FACES OF LIVER DISEASE
American Liver Foundation Annual Report 2014
About the American Liver Foundation

Founded in 1976, the American Liver Foundation (ALF) is the nation’s largest patient advocacy organization for people living with liver disease. ALF reaches more than 1.5 million people each year with health information, education and support services via its national office, 17 U.S. divisions and an active online presence. Recognized as a trusted voice for liver disease patients, ALF also operates a national toll-free helpline, educates patients, policymakers and the public, and provides grants to early-career researchers to help find a cure for all liver diseases.

For more information about ALF, please visit www.liverfoundation.org.
In 2014, the American Liver Foundation had much to be proud of. We expanded our programs, secured new partnerships, provided critical support to promising young researchers, boosted our presence on the national stage, and provided information and services to an unprecedented number of individuals living with liver disease, as well as their families, friends and those at risk.

In order to combat liver disease, we ramped up our advocacy and communications activities, engaging patient advocates to tell their stories. Thanks to their efforts, particularly their openness and frankness about living with serious liver conditions, they have helped lift the stigma, offering hope to millions of Americans. This led to our establishing our first national patient advisory committee of individuals who are living with or have been cured of hepatitis C. Future expansion will include advocates for other types of liver disease.

In fact, because of their participation, along with expert commentary from our national medical advisory committee members, we secured an unprecedented amount of national and regional media coverage. We were featured in approximately 65 media outlets, including The New York Times, NPR, Reuter's, The Chicago Tribune and WebMD. This platform helped us enormously in our goal of informing the public about liver health and disease issues and the many faces of liver disease.

With help from our public education programs, advocacy efforts and communications outreach, liver disease is finally getting the attention it deserves. As one of the top 10 leading causes of death for Americans between the ages of 25 and 64, liver disease has for a long time been hidden in the shadows. That is changing.

In this report, you will read about the Faces of Liver Disease – not just of patient advocates, but the faces of researchers working in laboratories across the nation who may one day discover cures, donors who support our work, ALF staff, volunteers and everyone that helps us on the national and regional level.

You are all the faces and voices of liver disease. And we thank you for the profound impact you make at ALF and for the people we serve.
ALF hepatitis C patient advocates show that "C is for the cure."
There are many faces of hepatitis C. In fact, some four million faces in the United States alone. Hepatitis C is the leading cause of liver failure and end-stage liver disease and is a major reason for liver transplants in the United States. Yet, millions of people are unaware that they have the virus and millions more do not know that they are at risk.

In 2014, the American Liver Foundation launched a national patient advisory committee (NPAC) comprised of men and women of all ages, backgrounds and life circumstances who are living with or were cured of hepatitis C. These patient advocates are communicating the message that you can be cured of hepatitis C but first you need to be tested. In the media and the halls of Congress, these patient advocates are calling for greater public education and awareness about liver disease—including hepatitis C—increased research funding, more widespread testing and improved access to quality care.

People like Navin Vij, a young doctor from Cleveland, who learned in his late 20s that he had contracted hepatitis C as an infant; and Carleen McGuffey, a mother of six, who learned during her last pregnancy that she had hepatitis C that was likely contracted some 25 years earlier. These are just two of the many faces of hepatitis C.

Navin and Carleen as well as several other NPAC members are featured in a multi-part video series, called “The Hidden Truth,” which you can find on the home page of the ALF website liverfoundation.org.

“I met an amazing researcher whose work helped lead to a cure for Hep C. It turns out ALF was one of his earliest grant supporters. Since I donate to ALF, I feel like I helped fund the discovery of my own cure.”

Carleen McGuffey, ALF Donor

The Face of Hepatitis C Could Be Yours

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Navin Nij, ALF Patient Advocate, pictured above.
Some friends would give you the shirts off their backs. Others would give you the lobes of their livers. That is just what John Chester did when his best friend’s brother needed a liver transplant in 2013.

Many people may not realize that livers for transplants can come from a living donor. It’s an exciting area and with the shortage of cadaver organs, it can help patients desperately waiting for new livers.

New Jersey resident Jeffrey Doerr was born with biliary atresia, a condition where bile ducts become inflamed and blocked soon after birth. This causes bile to remain in the liver, where it starts to destroy liver cells.

“I was pretty fortunate. I lived a normal life and didn’t get really sick until I was 27, which is unusual for my disease,” says Jeffrey. “But it eventually caught up with me—big time! I went from feeling great to needing an immediate transplant in a heartbeat.”

When friends and family learned that it was possible for individuals to donate part of their livers, they rushed to see if they could be living donors. There were high hopes that his younger brother Mark would be a match, but Mark’s liver was not big enough.

Says John, “I saw Mark at our college graduation party and he was not himself. Understandably he was worried about his brother. I always knew that Jeffrey had a liver condition but because he was always so healthy, I had never thought of it as life-limiting.”

