888-477-2669). A trained specialist will answer your questions and help you apply. As of June 22, 2005, Missouri residents can access ppaRXmo.org.

Win a New 2006 Nissan 350Z or \$25,000 cash



Tickets: \$100 per ticket
only 750 tickets are available



Drawing:
**Bid for Life Recognition
Dinner Auction**
Saturday, February 4, 2006
Sheraton Westport
**Special thanks to Lou Fusz for their
generosity in making this prize possible.*

Funds raised support the American Liver Foundation,
dedicated to research, education and advocacy.

For more information, please
call the Missouri Chapter at (314) 352-7377



New Nissan 350Z Entry Form

- I am interested in attending the Bid for Life 2006.
Please send me an invitation to the address below.
- Enclosed is my payment of \$ _____ for _____ ticket(s) at \$100 per ticket.
I understand that only 750 tickets are available and will be sent on a first-come first-served basis. If less than 500 tickets are sold, raffle will revert to a 50/50 cash raffle.
- My check, payable to the American Liver Foundation, is enclosed.
 Please charge my credit card Visa MasterCard AMEX

PLEASE SEND RAFFLE TICKET(S) TO:

Name _____

Address _____

City _____ State _____ Zip _____

Phone _____ Email _____

Credit Card # _____ Exp. Date ____/____

Signature _____

Please return completed form and payment to:
American Liver Foundation • 16 Hampton Village Plaza • St. Louis, MO 63109

Bid For Life: Raising Funds for Research in Liver Disease

The American Liver Foundation's 6th Annual "Bid for Life" recognition dinner auction, Saturday, February 26, 2005 at the Ritz-Carlton raised over \$325,000 to fund research and education in liver disease. Samuel Hamacher, executive vice president of Harbour Group, served as honorary chairman for this year's gala. Dr. Jeffrey and Nancy Crippin lead the planning committee. Sam Fox received this year's 2005 Leadership Award and Anna Maria and Wayne Winter received the 2005 Volunteer of the Year Award.

This year's "Bid for Life" gala was an overwhelming success. Five hundred people attended the event and this year was the highest attended for the gala. Some of the people in attendance included: Governor Matt Blunt, Lou and Laura Fusz, Trudy Busch, Sage Wightman, Missey Condie, Sam and Joanna Temperato, Dr. Timothy and Kim Eberlein, June and Flint Fowler, Joan and Don Quicksilver, Donald Suggs, Dr. Jeffrey and Jennifer Teckman, Susan and James Buford, Lenore and Edwin Pepper, Don and Mary Pillsbury Wainwright, Dr. Philip and Arleen Korenblat and many more.

The evening's festivities included music by Encore. ALF would like to thank the sponsors, members of the planning committee and all those who attended the gala to show their support for the American Liver Foundation.

Pictured at right, (top): David Wells, Sheri Kulkis, Pat Higgins, Gary Zieziula, Heidi Gearhart, James Brooks

(middle): Jeffrey and Nancy Crippin, Sam and Marilyn Fox, Wayne and Anna Maria Winter and Samuel and Jill Hamacher

(bottom): Ed Goodman, KEZK Radio, Heather Perkins receiving her \$12,000 raffle check and John Pertzborn, KTVI Fox 2



Fashion Show Promotes Organ Donation

Over 300 people attended the American Liver Foundation's 7th Annual Fashion Show and Sale, Friday, April 22, 2005, at Frontenac Hilton Hotel. This event raised just over \$44,000 to fund liver disease research and education. Carol Daniel of KMOX Radio served as Honorary Chair for this event.

This year's event featured models who were organ donors, organ transplant recipients and media celebrities. The models wore clothing from the French Shoppe and Chocolate Soup. The highlight of the show featured 3-year old Macie Scherrer and her escort. Macie received a liver transplant on May 19, 2003. Her escort was her living donor.

The staff of ALF would like to thank all those who showed their support by participating in this event. A special thank you goes to the Spotlight Sponsor, Astellas, our planning committee chairperson, Alesha Luxon and to all those who helped to plan this year's fashion show.



