

Our Mission The American Liver Foundation is the nation's leading nonprofit organization promoting liver health and disease prevention. We provide research, education, and advocacy for those affected by liver-related diseases, including hepatitis.

New England Chapter

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Liver Information For Everyone



Fall 2006

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Local News: Spotlight on Marysa Morin

Life turned upside down

Marysa Morin was a healthy fourteen year-old, spending her days dancing, doing homework and socializing with friends. During her freshman year of high school, her world changed. She became lethargic and her joints began to ache. After several doctor visits, Marysa underwent a liver biopsy and discovered she had autoimmune hepatitis, a progressive inflammation of the liver that is associated with an abnormality of the body's immune system. The disease is most common in adolescent or early adult females.

The Morins research and bond together

For the next several months, Marysa and her family read everything they could get their hands on about her autoimmune hepatitis. Her mother (a registered nurse) spoke with doctors and found a specialist well-versed in the disease — Dr. Maureen Jonas at Children's Hospital. It was tough at first, Marysa admits, trying to adjust to the medications and keeping her weight up in order

to stay healthy. She sought help from a nutritionist and was able to control her medicine and her diet. She was back on her feet and in school the following fall semester.

A new attitude

With the help of her large family, Marysa was able to regain strength and live a normal life. Before participating in the Football Walk for Liver Wellness in 2005, she spoke to 600 students at her school. Instantly, she had a team of walkers big enough to fill her own bus! This year "Marysa's Milestones" will once again hit the pavement to raise money for liver disease research. "People have no idea I have liver disease because I look normal," explains Marysa as she talks about the importance of educating her peers. Marysa leads a full life—babysitting, running and walking, and dreaming of studying to become a Physician Assistant in the future. Marysa's liver disease is currently in remission.

To join Marysa's walk team or make a pledge, log onto www.footballwalk.org.



Your Liver. Your Life.

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Letter from the director



"Welcome to the new look of our newsletter. We hope you enjoy it."

The changing of the seasons affords us an opportunity to celebrate a new beginning. I particularly like the fall because of the way New England lights up with colors that only a crayon box can match. This is a busy time of year for the American Liver Foundation New England Chapter, filled with exciting new programs and proactive opportunities to help educate, advocate and provide support in the fight against liver disease.

Exciting news in New England

Our annual Football Walk for Liver Wellness, which takes place on September 17, highlights patients and their families who make the five-mile journey to help raise awareness of their personal battles with the disease. On October 27, we will once again host the Irwin M. Arias, MD Symposium in Boston for doctors, fellows and researchers to pool their knowledge about the science of liver disease. For the first time ever, our Chapter is hosting a seminar on "Hot Topics in Liver Disease" on September 30, to update primary care physicians on liver disease prevention and treatment options.

We can't forget our great Boston Marathon® Run for Research® program. This fall, Team Manager Laura Dempsey is hard at work securing applications for the 2007 roster. We are proud to announce that our 2006 RFR team raised over \$1.1 million! We look forward to another successful and fun race in 2007.

The news from our office — we are growing. We have added a new staff member to enhance our educational programs and a communications specialist to help spread the word about liver disease research, education and advocacy. All staff members, both new and veteran, are diligently working on programs which will ultimately benefit some of the 30 million Americans affected by liver disease.

You make a difference

As we continue to roll out the Liver Wellness and Fatty Liver Disease campaigns, we would like to thank all of our supporters. Without our doctors, volunteers, walkers, runners, staff members and donors, it would not be possible to change the lives of patients with liver disease and fund the research grants that make future cures possible. Our newsletter is a reflection of the efforts of the New England Chapter. Have a wonderful fall.

Go Liver!

Kelly Leigh Beckett

Kelly Leigh Beckett
Executive Director, New England Chapter



The ALF salutes Tom Nealon

Like most first-time Run for Research® (RFR) members, Tom Nealon joined the team because he wanted to run the Boston Marathon®.