It was at the party that Mark told John about the severity of Jeffrey’s illness and the difficulty of finding an organ donor. John immediately offered his. For him, it was a reflex action. It was a long time since the days of being an Eagle Scout — the highest rank you can attain in the Boy Scouts. But the strength of character that John exemplified then did not fade with time. Recently John was awarded the Boy Scout’s Honor Medal With Crossed Palms, which is given to someone who has put himself in danger to save another’s life. Only 277 Honor Medals with Crossed Palms have been awarded since 1924.

It turned out that John and Jeffrey had the same blood type and John’s liver was big enough so that his entire right lobe could be transplanted into Jeffrey’s body. Livers regenerate (it is actually the only organ in the body that can) and John’s grew back within weeks of his surgery.

There are a number of tests involved when you are a living liver donor. Of course, there are CAT scans, MRIs and blood tests to ensure the physical health of the donor. But there are also psychological tests to ensure that the donor is emotionally healthy to have made the decision and did so of their own free will without coercion or expectation of a financial reward.

The summer was spent undergoing all of these tests. “Three days before the surgery was scheduled, I went toxic,” says Jeffrey. “There really wasn’t time to waste.”

The surgery was performed at the Hospital of the University of Pennsylvania. John was released after a little over a week and Jeffrey recovered in the hospital for two weeks.

“You don’t expect a 23-year old, fresh out of college to do such a remarkable and selfless act,” says Allan Doerr, Jeffrey’s father and a member of the American Liver Foundation’s national board of directors. “John saw an opportunity to help a friend and he did not hesitate. It was such a normal and natural thing to do. Our family is eternally grateful.”
Gretta Goodis is thankful for her diabetes. Because of her condition, doctors were able to diagnose her liver cancer at a very early stage.

The diagnosis of liver cancer was a surprise to Gretta’s doctors and Gretta herself as she was considered low-risk for primary liver cancer (though she really wasn’t) so she, like other low-risk individuals, was not screened as part of her annual physical examination. However, Gretta did have fatty liver disease, which is a risk factor for liver cancer as is diabetes. And at age 16, she had a bad reaction to a medication, which caused her liver to become inflamed.

Each of them, along with the fact that her grandmother died from liver cancer at age 50 and Gretta was already 52, should have caused her to be considered higher-risk.

Gretta was lucky.

Because her diabetes was monitored so closely, doctors saw that her liver enzymes were elevated and further tests revealed that she had three masses on her liver, two of which were cancerous.

Doctors at Johns Hopkins Hospital, one hour away from her York, PA home, removed the masses. No further treatment was needed. She continues to be followed regularly for any signs of recurrence, and things are still looking very positive.

“It is important to know your family history and push for more testing,” says Gretta. “There is a misperception that only alcoholics are at risk for liver cancer and that it isn’t a concern for women.”

Her 26-year-old son has slightly elevated liver enzymes and early signs of fatty liver disease so he is being watched closely and working with his doctor to prevent progression.

Five years after her diagnosis, Gretta is healthy and considered cured. Her diabetes is also now well controlled.

Adds Gretta, “I know how lucky I am and I treasure every day.”
Faces of Liver Disease

Liver Disease Happens – In Children Too

If you were challenged to pick the kid on the lacrosse team who had a liver transplant three years ago, you would be hard-pressed to identify 15-year old Nick Wallace. At only two weeks old, Nick was diagnosed with biliary atresia. He received his first surgery at three and a half weeks and ultimately needed a liver transplant when he entered adolescence. He received a new liver in September 2012 after waiting eight months for a match to become available.

Though he was in and out of the hospital for most of his young life, says Nick, “I never gave up. I always stayed positive and did the things I love to do.” This included surfing, skiing, swimming, playing baseball and golf and his favorite activity – lacrosse.

As much as Nick went through, he thinks of others. Understanding what it is like to be in the hospital for long stretches at a time, he started a foundation, Nick’s Picks, that delivers backpacks of toys and games to children who are in the hospital. “I admire Nick so much, more and more each day,” says his older sister Lexi who stayed with him every step of the way, including climbing into his hospital bed as he was wheeled into surgery. “His liver transplant has made him an even stronger person,” she adds.

That strapping 6’2’ young man? That is John McCarthy who was diagnosed with biliary atresia at just eight weeks old and spent most of the first two years of his life in the hospital. He was put on the transplant list at nine months old, his parents waiting a tense 11 months for a liver to become available. He just graduated SUNY Binghamton with a degree in biology and is planning to go to graduate school to study physical therapy.

Having a sick child, especially when you already have a toddler at home, places enormous stress on the family. Suddenly you are thrust into a world that you never expected to be in. “When John was diagnosed, there was very little information about biliary atresia,” says his mother Mary. “We quickly learned that we needed to be John’s advocates and peppered the doctors and nurses with questions to make sure that we understood everything about the disease and its treatments.”

Long Island natives, John’s family moved to Rochester, Minnesota where they lived for three months during his transplant. When asked what she would say to parents of a baby newly diagnosed with biliary atresia, Mary says, “Research as much as you can about the disease and the best places to be treated. Seek out support from others who have been there. Most of all, never give up hope.”