Pictured (top left to top right): One of the children models; 2005 St. Louis Fashion Show Planning Committee; Heather Hawk; One of the children models; Alesha Luxon and Carol Daniel, KMOX Radio; Macie Scherrer and Chris

Mark Shale: New Vendor for Kansas City Fashion Show

The 3rd Annual "Spring into Fashion" Show and Sale, Thursday, April 14, 2005 at Mark Shale on the Plaza in Kansas City raised just over \$25,000 to fund liver disease research and education. Amy Hawley, NBC Action News KSHB-TV, and Nycki Pace, Star 102 served as celebrity co-chairs for this year's event.

This year's fashion show featured organ donors and recipients and some of the Kansas City Chiefs Cheerleaders as models. The models were wearing Mark Shale's spring line.

The staff at ALF would like to thank all those who support the American Liver Foundation by participating in the event. A special thank you goes to the sponsors of the fashion show who include: Children's Mercy Hospital, KU Medical Center, Midwest Transplant Network, Schering Plough, NBC 41 and Star 102.

ALF would like to also extend their gratitude to the Kansas City Chiefs Cheerleaders for participating as models, the staff of Mark Shale for all of their hard work, Linda Loveless and Beth Vaughn of Arbonne International, and the hair designers from Deluxe Hair in Leawood, Kansas. Also thank you to Anne Peterson, health reporter and all others who participated in making the event a success.



Pictured above (clockwise, top left): Ruth Parker (liver donor) and Lindsay Carter (recipient of Ruth's liver donation); Dr. James Daniel of Children's Mercy Hospital with Jacob (liver recipient) and Stephanie Smirl; Honorary Co-Chairs, Amy Hawley of NBC Action News and Nycki Pace of Star 102; Todd Ashby (liver recipient).

SAVE THE DATE ■ SAVE THE DATE ■ SAVE THE DATE ■ SAVE THE DATE

Inaugural Greater Kansas City Golf Classic

to benefit

**The American Liver
Foundation**

Friday, October 14, 2005



www.drummfarmgolfclub.com

Registration & Lunch

11:00 a.m. - 12:45 p.m.

**Awards, Cocktails,
Hors d'oeuvres & Auction**

6:00 p.m.

For sponsorship information or registration forms, please call (913) 660-0250
or Email: nnolte@liverfoundation.org

Free Hepatitis Screening and Vaccinations Offered at PrideFest

The Missouri Chapter of the American Liver Foundation (ALF) is offering free hepatitis C (HCV) screening and free hepatitis A & B vaccines to participants of the 2005 St. Louis Pride Festival. Working in conjunction with several health-related agencies, the hepatitis component will be part of a broader healthcare initiative that will include health education and HIV testing. Screenings and vaccinations took place in Kansas City on June 4th and 5th at Liberty Park and will take place in St. Louis on June 25th and 26th at Tower Grove Park from 10 a.m. to 4 p.m..



Twenty-five million Americans are affected by liver disease—that is one in every 10 American. Hepatitis C infects an estimated 3.9 million people, 2.7 million are chronically infected and approximately 70% of people infected do not know they have the virus. Between



20 to 30% of people who have HIV also have hepatitis C and it accounts for the 25% of the deaths of people who have AIDS. Hepatitis B is 100 times more transmissible than HIV; however the Gay and Lesbian Medical Association reports that only 38.9% of men who have sex with men (MSM) get vaccinated.

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Sixty-one Percent Infection Rate at Methadone Clinic

The Missouri Chapter of the American Liver Foundation has partnered with the Center for Life Solutions to screen their patients for Hepatitis C. The Center for Life Solutions is a methadone clinic. The patients that are seen at the Center for Life Solutions are or were intravenous (IV) drug users.

