



AMERICAN LIVER FOUNDATION

# Impact Report

2021

# A Letter From Our Leadership

Dear ALF Supporter,

2021 was a transformational year for the American Liver Foundation (ALF). If the COVID-19 pandemic taught us anything, it was that we needed to refocus our program offerings, awaken our voice nationwide and broaden our overall reach.

At the beginning of the year, we did a deep dive to determine who our audience was and what their interests were. From our database to our social media platforms and even website traffic – no stone was left unturned. One of our largest findings was that people are most interested in liver health – not liver disease.

Throughout this report, you will see how we took what we learned and pivoted our efforts to better communicate our mission. From keeping patients apprised of updates in COVID-19 vaccinations, liver health and emerging clinical trials to planning a nationwide five-year initiative aimed to help prevent and detect liver disease earlier, affect better management and treatment of liver disease, reduce stigma associated with liver disease, address health inequalities, advance changes in federal policy and increase funding for research, 2021 was indeed a dynamic year.


In addition to refocusing our program and awareness strategies, ALF started to refocus its brand. Flipping through the pages in this report, you will see an array of new colors representing life, health, rejuvenation and the new ALF. We will launch the full brand late summer 2022.

At ALF, the patient is at the center of everything we do. We are focused, we are strong and we are grateful for you.

Sincerely,



Dan Weil  
Chair, National Board of Directors



Lorraine Stiehl  
Chief Executive Officer





## COVID-19 Response

Protecting liver patients, who are at greater risk of contracting COVID-19 and suffering more severe complications, was a top priority for ALF in 2021. We continued to educate the liver community through Town Hall style webinars, public Q&A sessions with medical professionals and more.



ALF held an educational program for caregivers of pediatric liver patients on how COVID-19 is affecting children. A Q&A session with participating medical experts followed. Participating medical institutions included:

- Children's Hospital at Montefiore
- Morgan Stanley Children's Hospital
- Mount Sinai Hospital Children's Hospital
- New York Presbyterian Children's Hospital
- Stanford Children's Health
- University of California San Francisco Benioff Children's Hospital

Tapping into our Helpline and social media platforms, ALF compiled our most frequently asked questions about liver disease and COVID-19 vaccines. These questions were answered in a virtual forum by Terry Box, MD, Associate Professor in the Department of Internal Medicine at the University of Utah School of Medicine. The recording can be found on our YouTube channel: [10 Questions about COVID-19 Vaccination and Liver Disease with Dr. Terry Box.](#)



Virtual COVID-19 Town Halls were held to enhance the liver community's knowledge of the COVID-19 vaccine. These meetings were held regionally to address and meet the specific needs of each community.

## Support by the Numbers



## Fast Facts about Liver Disease

- More than 100 million people in the U.S. have some form of liver disease.
- In 2020, 51,642 adults in the U.S. died from liver disease (15.7 per 100,000 population).
- Nonalcoholic fatty liver disease (NAFLD) is the most common cause of liver disease worldwide. The global prevalence of NAFLD is estimated as high as one billion.
- Research estimates NAFLD is present in up to 75% of overweight people (BMI of 25-29.9) and in more than 90% of people with severe obesity (BMI of 30+).
- NAFLD has become the most common form of childhood liver disease in the U.S., more than doubling over the past 20 years, partly because of the increase in childhood obesity. Studies estimate 5-10% of children have NAFLD.
- Nonalcoholic steatohepatitis (NASH) is expected to become the leading cause of liver transplantation in the United States by 2025.
- Liver cancer is the most rapidly growing cause of cancer deaths in the U.S. Liver cancer death rates have more than doubled since 1980.
- Approximately 15,000 children are hospitalized each year in the U.S. with pediatric liver diseases or disorders.

## Impact Through Public Awareness

### THINK LIVER THINK LIFE

ALF developed a nationwide five-year initiative to raise awareness of liver disease and increase early diagnosis and treatment. This initiative aims to ensure every American understands their risk for liver disease, can receive the appropriate diagnostic testing and care coordination and feels well-informed and supported throughout their liver journey. This new initiative will roll out to our first ten states starting in October 2022, adding ten additional states each year.

Alabama	New York
Arizona	Ohio
Florida	Pennsylvania
Kentucky	Texas
New Mexico	West Virginia

By 2026 – when ALF celebrates its 50th anniversary – this initiative will be active in all 50 states.



### NASH Patient Bill of Rights

Many patients don't understand the power they have over their own medical care, especially when it comes to the silent nonalcoholic fatty liver (NAFLD) and nonalcoholic steatohepatitis (NASH) epidemic. ALF gathered a small group of patients, caregivers and healthcare providers to identify and address the needs of NAFLD/NASH patients. These findings were compiled into a NASH Patient Bill of Rights and disseminated to the liver community via our social channels. This document was also presented to physicians at the American Association for the Study of Liver Diseases (AASLD) Annual Liver Meeting.