“My family and I are so grateful to the family who donated their loved one’s liver,” says John. “In the midst of their own unbearable tragedy, they thought about helping a child who...”
they didn’t know. I know how fortunate I am that I received a liver when so many children are waiting and I am taking full advantage at my second chance at life."

At 18, many girls across the country are busy picking out their prom dresses. And Grace Cummings is no different. She is also an avid ice hockey player.

Grace was born with a choledochal cyst in the biliary tract of her liver. At 12-days-old she had extensive liver surgery to remove the cyst, gall bladder and reroute parts of her intestines. She also was diagnosed with biliary atresia.

"I didn’t feel that different from other kids because I lived a pretty normal life except that I had to take medication every day," says Grace. “Eventually I was hospitalized more frequently but it didn’t affect my life all that much and I could still spend time with my friends and sister Meghan. I could still play hockey the same way I always had."

"Having these two conditions together was as likely to happen as winning the lottery twice," says Grace’s mother Colleen who, along with her husband George, worked tirelessly to find a liver donor by putting out the word in all communications channels, including making pleas for a donor, that went viral on the Internet. Incredibly, the family got the word that a new father offered to donate part of his liver to Grace. “We did not know this person and there are no words to describe how grateful we are at this man’s selflessness and kindness,” says Colleen.

Nick, John and Grace and their families are generous and loyal supporters of the American Liver Foundation. All participate in Liver Life Walks, Flavors and on-line fundraising efforts to help raise money for the Foundation’s Pacific Coast, Greater New York and Connecticut divisions, respectively. Together, they have raised thousands of dollars to support public education programs and research.

To children who are living with liver disease and awaiting a liver transplant, Grace tells them to “live life to the fullest and have hope as you wait.”
Education

The American Liver Foundation conducts a variety of education programs about liver health and wellness and ways to prevent, treat and live with liver disease. These programs are tailored for people of all ages, whether they are living with or at risk for liver disease.

In 2014, ALF’s Community Education Programs reached approximately 15,630 people through more than 500 presentations.

The Viral Hepatitis program targets individuals who have viral hepatitis or are at high risk of infection. Participants in the program learn about the liver, liver disease (specifically hepatitis C, as well as hepatitis A and B), risk factors, prevention, treatment options and other disease management strategies. The Viral Hepatitis program also provides perspectives from individuals living with hepatitis C. The program is held in several settings, including at community-based organizations, detox centers, correctional institutions, hospitals and faith-based organizations.

Love Your Liver is an interactive liver wellness education program targeted to elementary, middle and high school students. The program educates students about the liver and the actions they can take to maximize their liver health and prevent liver disease. Programs are taught in classroom settings as well as at after school programs, summer camps and other youth group-related locations.

Teens to Twenties is intended for high school and college-aged students, to inform them for a better understanding of the liver and liver-related diseases. The program focuses on liver health, including nonalcoholic fatty liver disease, risk factors and prevention of viral hepatitis, and more.

The Liver Wellness program provides a general overview of liver disease and liver wellness, covering a variety of topics including information about the liver, liver diseases as well as the importance of maintaining a healthy lifestyle to ensure good liver health. Liver Wellness is presented in community settings such as libraries, hospitals, civic organizations and in corporate settings as part of employee wellness programs.

Research

Approximately $350,000 was awarded to 11 early-career scientists from many of the nation’s leading academic institutions. These researchers are adding to our knowledge about liver disease with the goal of preventing its onset and finding better treatments and cures. Read about the 2014 grant recipients on page 16.

Advocacy

In March 2014, ALF participated in the Seventh Annual Liver Capitol Hill Day sponsored by the American Association for the Study of Liver Diseases. ALF brought a contingent of patient advocates who called on Congressional leaders to make liver disease research a funding priority and improve access and delivery of care.

ALF also advised on the U.S. Preventative Services Task Force Draft Recommendations for Hepatitis B Screening, providing key information about hepatitis B and critical screening guidelines that should be included in their final recommendations. The American Liver Foundation, along with the National Alliance for Hispanic Health, called on the U.S. Food and Drug Administration to provide clarity on drug names recommending that all biologic medicines, including
biosimilars, have distinguishable names to better ensure effectiveness and safety once a medication is approved. This would better inform clinicians and help improve patient outcomes, particularly in minority populations.

The American Liver Foundation endorsed a re-thinking of current liver allocation guidelines to decrease geographic disparities. ALF issued a statement in conjunction with a public forum that the Organ Procurement and Transplantation Network (OPTN) and the United Network for Organ Sharing (UNOS) held to review a proposal that would alter the map of how donated livers are distributed nationwide.

The American Liver Foundation, in concert with the National Task Force on Hepatitis B, endorsed the Immunization Action Coalition’s (IAC) national initiative, Give Birth to the End of Hep B, a campaign to promote the hepatitis B vaccine birth dose immunization for all newborns.