Six years later, with 23 marathons under his belt, Tom is our leading fundraiser (raising over \$70,000 this year alone) and has created a lifelong bond with his patient match Zac Rue, a four-year old Needham, MA, resident who suffers from biliary atresia. Biliary atresia affects approximately one infant in every 15,000 live births. Most of these children require a surgical procedure, and possibly a liver transplantation, in order to survive.

Although Tom runs marathons in Miami, Chicago and New York, Boston is the only one for which he holds a major fundraising campaign. Zac has become a symbol of inspiration for Tom. "The real thrill for me is when I first see Heather, Zac and Hannah as part of the spirited RFR cheering section (mile 16 of the Boston Marathon®). The thought of seeing them has driven me to this point in the race," he explains.

To date, Tom's valiant efforts have raised \$220,000 for the Biliary Atresia Fund for the Cure, a fund that is designed to support researchers in their efforts to initiate new areas of investigation that address novel and important questions related to biliary atresia. Since 2004, he has nurtured a wonderful relationship with Zac, his sister Hannah and their parents Heather and Tom. Tom is not afraid to ask anyone to support his campaign. This year, Tom finished the Boston Marathon® in 5:29:59, a fantastic accomplishment!

To join Tom in support of the Biliary Atresia Fund for the Cure, please send a donation to ALF New England Chapter, 88 Winchester St., Newton, MA 02461.

Our Upcoming Events

9/17/06

Football Walk for Liver Wellness

Time to carry the ball with care — to the liver finish line! The New England Chapter will once again host the Football Walk for Liver Wellness, a five-mile



walk to promote liver health and help raise funds to prevent, treat and eventually cure liver disease.

Registration begins at 9 a.m. along the South Boston Waterfront. The walk will start promptly at 10:15 a.m. Hundreds of patients, families and supporters participate in this spectacular event filled with entertainment and food. There is still time to volunteer, sign up to walk or make a pledge in honor of a participant. If you're ambitious, form your own team! Contact Elizabeth Buell at 617.527.5600 or ebuell@liverfoundation-ne.org.

P.S. Did you know that your liver weighs about three pounds and is similar in size, shape and color to a football?

9/30/06

Hot Topics in Liver Disease

The New England Chapter is honored to host New England area Primary Care Physicians, Physician Assistants and Nurses at the Hilton Hotel in Dedham, MA. Lectures featuring the most up-to-date information about liver disease including new treatments for hepatitis B and fatty liver.

For more information, contact Sam Scott at 617.527.5600 or sscott@liverfoundation-ne.org.

9/06

Run for Research® is Underway!

It is time again for runners to think about pounding the pavement for 26.2 glorious miles! Applications for the American Liver Foundation Run for Research® team are currently being accepted. Come join our 240-plus member team and run the Boston Marathon® race course wearing orange on April 16, 2007. You don't have to be a super athlete to join; we'll show you how to run, how to raise money and complete one of the greatest athletic achievements of your life!

For more information or applications, please contact Laura Dempsey at 617.527.5600 or ldempsey@liverfoundation-ne.org or log onto www.liverteam.org.

10/22/06

Country Music / Oldies Tunes Benefit Jamboree

Come join John Penny and his award-winning country music band, along with singer Jilly Martin and top oldies attraction Reminiscence, to help fight liver disease. The event takes place from 2 p.m. to 8 p.m. at the American Legion Hall in Waltham, Massachusetts, with raffle and door prizes as well as an auction. This is the 14th annual Jamboree to benefit the American Liver Foundation. The event was created by John Penny who received a liver trans-



The John Penny Band

plant in 1992. John says holding this concert is the least he can do to help others who suffer from liver disease.

Tickets, at the door, are \$12 for adults, \$2 for children under 12. All proceeds go to the American Liver Foundation. For more information, please contact John Penny at 781.891.7800 or log onto www.johnpennyband.net.