*Warren Hall, ALF's National Manager, Support Services dressed as George Washington to deliver the NASH Bill of Rights.*



## Impact Through Advocacy



### Hill Day

ALF's advocacy week took place May 10-14, 2021. Patient advocates, physicians and staff participated in virtual legislative visits with key Members of Congress to discuss ALF's legislative priorities. We conducted over 75 legislative meetings and represented over 30 states.

Those who were unable to participate in the event were encouraged to send letters to their local Members of Congress. Over 700 letters were sent that week and more than 300 new advocates joined our Advocacy Action Center.

Senator Kirsten Gillibrand (NY) recorded a [video](#) praising ALF's Advocacy efforts on Capitol Hill.

### Building New Advocacy Initiatives

ALF started working on a plan to expand its reach nationally and began building a larger volunteer network to include patient advocate leaders from all 50 states. These leaders will engage in local advocacy efforts, health education, media interviews, support groups, coalitions and most importantly, they will connect with other liver patients and their families. We are currently identifying four regional leaders and 50 state leaders across the country.



In December 2021, we held a [webinar](#) providing an update on the status of our legislative priorities including liver disease research and funding, public health and awareness, health coverage and access issues.

## Impact Through Education



### Liver Cancer Patient Conference

The second annual [The Educated Patient: Liver Cancer Conference](#) aimed to educate and empower those faced with a liver cancer diagnosis. Topics included liver cancer education 101, screening, treatment options, scientific breakthroughs, nutrition, COVID-19, racial disparities and navigating clinical trials. Our third [conference](#) is scheduled for October 15-16, 2022.

### Progression of Liver Disease Campaign

The Progression of Liver Disease Awareness Campaign focuses on reaching at-risk individuals, liver patients, caregivers and healthcare providers to increase awareness of end-stage liver disease in underserved populations. Components of the campaign include:

- Progression of Liver Disease [animated video](#)
- [Health disparities](#) in liver disease in partnership with the Hepatitis B Foundation
- Progression of Liver Disease [Infographic](#)
- Health Disparities in Viral Hepatitis with the CDC
- Social media awareness, including a virtual [toolkit](#)



### Wilson Disease Webinar

In collaboration with the Canadian Liver Foundation, ALF held a [patient education webinar](#) on Wilson Disease, emerging treatments and genetic testing.

### Alpha-1 Antitrypsin Disease (AATD) Videos

To raise awareness around this rare genetic disease, ALF created a short [three-part series](#) about AATD basics. The series featured frequently asked questions from our social media platforms and free national Helpline.

### Palliative Care Webinar

This [webinar](#) explored the differences between palliative and hospice care, reviewed palliative care benefits and explored how it can help patients manage symptoms.

### Animated Videos

ALF created new animated videos focusing on mind-body stress management techniques and the [progression of liver disease](#).

### National Community Education Programs

Community Education Programs are at the core of our mission. ALF's national programming provides an opportunity for a greater audience to participate. Programs that took place in 2021 included Alcohol and Liver Disease, Liver Wellness and Viral Hepatitis.

## 2021 Distinguished Scientific Achievement Award



ALF's Distinguished Scientific Achievement Award (DSAA) is a prestigious award given annually to a scientist who has made a major contribution to liver disease research in basic science or towards the prevention, treatment or cure of liver disease.

Guadalupe Garcia-Tsao, MD, FRCP, Professor of Medicine at Yale University School of Medicine and Chief of Digestive Diseases at the VA-Connecticut Healthcare System was awarded our 2021 DSAA for her scientific achievements in cirrhosis, portal hypertension and related complications.

## Impact Through Clinical Trials

Clinical trials are important in discovering new treatments for all types of disease including new ways to detect, diagnose and reduce disease development in new patients. In 2021, ALF broadened its clinical trial offerings to include trials for ascites, cirrhosis, hepatic encephalopathy (HE), nonalcoholic fatty liver disease (NAFLD)/nonalcoholic steatohepatitis (NASH) and primary biliary cholangitis (PBC).



## Impact Through Diversity, Equity & Inclusion

ALF's Diversity, Equity and Inclusion (DEI) Council will expedite our ability to bridge the gap in healthcare and address health disparities, nationwide. Current efforts are underway to recruit new members to help us achieve greater diversity, equity and inclusion in the liver community.

### + **Black Health Matters Fall Health Summit**

ALF had a virtual booth during the [blackhealthmatters.com](https://blackhealthmatters.com) Black Health Matters Fall Summit to educate participants on liver health and wellness in the Black community.