ALF partnered with NeedyMeds to create a Drug Discount Card for uninsured and underinsured patients and their families. The card is accepted at 63,000 pharmacies throughout the U.S. and can save people as much as 80% on drug prices when used without insurance. NeedyMeds is a national organization that provides information to individuals who cannot afford medications and health care costs.

Support Services
The American Liver Foundation provides the public with a wealth of information about liver disease prevention, screening/testing and treatment. It operates a National Helpline to answer questions and three educational websites: liverfoundation.org and two that are dedicated to hepatitis C and hepatic encephalopathy, hepc123.org and he123.org.

National Helpline
ALF’s 1-800-GO-LIVER (1-800-465-4837) National Helpline is a go-to resource for patients and families providing answers to and guidance on the public's many questions and concerns about liver disease. This includes how to find a doctor, information about the latest treatments and about financial assistance programs and clinical trials. In 2014, ALF's National Helpline responded to more than 5,000 callers seeking information. For those with limited English proficiency, the Helpline also offers real-time interpretation services in 20 languages.

Educational Materials
ALF produces educational materials on 31 liver health topics — available to the public at no cost — including biliary atresia, cirrhosis, hepatitis C, fatty liver disease and liver cancer. ALF also offers information about liver health and wellness, diet, managing medications, what to do when you are newly diagnosed and financial assistance resources. Materials are available in many languages, including Spanish, Chinese and Russian.
2014 National Highlights

In addition to the success of our education and outreach initiatives, ALF created new programs and aligned with corporate and nonprofit partners on a variety of outreach efforts. These included:

Launch of a National Patient Advisory Committee

Through the generous support of Gilead Sciences, ALF launched its first national patient advisory committee (NPAC), comprised of 30 members who are living with or were cured of hepatitis C. These individuals are helping to guide ALF’s communications activities around hepatitis C. We kicked off the NPAC with a three-day meeting in New York City in late 2014 where members participated in media training exercises and heard presentations about hepatitis C communications messaging and ALF public education activities. They have already begun to put what they learned into practice speaking to their communities, the media and Congressional leaders.

Webinar Series

ALF launched its webinar series in 2014 with three webinars about hepatic encephalopathy and one on hepatitis C: HE: A Patient’s Perspective; Treating HE: A Physician’s Perspective; HE: Ask the Experts; and Hepatitis C: Treatment Options and the Patient Experience. Hundreds of people nationwide tuned in to each webinar.

The webinar series is designed to inform patients and caregivers about different types of liver disease and allow them to engage with clinicians and patient advocates. The HE webinars were supported by Salix Pharmaceuticals and the hepatitis C webinar was supported by Merck.

Know Your Dose

The American Liver Foundation partnered with the Acetaminophen Awareness Coalition on its Know Your Dose Campaign, designed to raise awareness and offer practical advice for safe acetaminophen use.

Liver Cancer Awareness Campaign

The American Liver Foundation kicked off a multimedia campaign in conjunction with Liver Cancer Awareness Month. Sponsored by Bayer Healthcare and Onyx Pharmaceuticals, the campaign featured ads on New York City and San Francisco public transit systems, including on subways and buses as well as national outreach efforts through a special issue of ALF’s October newsletter and a radio media tour. Ghassan Abou-Alfa, MD, medical oncologist at Memorial Sloan-Kettering Cancer Center, chair of the Hepatobiliary Task Force of the National Cancer Institute and a member of the American Liver Foundation’s national medical advisory committee, participated in a radio media tour, along with ALF Chief Executive Officer and National Board Chair Tom Nealon, which featured interviews with approximately 15 radio stations across the country. The goal of the campaign is to generate greater awareness about the risks of liver cancer and encourage people at risk to speak to their doctors about the disease.
600,000 people a year die from liver cancer worldwide.

Are you at risk?

Talk to your doctor if you have any of the following risk factors:
- Hepatitis B or Hepatitis C
- Fatty Liver (associated with Obesity and Diabetes)
- Excessive Alcohol Consumption
- Certain Metabolic Diseases

Learn more about these risk factors at www.liverfoundation.org/livercancer or call 1-800-GO-LIVER
Connecticut
On January 9, 2014, after 16 plus weeks of dedicated training, 13 runners from the tri-state area came together to run in the Walt Disney World® Marathon Weekend as part of the Liver Life Challenge Connecticut Division team, raising awareness and funds for the American Liver Foundation. The team included liver transplant recipients, those who lost a loved one to liver disease, healthcare providers, transplant surgeons, pharmaceutical representatives, caregivers, and family members. They collectively ran a total of 275 miles in two days and raised $45,000 for the American Liver Foundation Connecticut Division.

Desert Southwest
The American Liver Foundation’s Desert Southwest Division hosted its inaugural Flavors of Dallas event on June 25, 2014. More than 150 guests were treated to five-course meals prepared tableside by 14 of Flavors of Dallas premier chefs dining on such mouth-watering dishes as summer squash carpaccio, Maryland style jumbo lump crab cakes and lemoncello chocolate hazelnut semifreddo with macerated blueberries, cocoa nibs and biscotti.