Hepatitis C is spread by contact with infected blood, which can occur by the following:

- Sharing works, including needles, syringes, cookers, cotton, water, water glasses, or other containers used to rinse needles.
- Unprotected sex with an infected partner. This does not happen often, but one should still practice safer sex to reduce your risk of HIV and hepatitis B and C.
- Being born to an infected mother.
- Blood transfusions received before July 1992.
- Exposures to blood in the workplace through needle stick injuries.

Most people with hepatitis C do not show symptoms and they have been infected with the virus and feel fine for many years. Hepatitis C infects an estimated 3.9 million people, 2.7 million are chronically infected and approximately 70% of people infected do not know they have the virus.

The program started March 15, 2005 and ended May 15, 2005 screened 39 patients. Twenty-four came back positive which is a 61.5% infection rate. The Centers for Disease Control's estimation for the general population with people who have hepatitis C is 1.8%.

ALF hopes to screen as many at-risk individuals as possible for hepatitis C. For those individuals who test positive, appropriate counseling and treatment referrals systems are in place to serve them with the necessary tools to help them through treatment and to stop the spread of the virus.

ALF and *Super Size Me* Team Up

In an effort to help create a healthier community, the American Liver Foundation has teamed up with *Super Size Me* to promote the Educationally Enhanced *Super Size Me* DVD. *Super Size Me* is a critically-acclaimed documentary from filmmaker Morgan Spurlock. He graphically explores the correlation between fast food, lack of exercise, inadequate nutritional and physical education and the obesity epidemic that currently plaguing our nation.

Nonalcoholic Fatty Liver Disease (fatty liver disease, or NAFLD) is a growing problem due to the increasing number of overweight individuals in America. One in 50 Americans are afflicted with NAFLD. Fatty liver is the accumulation of fat in liver cells. It is common in patients who are very overweight or have diabetes mellitus.

Some 150 million Americans, 61 percent of adults, are overweight enough that it poses a risk to their health, according to the American Academy of Child and Adolescent Psychiatry, and between 16 and 33 percent of children and adolescents are obese. In March 2004, the Centers for Disease Control and Prevention (CDC) named obesity as the fastest growing killer in the United States, second only to tobacco.

The Educationally Enhanced *Super Size Me* DVD is now available for purchase from the *Super Size Me* web site (<http://supersizemestore.com/info/howtouse.html>) for \$39. This DVD includes the complete documentary on DVD, supplemented with standards-based lesson plans that address a variety of curriculum areas for Grades 6-12.

This product was created for individual or group learning in school, after-school programs, homes, community and health organization or by anyone who is concerned and interested in educating young people about the serious consequences of poor eating, diet, nutrition and related lifestyle choices and helping them to improve their skills and knowledge in these areas.

The American Liver Foundation fully supports the educational efforts of *Super Size Me* and we hope that you and your organization will pass on the valuable lesson portrayed in this documentary. Please contact the American Liver Foundation Missouri Chapter at (866) 455-4837 or by e-mail at missouri@liverfoundation.org for more information.

Hepatitis B and Asian Americans

Hepatitis B is a serious viral infection that is common among Asian Americans than other racial or ethnic groups in the United States. Hepatitis B virus (HBV) is very common in many countries in Asia. Anyone who has not been vaccinated can get infected with HBV, but people from areas of the world where the virus is prevalent are more likely to become long-term carriers of HBV, and they may not know it. In regions where HBV is common, the virus may have been acquired early in life – during infancy and early childhood. Because children’s bodies do not fight the virus as an adult’s would, these early cases often develop into chronic (long-term) hepatitis B, and it can be spread to others. Approximately one of every ten Asian American is chronically infected with HBV.

Hepatitis B is spread by contact with infected body fluids. These fluids include blood, semen, vaginal secretions, and saliva. Among Asian Americans and immigrants from Asian countries where HBV is common, the virus is typically spread unknowingly from a mother to her infant at birth, or in early childhood from close contact with infected family members.

HBV infection can be prevented by vaccination. Vaccination can also prevent the consequences of HBV infection, including cirrhosis and liver cancer. “Catch up” vaccination is needed for many Asian American children and adolescents. Of Asian Americans and Pacific Islanders born after 1993, 90% received HBV vaccine in time to prevent infection, but many born in the U.S. before 1993 and those born in countries where hepatitis B vaccine is not routinely given to newborns have not been vaccinated.