10/27/06

16th Annual Irwin M. Arias, MD Symposium / Bridging Basic Science and Liver Disease

Every year, the ALF New England Chapter invites liver specialists, researchers, fellows, residents and students to explore the latest advances in basic science related to liver function and disease, to identify major indicators of liver disease and prognosis and review important advances. Some of the most prestigious members of the medical community will lecture during the symposium.

Some of the seminars of the day include "The Iron Balancing Act," "The Hepatitis C Virus Comes of Age," and "The New World of RNA." Speakers hail from Italy, Maryland, New York, Japan and Cambridge. As always, the Chapter extends a warm thank you to Dr. Arias for his continued support and guidance for this special day.

For more information and registration, please contact Elizabeth Buell at 617.527.5600 or at ebuell@liverfoundation-ne.org.

National News: Fatty liver disease and NASH

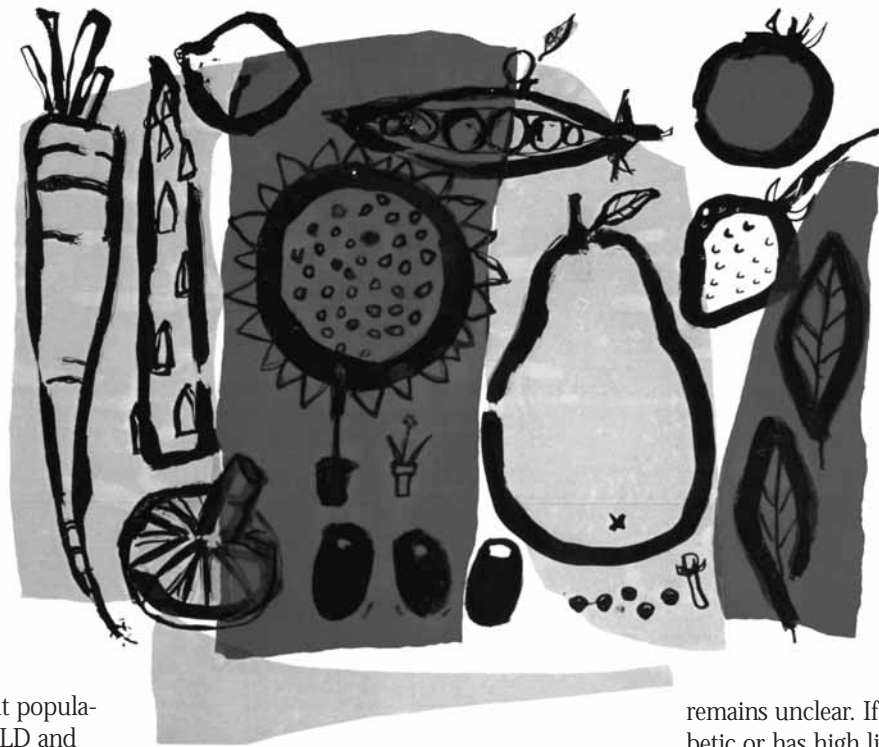
By Fredric Gordon, MD
Medical Director of
Liver Transplantation
Director of Hepatology,
Lahey Clinic

Recently, a great deal of media attention has been given to fatty liver disease. Alcoholism is a well known cause of fatty liver; however, as more and more of the US population becomes overweight, another entity, nonalcoholic fatty liver disease (NAFLD), has been found to be a frequent cause of fat accumulation in the liver. It is estimated that over a quarter of the American adult population may be affected by NAFLD and the American Liver Foundation wants to educate you on the particulars of NAFLD.

What is fatty liver?

Fatty liver is the accumulation of fat in liver cells. Fatty liver is common in patients who are very overweight or have diabetes mellitus. Eating fatty food alone does not produce a fatty liver. Fatty liver can be the result of weight gain from a poor diet, diabetes mellitus and certain drugs such as corticosteroids and methotrexate. Presently an abandoned procedure, intestinal bypass surgery for obesity has also been linked to NAFLD. Several studies show that fatty liver is one of the most common causes of isolated minor elevation of liver enzymes found in routine blood screening.