Special guests included ALF’s CEO and National Board Chair Tom Nealon and National Board Members Allan Doerr and Michael Kerr. Mr. Kerr was the evening’s “Fund The Mission” speaker.

This is part of the Desert Southwest Division’s expansion into the Dallas/Fort Worth area.

Great Lakes
On October 25, 2014, ALF’s Great Lakes Division hosted its first Annual Liver Symposium. The division’s medical advisory committee (MAC), under the leadership of Committee Member and Symposium Chair Rockford Yapp, MD, gastroenterologist at Digestive Health Services, developed the agenda for this event, which included continuing medical education credits for healthcare professionals and sessions for patients and the general public. MAC members presented information about hepatitis C, non-alcoholic steatohepatitis (NASH), hepatocellular carcinoma, cirrhosis and transplantation to 75 professionals. Sessions on liver wellness and advancements in hepatitis C treatments were presented to more than 50 patients and the general public.

This free educational event was made possible through the generous support of community members and sponsors, including Gilead Sciences; AbbVie; Aureus; Onyx; Novartis; BiocureRX; BriovaRX; Bristol Myers-Squibb; CVS Health; Diplomat Pharmacy; Merck; Northwestern Medicine-Kovler Organ Transplantation Center; Salix Pharmaceuticals; University of Wisconsin; and Walgreens.

Greater Los Angeles
The American Liver Foundation’s Greater Los Angeles Division held its 11th Annual Flavors of Orange County gala on August 24, 2014, featuring 11 chefs from some of the best restaurants in Orange County. John Hoefs, MD, professor emeritus at UC Irvine and the Liver Specialty Center in Irvine, was honored with the Healthcare Visionary Award. The event was sponsored by Wells Fargo; Fairmont Newport Beach; Bristol Myers-Squibb; Callahan & Blaine; UC Irvine Health; Salix Pharmaceuticals; Riviera Magazine and Loma Linda University Transplant Institute.

Greater New York
More than 350 people gathered at New York City’s Gotham Hall on September 23, 2014, raising $380,000 to support the American Liver Foundation’s Greater New York Division. The 14th Annual Honors Gala recognized Lewis Teperman, MD, director of the Mary Lea Johnson Richards Organ Transplantation Center at NYU Langone Medical Center, with the Physician of the Year award. Other honorees included Rocco Andriola Esq., managing director of Millennium Partners, who received the Spirit of New York Award and Robert Pollicino, executive vice president and chief financial officer of the Madison Square Garden Company, who received the Liver Champion Award. Gilead Sciences received ALF’s Corporate Partner of the Year Award.

Mr. Pollicino has been a devoted ALF volunteer and division board member since his wife Gina’s hepatitis C diagnosis in 1994.

Salix Pharmaceuticals was the presenting sponsor of the event for the second year in a row. John Elliott of WCBS-TV served as emcee.

Heartland
The Heartland Division hosted a record-breaking fifth Annual Liver Life Walk Cincinnati in June 2014. Five hundred forty six walkers, representing 36 teams, raised $51,174 for the American Liver Foundation. The event included an inspirational group of patients, liver donors and recipients, family members and friends.
Mid-America

The Annual Gift of Life Fashion Show held on April 25, 2014, showcased spring fashions modeled by transplant recipients, living organ donors and local media celebrities. This event has been promoting organ and tissue donation for 16 years and has resulted in more than 1,000 individuals signing up for both the Missouri and Illinois organ and tissue donor registries. World Wide Technology Inc. was the presenting sponsor.

Mid-Atlantic

On October 18, 2014, the Mid-Atlantic Division’s medical advisory committee hosted a symposium on hepatitis C and fatty liver disease for clinicians. The program highlighted current research, disease management and prescribing guidelines with the goal of ensuring better diagnostic and treatment approaches for two of the most pressing public health issues. Attendees included primary care physicians, liver disease specialists, fellows, medical students, nurses, physician assistants and allied health care professionals from eight academic institutions in Eastern and Central PA, Delaware and Southern New Jersey area.

New England

On November 7, 2014, the New England Division held its 24th Annual Irwin M. Arias Symposium: Bridging Basic Science and Liver Disease. A distinguished panel of leading biomedical scientists and physicians presented topics specific to liver biology and disease to an audience of students, fellows and scientists. More than 100 people attended.

Northern California and Nevada

On June 13, 2014, the Northern California and Nevada Division led a team of 19 climbers to the summit of Mt. Shasta -- the second highest peak in the Cascades -- on an overnight climb to raise funds for ALF. This is part of ALF’s Liver Life Challenge event. Fourteen of the 19 hikers made it to the summit.