Hepatitis B infection is serious. Chronic (long-term) HBV infection can result in cirrhosis (scarring of the liver), liver failure, and liver cancer. Because hepatitis B infection is more common among Asian Americans, so are its complications. For example, among Chinese American men, incidence of liver cancer is about 5 times higher than in Caucasian men and about 3 times higher than in black or Hispanic men.

Most patients with chronic HBV infection do not have symptoms and are unaware that they are infected until they have very advanced liver disease. More than two-thirds of those who become infected with hepatitis B have no obvious sign or symptoms, and symptoms are less common in children than adults. Thus, many people who become carriers—and can pass the virus on to others—never know it. Even when typical symptoms (including fatigue, jaundice, nausea, abdominal pain, and loss of appetite) do become apparent, they are not always recognized as being caused by the hepatitis B virus. This is why screening for the virus is so important.

Asian Americans from countries with high prevalence of HBV infection and those with a family history of liver disease or hepatitis B should be screened for hepatitis B infection. Those who test positive should be evaluated to assess severity of liver disease and to determine if treatment will be of benefit. Those who have not been exposed to the virus should be vaccinated.



5th Annual

GOLF CLASSIC



algonquin
golf club



Monday, September 26, 2005

Event Includes:

- Buffet Lunch
- 18 Hole Four Person Scramble
- Cocktails and Hors d’oeuvres
- Silent & Live Auction

- Registration** - 10:30 a.m.
- Lunch** - 11:00 a.m. - 12:15 p.m.
- Shotgun Start** - 12:30 p.m.
- Awards** - 6:00 p.m.

All proceeds benefit the American Liver Foundation’s work in research and education for liver diseases, patient and public programs, and organ donor awareness.

I am interested in...

Joining the planning committee

Participating as a team captain

Registering in the event

Volunteering at the event

Sponsorship information

Name _____

Address _____ City _____ State _____ Zip _____

Phone _____ Fax _____ Email _____

For more information call (314) 352-7377 or register online at www.liverfoundation.org/missouri

Support Groups in Missouri Chapter Region

Serving Missouri-Eastern Kansas-Southern Illinois

Kansas City Metro Area

- ❖ Kansas City, KS – Liver Transplant Support Group – First Wednesday of each month, KU Medical Center, Wyandotte Room, 7:00 p.m. Parking garage and street parking available, Contact: Greg at (816) 455-2940.
- ❖ Kansas City, MO – VA Hepatitis Support Group- Third Tuesday of each month, Kansas City VA Hospital, 7th floor of Research Bldg., Room 700, 4:00-6:00 p.m., Contact: Ruth Corbett at (816) 861-4700, ext. 7046.

Mid-Missouri

- ❖ Columbia, MO – Hepatitis C Information Group – Second Monday of each month, University Hospital, Conference Room GL11, 7:00-8:30 p.m., Contact Bruce Burkett at (573) 682-1714 or email mocha@mcmsys.com.
- ❖ Jefferson City, MO – Hepatitis C Information Group- Third Sunday of each month, Eagle's Lodge, 1411 Missouri Blvd., 4:00-5:30 p.m., Contact Bruce Burkett at (573) 682-1714 or email mocha@mcmsys.com.
- ❖ Lake of the Ozarks, MO – Hepatitis C Information Group – Third Sunday of each month, Lake General Hospital, Conference Room D-Cafeteria, 1:00-2:30 p.m., Contact Bruce Burkett at (573) 682-1714 or email mocha@mcmsys.com.
- ❖ Springfield, MO – Hepatitis C Information Group – Second Wednesday of each month, The Doctor's Hospital, Doctor's Conference Room, 2828 North National Avenue, 7:00-9:00 p.m., Contact Bruce Burkett at (573) 682-1714 or email mocha@mcmsys.com.
- ❖ Sedalia, MO – Hepatitis C Information Group – Second Thursday of each month, Pettis County Health Department, 7:00-9:00 p.m., Contact Bruce Burkett at (573) 682-1714 or email mocha@mcmsys.com.
- ❖ Hannibal, MO – Hepatitis C Information Group - Second Wednesday of each month, Marion County Health Department, 5:30-7:00 p.m., Contact Bruce Burkett at (573) 682-1714 or email mocha@mcmsys.com.
- ❖ Mid-Missouri Hepatitis C Support Group – Third Monday of each month, 7:00 p.m., Fort Leonard Wood Army Hospital, St. Robert, MO, Contact: Chuck or Joyce Lynn at (573) 336-3029 or email help4hepc@yahoo.com.
- ❖ Mid-Missouri Liver Transplant Support Group – First Wednesday of each month, 2:00-3:00 p.m., Room D237, VA Hospital, 800 Hospital Drive, Columbia, MO, Contact: Suzanne Opperman at (573) 814-6334. This meeting is for pre and post transplant patients. Every other month a guest speaker will present information.