A simple fatty liver without liver enzyme elevations or other signs of liver inflamma-



A healthy diet that includes lots of fruits and veggies helps keep your liver working at its best.

tion does not require medical treatment. Doctors suggest that a patient with NAFLD control their weight and manage their diabetes mellitus with diet, medication, or insulin in order to help decrease the fat content in the liver.

NASH defined

Nonalcoholic steatohepatitis (NASH), on the other hand, is the accumulation of fat in the liver associated with inflammation and damage to the liver cells. The inflammation caused by NASH, may result in progressive scarring of the liver and even cirrhosis. Studies show that 20 to 40 percent of people who are grossly overweight will develop NASH, including children. Unfortunately

NASH does not cause any signs or symptoms that alert the person that there is a liver problem. In most cases, NASH causes a slight increase in liver enzyme tests, as do other forms of liver disease. A liver biopsy is often performed to assess the degree of damage and, determine whether the condition is NAFLD or NASH.

Treatment options

The optimal treatment for NASH

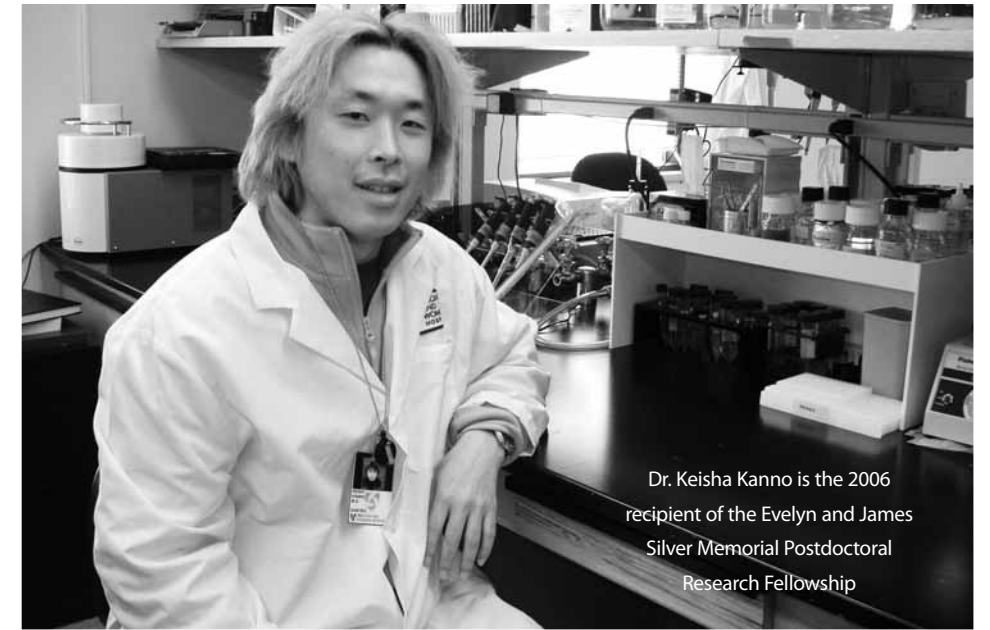
remains unclear. If a patient is obese, diabetic or has high lipids (fats) in their blood, they are advised to control their weight and blood sugar, as well as lipids. Even for patients with NASH who are not overweight, a low fat diet is prescribed. As with other liver diseases, patients should avoid alcohol as well as any other substances that can damage the liver.

As obesity continues to be an epidemic in this country, so too will the growth of many other diseases, including NASH and NAFLD. The growing concern for patients with NASH and NAFLD is carefully monitored by the American Liver Foundation. More and more calls are coming into the national hotline asking our trained staff how to learn more about fatty liver disease. For more information, contact the American Liver Foundation New England at 617.527.5600.