Pacific Coast

The American Liver Foundation’s Pacific Coast and Hawaii Division hosted its 11th Annual Flavors of San Diego at the Grand Del Mar on September 7, 2014. More than 270 guests enjoyed a five-course gourmet dinner prepared by 25 of Flavors of San Diego premier chefs, dining on delights such as grass-fed filet topped with prawns; lobster tails steamed with cardamom seeds; crab cakes; oysters on the half shell and dark chocolate pudding cake with raspberry coulis. Honoree Tarek Hassanien, MD, of Southern California Liver Centers, donated more than $20,000. This was the Pacific Coast Division’s most successful Flavors event to date. Other special guests included Lynn Seim, executive vice president and chief operating officer of the American Liver Foundation’s national office and Liver Life Champion Phyllis Ward who was the evening’s “Fund The Mission” speaker.

Rocky Mountain

ALF’s Rocky Mountain Division showed their support for World Hepatitis Day on July 28, 2014. Working with Avella Specialty Pharmacy, Denver Colorado AIDS Project and Colorado Department of Public Health and Environment, the American Liver Foundation was part of a hepatitis C testing day that took place in Denver. The group provided rapid hepatitis C testing, educational information about the virus and other diseases and linkage to care.
In 2014, the American Liver Foundation hosted more than 64 events across the country. These events brought together local communities in support of a common goal: to help raise awareness and further the mission of the American Liver Foundation to promote liver disease education, research and advocacy. More than $6,549,117 was raised in 2014.

Flavors

Flavors is the American Liver Foundation’s signature event, a culinary experience that goes beyond the traditional gala and provides each table of attendees with a local chef who prepares a multi-course dinner tableside. The event showcases the signature dishes of ALF’s culinary experts and takes guests beyond the usual restaurant fare. Supporters unleash their inner “foodie” and experience a distinct evening of dining while helping to fund the research, education and advocacy efforts of the American Liver Foundation.

Flavors was first created in 1991. Today the event is hosted by ALF in 20 cities across the country and raises millions of dollars annually to support the work of the American Liver Foundation. ALF’s culinary masters include local celebrity chefs, James Beard Award winners, and even a past winner of Bravo’s Top Chef.

Liver Life Walk

More than a walk, the Liver Life Walk unites communities in the fight against liver disease. Funds raised by the Walks are used for life-saving research, education, support and advocacy.

In 2014, more than 12,983 walkers from coast-to-coast pounded the pavement to change the face of liver health, bringing much-needed awareness and financial support to the needs of millions of Americans who are battling more than 100 different types of liver disease.

Liver Life Challenge

The Liver Life Challenge brings together teams from across the country to participate in endurance events. The American Liver Foundation Liver Life Challenge participants have conquered everything from marathons to mountain climbs and generated millions of dollars in the process. Run for Research, a Boston Marathon training team, is the organization’s longest-running and most successful event.
Funding the Mission

Why I Walk

“Hi my name is Jouel. You can see me with my dad (photo on right) at a Liver Life Walk.

We walk because I have biliary atresia (BA). What’s biliary atresia, you ask? BA is a condition that affects babies. I was born without a little duct called the bile duct, and although it’s small, it’s VERY important.

I had major surgery to create a bile duct for me out of my small intestines. The surgery doesn’t solve the entire problem. Doctors say there is a big chance I will need a liver transplant at some point. I know I will be OK. I just want my mommy and daddy not to worry; you know grown-ups worry.

At the Liver Life Walk, we honor people who, like me, have liver conditions. The Walk gives children like me a chance at becoming all the things we want to be when we grow up. See you there!”

“AbbVie is a biopharmaceutical company focused on tackling the world’s toughest health challenges. We believe to do that, we must not only develop innovative therapies, but also invest in the communities we serve. It has been our honor to support the American Liver Foundation’s patient programs and community-based events dedicated to helping end liver disease across the U.S.”

Lutz Schlict, Vice President, U.S. Virology, AbbVie
Research is integral to the work of the American Liver Foundation and is essential to finding new ways to prevent, treat and cure liver disease. Supporting early-career scientists is critical to this effort.

In fiscal year 2014, ALF provided a $225,000 Liver Scholar Award to one young investigator and 10 Postdoctoral Research Fellowship Awards totaling $125,000 to early-career scientists from many of the nation’s leading academic institutions.

Our Grantees:

2014 Liver Scholar

New England Run for Research Liver Scholar
Andrew Cox, PhD
Brigham and Women’s Hospital
Boston, MA
Role of the hippo pathway in cell fate determination and cancer
Mentor: Wolfram Goessling, MD, PhD

2014 Postdoctoral Research Fellowships

Charles Trey, MD Memorial Postdoctoral Research Fellowship
Marta Skowronska, PhD
University of Miami Miller School of Medicine
Miami, FL
Role of endothelial NMDA Receptors in the Pathogenesis of Hepatic Encephalopathy
Mentor: Michael Norenberg, MD

Herman Lopata Memorial Hepatitis Postdoctoral Research Fellowship
Nicholas Van Buuren, PhD
Stanford University
Stanford, CA
Suppression of drug-resistance during antiviral therapy against HCV
Mentor: Karla Kirkegaard, PhD