Southern Missouri

- ❖ Farmington, MO- Hepatitis Support Group-First Tuesday of each month, L.I.F.E. Center in Farmington, Contact: Deborah Phelps at (573) 701-0680.
- ❖ Hepatitis Support Group of Southeast MO (Cape Girardeau) – Fourth Thursday of each month, Option Care, 61 Doctors' Park, Contact: Bettye Crockett at (573) 335-3960.

- ❖ Southwest Missouri Hepatitis Support Group- Second Tuesday of each month, Neosho Recreation Center, Room 103, 6:30-8:30 p.m., Contact: Donna Carnicle at (417) 451-7969 or Rita Liles at (417) 455-0784. NOTE: Meetings are open to all patients with liver disease.

St. Louis Metro Area

- ❖ Post Liver Transplant Support Group – Fourth Wednesday of each month, Saint Louis University Hospital Learning Resource Center, 1:00 p.m., Contact: Betsy Mackey at (314) 577-8867.
- ❖ Post & Pre Liver Transplant Support Group – Third Wednesday of each month, Barnes-Jewish Hospital – Center for Advanced Medicine, 3rd Floor, Farrell Conference Room, 7:00-9:00 p.m., Contact Teri Novak, MSWLCSSW at (314) 362-1956 for more information.
- ❖ St. Louis, MO – HEPSCO – Usually second Monday of each month; however, schedule may change. Please call ahead. Clayton Library, 7:00 p.m. Contact: Nancy at (314) 428-7973.

Illinois

- ❖ Springfield, IL – Hepatitis C Support Group- Third Monday of each month, 6:00-8:00 p.m, Springfield Department of Public Health, 1415 E. Jefferson, Contact Don Hunt at (217) 789-2182.

National

- ❖ PBCers Online Support Groups – PBCers Chatroom has weekly scheduled chats and is available for other chats anytime, 24 hours a day. Scheduled Chats: Tuesday 2:00-4:00 p.m. EST, Sunday, 8:00-10:00 p.m. EST. To subscribe to PBC Digest or to enter the chatroom, go to <http://pbcers.org>.

Get the New American Liver Foundation *LIVERight America!* Wristband



To date, 25 million Americans are affected — that's one in every 10 Americans. Despite its impact on the health of Americans, diseases that effect the liver are not widely known or recognized. The *LIVERight America!* wristband is designed to pay to tribute those who are working to promote liver wellness and fighting to prevent liver disease.

Show your support by wearing the *LIVERight America!* wristband and share one with your friends and family. The wristband is a red, white and blue tie-dyed design. To purchase a wristband for \$2 each, contact the American Liver Foundation Missouri Chapter at (314) 352-7377 or visit www.liverfoundation.org/missouri or email at missouri@liverfoundation.org.