Dr. Keisha Kanno, MD, PhD of Brigham and Women's Hospital in Boston, Massachusetts, was awarded the Evelyn and James Silver Memorial Postdoctoral Research Fellowship in 2006. In 2006 alone, the American Liver Foundation awarded over \$2.6 million to 23 Liver researchers nationwide. Dr. Kanno is a local example of how ALF strives to make changes in liver disease through our research awards. He will study nonalcoholic Fatty Liver Disease (NAFLD) over the course of a year.

Can you tell us about your background in medicine?

In my childhood in Japan, my father, who was a great researcher and scientist, often told me that there is nothing more interesting than research. I did not understand what



Dr. Keisha Kanno is the 2006 recipient of the Evelyn and James Silver Memorial Postdoctoral Research Fellowship

ALF Awards Researchers over \$2.6 million in grants for 2006

he actually meant until I became a professional researcher myself. After completing clinical training as a general physician at Hiroshima University Medical Hospital in 1997, I began my formal training in gastroenterology and hepatology. I then entered the Graduate School of Biomedical Sciences, Hiroshima University in 2000, focusing on liver pathophysiology research. In 2004, I received a PhD based on my studies of hepatic fibrogenesis.

How does your work help us better understand NAFLD?

I'm trying to understand how the liver cells handle fat metabolism. There are many enzymes and chemical reactions that take place, and I am examining the possible interaction of two specific proteins. One is a protein that binds to fats, called phosphatidylcholine transfer protein, the other is a newly described enzyme referred to as thioesterase superfamily. My research project will concentrate on characterizing the physical properties by which these proteins interact. I will also explore the metabolic consequences of the interactions.

How did you become interested in liver disease research?

It was during the initial three years of my clinical experiences that I became interested in hepatobiliary diseases. Because the liver is one of the most mysterious organs with its multiple functions, I was not only intrigued by treating patients with liver disease in the clinic but also became curious about research in the area of liver disease. Before I joined Dr. Cohen's laboratory at Brigham and Women's Hospital in 2004, I investigated the mechanism in which renin-angiotensin system contributes to the development of hepatic fibrosis. At that time, nonalcoholic steatohepatitis (NASH) aroused my interest as one of the common causes of hepatic inflammation and fibrosis.

Do you have any idea of how many people are affected by this disease?

In most cases, NAFLD is diagnosed in people who are overweight or obese. In the US, about one-third of the population ages 15 or older is overweight or obese. Because NAFLD describes a spectrum of hepatic conditions ranging from simple fatty liver

to liver cirrhosis, its true prevalence is not known. However, some estimates suggest a quarter of the American adult population has NAFLD, and it is quite certain that NAFLD has become a growing problem.

What do you hope to accomplish with this research?

Although the metabolic syndrome and insulin resistance are proved to be important risk factors for the development of NASH, the mechanism responsible for its pathogenesis is poorly understood. I certainly believe that phosphatidylcholine transfer protein is one of the key molecules that is involved in regulating fat accumulation in liver, and that study of it will provide better understanding of fat metabolism by the liver and to the molecular causes of NAFLD.

How has the ALF grant program helped?

My grant has allowed me to concentrate more on my current studies without having to worry about personal finances. Moreover, the prestige associated with this award will be a great asset for my future efforts to establish an independent liver research program.

Ask the expert: Hepatitis B prevention and treatment

By Daniel S. Pratt, MD

Assistant Professor of Medicine,
Harvard Medical School
GI Unit, Massachusetts General Hospital

Know the Facts about Prevention

Hepatitis B is a significant problem worldwide. Of the approximately 6.5 billion people in the world, almost a third have evidence of having been exposed to hepatitis B, 400 million patients are chronically infected, and as many as 1 million patients per year will die as a result of hepatitis B. Approximately 1.2 million people are chronically infected in the United States.