Hepatitis Fund for the Cure Postdoctoral Research Fellowship
Doan Dao, MD
The University of Texas Southwestern Medical Center
Dallas, TX
Determination of Host Factor(s) Creating a Self-tolerant Milieu and Enforcing the “Immune Tolerance” Phase of Chronic Hepatitis B Virus Infection
Mentor: Bruce A. Beutler, MD

Congressman John Joseph Moakley Postdoctoral Research Fellowship
Yoon Seok Noh, PhD
University of California, San Diego
La Jolla, CA
The role of Gp130 in Tak1-mediated pathogenesis of Hepatocellular carcinoma
Mentor: Ekihiro Seki, MD, PhD

PSC Research Fund Postdoctoral Research Fellowship
Sumera Rizvi, MD
Mayo Clinic, Rochester
Rochester, MN
PDGF Sensitization of Cancer-Associated Fibroblasts to Apoptosis Confers a Chemopreventive and Chemotherapeutic Effect in Cholangiocarcinoma
Mentor: Gregory Gores, MD

John M. Vierling, MD Postdoctoral Research Fellowship
Raymond Hickey, PhD
Mayo Clinic, Rochester
Rochester, MN
Autologous cell and gene therapy for liver disease
Mentor: Scott Nyberg, MD, PhD

Thomas F. Nealon, III Postdoctoral Research Fellowship Honoring Zachery Rue
Cafar Ozdemir, PhD
Brigham and Women’s Hospital
Boston, MA
Thioesterase Superfamily Member 1 (Them1) Promotes Hepatic Steatosis and Metabolic Inflammation
Mentor: David Cohen, MD, PhD

Roger L. Jenkins, MD Postdoctoral Research Fellowship
Davide Povero, PhD
University of California, San Diego
La Jolla, CA
Hepatocyte-derived microparticles as pro-fibrogenic modulators and potential biomarkers for early diagnosis and therapy of NAFLD and NASH.
Mentor: Ariel Feldstein, MD

Dean Thiel Memorial Postdoctoral Research Fellowship
Zenobia Cofer, PhD
Children’s Hospital of Philadelphia
Philadelphia, PA
Epigenetic regulation of Hedgehog signaling in biliary atresia disease progression and development
Mentor: Randolph Matthews, MD, PhD

Thomas E. Starzl, MD Postdoctoral Research Fellowship
Lena Tomkoetter, PhD
NYU School of Medicine
New York, NY
The Role of Dectin-1 in Liver Fibrosis
Mentor: George Miller, MD
Obesity is a serious public health problem affecting more than two billion people worldwide. It is associated with multiple disorders including diabetes, cardiovascular diseases and liver damage. And it is the main reason for the development of non-alcoholic fatty liver disease (NAFLD), which, over time, can severely damage the liver.

Dr. Povero and his colleagues focus on NAFLD, which can be present in the body in two ways: as non-alcoholic fatty liver (NAFL) in which liver cells, known as hepatocytes, accumulate excessive fat leading to cell toxicity. And a more severe type of liver disease called non-alcoholic steatohepatitis (NASH), in which fat-induced toxicity is accompanied by inflammation, hepatocyte cell death and scarring of the liver.

Dr. Povero's American Liver Foundation grant supports his research in two main aspects of this disease:

• Understanding the link between damaged hepatocytes due to excessive fat accumulation and other surrounding liver cells, namely hepatic stellate cells, which are responsible for the scarring of the liver; and

• Developing non-invasive and reliable tests for the early diagnosis of NASH.

In order to address these two areas, Dr. Povero is investigating the role that microparticles (MPs) play within the process. MPs are small particles that are released by hepatocytes (liver cells) due to fat-induced toxicity and have very diverse biological traits that can be transferred to a target cell and induce a variety of cellular responses. His team is looking at the role of MPs as effective cell-to-cell communicators involved in hepatic stellate cell activation, as well as their potential use as a diagnostic tool for early and advanced stage NASH.

What Dr. Povero hopes to achieve is to better understand the link between damaged or stressed, hepatocytes due to fat-induced toxicity and the activation of hepatic stellate cells during liver fibrosis. Liver fibrosis plays a crucial role in the progression from early stage NASH to the advanced and end stages of the disease. For this reason, understanding the mechanisms of fibrosis is one of the main goals in the quest to develop novel therapeutic tools for advanced NASH.

Key to developing any treatment is being able to create measurable indicators – known as biological markers or biomarkers -- circulating in the bloodstream that indicate that the disease has progressed. These indicators could be used to effectively diagnose the presence of NASH at the earliest possible stages and track whether treatment is effective.

Biomarkers for an accurate and early diagnosis of NASH are currently in great need. The majority of tests currently available for the diagnosis of this disease lack sensitivity and specificity.

On a basic research level, Dr. Povero's work will allow for better understanding of the molecular pathogenesis of NASH, with a particular focus on liver fibrosis. On a translational level – meaning when research conducted in the lab has been shown to be effective and can now be applied in the clinical setting -- his research will have two main goals: to discover and develop novel, individualized and non-invasive biomarkers for an early and accurate diagnosis of NASH leading to personalized medicinal strategies; and to identify novel and potential therapeutic strategies for liver fibrosis.