PrideFest Screenings

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Last year in St. Louis, 287 participants received vaccinations for hepatitis A and B. Fifty-seven participants were screened for HCV and two individuals tested positive for contracting the virus. The infection rate for this event alone was 3.5% which is twice the general population of 1.8% as reported by the Center for Disease Control.

In Kansas City, 236 participated in receiving hepatitis A and B vaccinations last year. Hepatitis C screenings were not offered in 2004; however, HCV screenings were available to participants at the KC PrideFest.

ALF is partnering with over 15 different agencies to provide health services to the participants attending these two festivals. Through partnership and promotion, ALF hopes to increase the number of screenings and vaccinations. For those individuals who test positive, appropriate counseling and treatment referrals systems will be in place.


For more information about the program, contact the Missouri Chapter of the ALF at 314-352-7377 or email at missouri@liverfoundation.org.

Join the American Liver Foundation Outreach Committee

We are looking for volunteers to join the American Liver Foundation Outreach Committee. A committee is now forming in St. Louis. The purpose of this committee is to help spread the word about liver wellness and disease prevention. You will be able to take part in a committee that will help in the following areas:

- Speaking engagements
- Presenting information to the public through a speaker's bureau
- Attending health fairs
- Setting up and maintaining support groups
- Coordinating Liver Updates

The committee will meet quarterly. The first meeting will be **Tuesday, July 19, 2005**, 6:00 p.m. at the American Liver Foundation, 16 Hampton Village Plaza, Suite 215, St. Louis, MO 63109. If there are other areas in Missouri, Eastern Kansas and Southern Illinois interested in starting up an Outreach Committee, please contact the Missouri Chapter Office at 1-866-455-4837.



DRIVE AWAY

Liver Disease!

Get rid of your old car or boat without the hassle of advertising, fixing or selling it.

Help fight hepatitis and other liver diseases by making a tax deductible donation of your used vehicle to the American Liver Foundation.

For more information about the program, or to donate your vehicle, call 1-800-GO-LIVER or 1-800-456-5517.

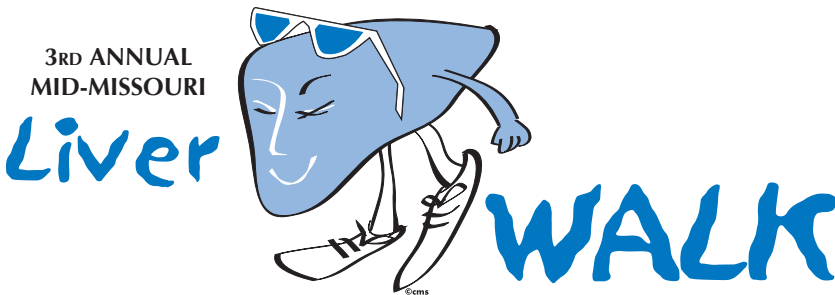
I am interested in joining the American Liver Foundation Outreach Committee.

Name _____

Address _____

Phone Number _____

Email _____



AMERICAN LIVER FOUNDATION—MISSOURI CHAPTER

T-Shirts, Giveaways, Fundraising Prizes, Food, Music, Fun and Much More!

Prizes awarded to the highest individual fundraiser and largest team.

Saturday, October 8, 2005
Rock Bridge High School Track
4303 S. Providence Road • Columbia, MO

RAIN OR SHINE

Check-in opens at 9:00 p.m.

Walk begins at 10:00 a.m.

No Registration Fee

Raise \$50 or more in pledges and receive a Liver Walk t-shirt

Proceeds from the Liver Walk will help fund the American Liver Foundation research and educational programs in the Mid-Missouri area.

For more information contact 1-866-455-4837 or missouri@liverfoundation.org • Register online at www.liverfoundation.org/missouri

I am interested in...

Joining the planning committee

Participating as a team captain

Registering in the event

Volunteering at the event

Sponsorship information

Name _____

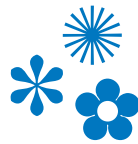
Address _____ City _____ State _____ Zip _____

Phone _____ Fax _____ Email _____

SAVE THE DATE!