It is critical that carriers of hepatitis B receive the necessary counseling to reduce the risk of transmission to others. The risk is greatest for the sexual partners of chronic carriers of

"Universal vaccination of newborns and targeted vaccination of high-risk adults provide great promise for the prevention of chronic hepatitis B. For patients already infected, there are a number of effective therapies available to prevent complications of the disease."

hepatitis B and the babies of mothers with chronic hepatitis B, specifically during the birth process. Others at high risk include household contacts of patients with hepatitis B, healthcare workers, IV drug users, patients with other forms of chronic liver disease, and patients on chronic hemodialysis. Carriers of hepatitis B should be careful about covering open cuts and cleaning up blood spills as hepatitis B can survive outside of the body for extended periods.

In addition to understanding transmission, those at greatest risk for contracting the infection should be vaccinated to provide long-term immunity. The vaccine is very effective with a response rate of 95%, although there are some groups that have lower response rates such as patients with cirrhosis.

Many countries, including the United States, have implemented universal hepatitis B vaccination of all newborns regardless of the mother's disease status. Not surprisingly, the greatest benefit of such a program has

been seen in those countries with the highest rates of hepatitis B infection. For example, Taiwan instituted universal vaccination in 1986 and there is already a clear

reduction in the rate of chronic hepatitis B infection and there has been a 50% reduction in liver cancer in children.

Suggestions for Treatment

For people already infected with hepatitis B, the focus turns to preventing complications of the disease, specifically progression to cirrhosis/end-stage liver disease and development of hepatocellular carcinoma. There are now 5 drugs approved for the treatment of chronic hepatitis B in the United States — interferon alfa-2b, pegylated interferon alfa-2a, lamivudine, adefovir, and entecavir. There are also a number of other drugs that will be approved in the next several years. Current challenges in the management of chronic hepatitis B include identifying which patients will benefit from treatment, what drug or combination of drugs will be most effective for the individual patient, and determining the correct endpoints of treatment.

Liver Facts At A Glance

The liver is one of the body's largest organs, performing hundreds of functions every day. It removes harmful substances from the blood, makes bile to help digest fat, and stores energy.

30 million Americans—one in every 10—are or have been affected by a liver, biliary, or gallbladder disease.

Liver disease and cirrhosis are the 7th leading cause of death among adults between the ages of 25 and 64 in the U.S.

Many forms of liver disease are preventable, and many more, if detected early, can be treated effectively.

About 15,000 children are hospitalized every year with pediatric liver diseases or disorders.

There are more than 100 types of liver disease, but hepatitis A, B, and C are the most common.

There are vaccines that can protect you against hepatitis A and B, but not hepatitis C.

Chronic hepatitis C and alcoholic liver disease are the leading causes of cirrhosis in the U.S.

About one-third of the U.S. population becomes infected with hepatitis A during their lifetime, though most recover in a few weeks.

More than four million Americans have been infected with hepatitis C; it is responsible for 8,000-10,000 deaths annually.

1.4 million Americans are chronically infected with hepatitis B; it is responsible for 5,000 deaths annually.

Hepatitis B and C significantly increase the risk of liver cancer, one of the only cancers currently on the rise in the U.S.

Hepatitis C is the number one reason for liver transplantation in this country.

Nonalcoholic fatty liver disease (NASH), an obesity-related chronic liver disease, may affect as many as one in every four adults over the age of 18.

In 2004, there were nearly 18,000 individuals on the waiting list for a liver transplant. That year, about 1,300 people died while waiting for a suitable donor.

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.

1-800-GO-LIVER

1-800-456-5517

www.liverfoundation.org



DO WE HAVE YOUR EMAIL ADDRESS?

To be included in periodic updates about New England Chapter events, please send an email to lpark@liverfoundation-ne.org with your email address and we will add you to our list.

Join the Run for Research[®] Team!



Applications for 2007
will be accepted beginning
September 6, 2006
www.liverteam.org

Make A Difference

Join the fight against liver disease by donating to the American Liver Foundation New England Chapter. Your support provides hope to millions of Americans for a healthier tomorrow. Thank you!

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