NAFLD is one of the most common forms of chronic liver disease and occurs in approximately 30% of adults and 10% of children in Western countries. Patients with NAFLD can develop NASH. The diagnosis of NASH requires a liver biopsy, which is invasive, costly and associated with possible significant complications. There are no Food and Drug Administration (FDA) approved medications for NASH, though drugs are in development. Since obesity is a major risk factor, modifications in diet and exercise with the goal of at least a seven percent reduction in body weight is recommended.
Join Us and Give

With your support, the American Liver Foundation can continue to educate the public about liver health and wellness, provide assistance to families and caregivers and work to find better treatments and cures.

Please help us continue this vital work by giving to the American Liver Foundation at www.liverfoundation.org/donate.

Program Services

- Patient Services: $1,303,987
- Public Education: $1,543,042
- Community Services: $1,345,437
- Professional Education: $934,718
- Research: $315,018

Program Expenses

- Program Services: $5,442,202
- Fundraising: $1,180,223
- Management: $548,494
### Financials

#### Balance Sheet

<table>
<thead>
<tr>
<th>Assets</th>
<th>2014</th>
<th>2013</th>
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<tbody>
<tr>
<td>Cash and Cash Equivalents</td>
<td>$1,176,018</td>
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<td>Investments</td>
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<td>Contributions Receivable</td>
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<td>Prepaid Expenses and Other Assets</td>
<td>234,567</td>
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<td>Property and Equipment, Net</td>
<td>346,916</td>
<td>419,372</td>
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<td><strong>Total Assets</strong></td>
<td><strong>$4,497,765</strong></td>
<td><strong>$4,031,913</strong></td>
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<table>
<thead>
<tr>
<th>Liabilities and Net Assets</th>
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<tbody>
<tr>
<td>Liabilities:</td>
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<tr>
<td>Accrued Expenses</td>
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<td>Payroll &amp; Related liabilities</td>
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<td>Funds Held on Behalf of Others</td>
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<td>Awards and Grants Payable</td>
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<td>Deferred Rent Payable</td>
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<td>Loan Payable</td>
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<table>
<thead>
<tr>
<th>Net Assets Surplus/(Deficit)</th>
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<tr>
<td>Unrestricted</td>
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<tr>
<td>Temporarily Restricted</td>
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<tr>
<td>Permanently Restricted</td>
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<td>992,035</td>
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<td><strong>Total Net Assets</strong></td>
<td><strong>2,211,695</strong></td>
<td><strong>1,159,108</strong></td>
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</table>

| **Total Liabilities and Net Assets**        | **$4,497,765** | **$4,031,913** |

#### Statement of Activities

<table>
<thead>
<tr>
<th>Public Support &amp; Revenues</th>
<th>2014</th>
<th>2013</th>
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<tbody>
<tr>
<td>Contributions</td>
<td>$2,483,904</td>
<td>$2,163,307</td>
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<td>Investment Income, Net</td>
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<td>(40,856)</td>
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<td>Other</td>
<td>1,523</td>
<td>3,475</td>
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<td>Special Events, Net of Direct Expenses</td>
<td>5,579,833</td>
<td>5,084,163</td>
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<td><strong>Total Public Support &amp; Revenues</strong></td>
<td><strong>8,223,506</strong></td>
<td><strong>7,210,089</strong></td>
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<table>
<thead>
<tr>
<th>Program Services</th>
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<tbody>
<tr>
<td>Public Education</td>
<td>1,543,042</td>
<td>1,176,519</td>
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<tr>
<td>Research</td>
<td>315,018</td>
<td>505,152</td>
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<tr>
<td>Professional Education</td>
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<td>939,090</td>
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<tr>
<td>Patient Services</td>
<td>1,303,987</td>
<td>1,299,258</td>
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<tr>
<td>Community Services</td>
<td>1,345,437</td>
<td>1,139,133</td>
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<tr>
<td><strong>Total Program Services</strong></td>
<td><strong>5,442,202</strong></td>
<td><strong>5,059,152</strong></td>
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<table>
<thead>
<tr>
<th>Supporting Services</th>
<th></th>
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<tbody>
<tr>
<td>Management &amp; General</td>
<td>548,494</td>
<td>555,997</td>
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<tr>
<td>Fundraising</td>
<td>1,180,223</td>
<td>1,326,477</td>
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<tr>
<td><strong>Total Support Services</strong></td>
<td><strong>1,728,717</strong></td>
<td><strong>1,882,474</strong></td>
</tr>
</tbody>
</table>

| Total Cost of Program & Supporting Services| **7,170,919** | **6,941,626** |

| Change in Net Assets                       | 1,052,587 | 268,463 |
| Net Assets, beginning of year              | 1,159,108  | 890,645 |
| **Net Assets, end of year**                | **$2,211,695** | **$1,159,108** |
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