2005 American Liver Foundation's Run/Walk

MISSOURI CHAPTER



SATURDAY JULY 9, 2005



Forest Park - Upper Muny Parking Lot
~ RAIN OR SHINE ~

\$20 if registered before June 25th
\$25 June 26th - day of race

YOUR LIVER KEEPS YOU RUNNING

2-MILE WALK:

Registration 7:30 a.m.
Warm-Up 8:15 a.m.
Walk Begins 8:30 a.m.

**Awards
presented to:
Largest Team &
Top 2 Highest
Individual
Fundraisers**



PACKET PICK-UP
July 7th & 8th 5:00-8:00 p.m.
ALF Office

4-MILE RUN:

Registration 6:30 a.m.
Warm-Up 7:15 a.m.
Race Begins 7:30 a.m.

**Awards:
1st Place overall
male and female
1st, 2nd & 3rd Place
in 10 year age
groups: 19 & under
to 70 & over.**

For more information contact **(314) 352-7377**
or rmattler@liverfoundation.org

Registration and sponsor forms on back

- OR -

to register or sponsor online until June 25, 2005,
visit www.liverfoundation.org/missouri

PRIZES!

PLEDGE LEVEL

\$5,000
\$2,500
\$1,000
\$500
\$250
\$100

THANK YOU GIFT

27"Zenith TV
DVD / VHS Player
MP3 Player
Hooded Sweatshirt
Pedometer
Visor



KIDS 12 & UNDER WALK FOR FREE!
KIDS IN WAGONS AND DOGS ON LEASHES ARE WELCOME!
KIDS T-SHIRTS AVAILABLE - \$5 EACH

I am interested in...

- Joining the planning committee
- Participating as a team captain
- Registering in the event
- Volunteering at the event
- Sponsorship information

Name _____

Address _____ City _____ State _____ Zip _____

Phone _____ Fax _____ Email _____

New Alternatives to Liver Biopsy

Many hepatitis C patients are familiar with liver biopsies. This is the primary method physicians use to measure the amount of liver fibrosis – the scarring caused by inflammation due to hepatitis C. This method also helps to guide physicians in their treatment decisions.

Liver biopsies do have some risks associated with it because it is like going through surgery. In performing a liver biopsy, physicians use a needle to extract a small piece of tissue from the liver. During the procedure, patients lie on their side while the doctor locates the liver and inserts the needle to extract the sample. Afterward, patients typically must remain lying on their side for one or two hours to guard against complications.

Following this short recovery period, patients are advised to go home and remain in bed for eight to 12 hours and to avoid physical exertion for several days to allow the incision and the liver to heal. Nearly 30 percent of patients undergoing a liver biopsy experience pain. It often is described as a dull ache in the right upper quadrant or should and typically lasts fewer than two hours. Severe abdominal pain that does not subside is alarming, possibly indicating a serious complication such as intraperitoneal hemorrhage or biliary leak. Accidental biopsy of other organs, bleeding and infection are other complications, but their occurrence is rare.

Recently, two new noninvasive laboratory panels using simple blood tests hit the diagnostic market. These tests may give physicians and liver patients an alternative option to the liver biopsy.

HCV Fibrosure, from Laboratory Corporation of America in Burlington, N.C. and Fibrospect II, from San Diego based Prometheus Laboratories, were introduced in the United States. The blood test was first developed by renowned liver researcher Dr. Thierry Poynard at Pitie-Salpetriere Hospital in

Paris, the LabCorp test has been available in Europe under the name FibroTest for a couple of years. The test was made available in the United States under a licensing agreement with BioPredictive Inc.

These tests work basically the same. Blood is drawn in a doctor's office or clinic and sent to the companies or labs certified by the test makers for analysis. Patients are asked to fast for at least eight hours prior to the test. The noninvasive testing uses a combination of six serum biochemical markers plus age and gender in a patented algorithm to determine the degree of liver fibrosis. The algorithms compare the difference between a healthy liver and that of a hepatitis patient. The tests provide a linear biochemical assessment of fibrosis stages and give doctors a numerical, quantitative estimate of liver fibrosis.

Coverage by insurance companies varies, but at a cost of about \$350 for noninvasive testing, it is far less than that the \$1,500 to \$2,000 cost of a biopsy without complications. As the tests gain popularity among doctors, they likely will gain acceptance by more insurance companies.

The blood tests are not free from its shortcomings. Some of these shortcomings include lack of prospective data to see if changes in markers can follow changes in fibrosis with treatment or changes due to the natural course of the diseases. Also, some of the available maker panels have not been validated in other chronic liver disease states. More research is needed before doctors will stop doing liver biopsies, but today even the reliability of liver biopsies has come under close scrutiny.

Hepatitis C patients should speak to their physicians about their options when examining the level of fibrosis in their liver.

Source: Marc C. Botts, *Cutting Out the Biopsy, Hepatitis*, April-June 2005

2ND ANNUAL HALLOWEEN COSTUME BASH

TO BENEFIT
American Liver Foundation
MISSOURI CHAPTER

AMERISTAR CASINOR
ST. CHARLES

BOTTLENECK BLUES BAR

THURSDAY, OCTOBER 27, 2005 6 PM

COSTUME PRIZES

INDIVIDUAL TICKET \$20

LIVE ENTERTAINMENT

For more information call (314) 352-7377 or register online at www.liverfoundation.org/missouri

UPCOMING EVENTS

June

Hepatitis C Screening— Kansas City Pride Festival

Saturday, June 4, 2005-
Sunday, June 4, 2005
Liberty Memorial South Lawn;
Kansas City, MO

Hepatitis C Screening— River City Health Fair

Wednesday, June 8, 2005
River City Health Clinic;
Cape Girardeau, MO

Hepatitis C Screening— St. Louis Pride Festival

Saturday, June 25, 2005-
Sunday, June 26, 2005
Tower Grove Park; St. Louis, MO

July

Liver Run/Walk

July 9, 2005
Forest Park, Upper Munny
Parking Lot; St. Louis, MO

September

5th Annual Golf Classic

Monday, September 26, 2005
Algonquin Golf Club; St. Louis, MO

October

Liver Awareness Month

3rd Annual Mid-Missouri Liver Walk

Saturday, October 8, 2005
Rock Bridge High School Track;
Columbia, MO

Innugural Greater Kansas City Golf Classic

Friday, October 14, 2005
Drumm Farm Golf Club; Kansas City, MO

Halloween Bash

Thursday, October 27, 2005
Ameristar Casino St. Charles
Bottleneck Blues Bar; St Charles, MO

February 2006

Bid For Life Dinner Auction

Saturday, February 4, 2006
Sheraton Westport; St. Louis, MO

For more information on any of these events, please
call us at (314) 352-7377 or toll free 1-866-455-4837

Nutrition and for your Liver: *Eat for Health!*

Since everything we eat must pass through the liver, special attention to nutrition and diet can help keep me healthy. Here are some tips on eating for health – healthy liver, healthy you!

- Eat a well-balanced, nutritionally adequate diet. If you enjoy food from each of the four food groups, you will probably obtain the nutrients you need.
- Cut down on the amount of deep-fried and fatty foods you and your family consume. Doctors believe that the risk of gallbladder disorders (including gallstones, a liver-related disease) can be reduced by avoiding high-fat and cholesterol foods.
- Minimize your consumption of smoked, cured and salted foods. Taste your food before adding salt! Or try alternative seasonings in your cooking such as lemon juice, onion, vinegar, garlic, mustard, cloves, sage or thyme.
- Increase your intake of high-fiber foods such as fresh fruits and vegetables, whole grain breads, rice and cereals. A high-fiber diet is especially helpful in keeping me healthy.
- If you are dieting to lose weight, make sure that you are getting all the vitamins and minerals your body need to function properly.

Proper nutrition will help keep you and your liver healthy. In addition, a regular exercise routine, two or three days a week, will help keep you and your liver healthy, too.