### + **The Association of Black Gastroenterologists and Hepatologists**

In collaboration with Jeremy Louissaint, MD of University of Michigan Health System and Ashley Spann, MD of Vanderbilt University Medical Center, ALF created a blog feature about health disparities, titled, "[Disparities in Liver Disease in the African American Population](#)".

### + **Blackdoctor.org Series**

ALF hosted a virtual webinar series in partnership with [Blackdoctor.org](https://blackdoctor.org) focusing on liver disease and Black health. The first event featured Nadege Gunn, MD, Medical Director and President of the Research Impact Institute and has over 11,000 YouTube views.

### + **Telemundo Awareness Interview**

Rita Lepe, MD of the Texas Liver Institute and ALF National Medical Advisor, participated in a public awareness [interview](#) with Telemundo about viral hepatitis and Hispanic/Latino Health.

### + **Nurse Education Series: Liver Transplant Disparities in Black Patients**

We partnered with the Black Liver Health Initiative at New York Presbyterian Hospital to discuss and address liver transplant disparities in Black patients. The event was led by Veronica Roye DNP, MS, FNP-BC, Liver Transplant Coordinator and Nicole Golden DNP, FNP-BC, Nurse Practitioner at Columbia University Irving Medical Center.

### **Other DEI Partner Collaborations Include:**

- National Black Family Awareness Week
- African American Wellness Project
- American Indian Cancer Foundation
- American Muslim Health Professionals

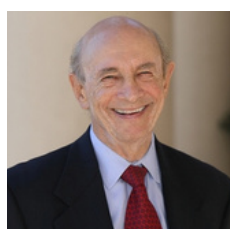


# Impact Through Events

## 45th Anniversary Leadership Celebration

2021 marked ALF's 45th year of excellence in the liver community. Our 45th Anniversary Leadership Celebration was a virtual salute to four and a half decades of leadership and research advancements in the liver space.

The event featured an exclusive patient-led discussion with 2020 Nobel Prize in Physiology or Medicine recipients Harvey Alter, MD, National Institutes of Health, Michael Houghton, PhD, DSc, University of Alberta, Canada and Charles Rice, PhD, Rockefeller University for their discovery of the Hepatitis C virus. ALF also recognized its 2020 Distinguished Scientific Achievement (DSAA) Awardee, Gyongyi Szabo, MD, PhD, Hon ScD, Mitchell T. Rabkin, M.D. Chair, Professor of Medicine and Faculty Dean of the Harvard Medical School and Chief Academic Officer, Beth Israel Deaconess Medical Center and Beth Israel Lahey Health for her contributions to understanding key mechanisms of inflammation in liver diseases and the importance of those pathways in progression of chronic liver diseases to fibrosis and cirrhosis.



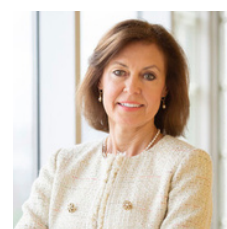
Harvey J. Alter, MD



Michael Houghton,  
PhD, DSc



Charles M. Rice, PhD



Gyongyi Szabo, MD, PhD,  
Hon ScD

## NATIONAL Legacy Gala

ALF's first annual National Legacy Gala hosted patient families, medical professionals, organizational partners and business visionaries from the healthcare, pharmaceutical and biotech industries. Award Recipients included: Irwin Arias, MD, Emeritus Sr. Scientist, National Institute of Child Health and Human Development and National Institute of Health, Emeritus Professor, Department of Medicine, Gastroenterology and Liver Diseases at the Albert Einstein College of Medicine and Emeritus Professor, Physiology and Medicine at Tufts University School of Medicine, *Lifetime Achievement Award*; James Boyer, MD, FACEP, Ensign Professor of Medicine and Emeritus Director of the Liver Center at Yale University School of Medicine, *Founders Award*; Boston Athletic Association, *Endurance Award*.

Numerous luminaries were in attendance including world-renowned health advocate physicians, best-selling authors and siblings: Sanjiv Chopra, MD and Deepak Chopra, MD, FACP. Also present were National Legacy Gala Honorary Committee Chairs and Liver Patient Family: Bakari Sellers, CNN Political Analyst and Ellen Rucker Sellers, Co-Owner, Rucker Roots. View the livestream event on our YouTube Channel.



Left to Right: Dr. Sanjiv Chopra,  
Dan Weil, Dr. Deepak Chopra



Left to Right: Dan Weil, ALF  
National Board Chair; Lorraine  
Stiehl, ALF CEO; Ellen Rucker-  
Sellers, Bakari Sellers.

## Impact Through Events, Continued

### CUISINE FOR A CAUSE



Cuisine for a Cause, took place virtually on April 24, 2021. We welcomed 430 guests and raised nearly \$200,000. Guests were mailed pre-packaged HelloFresh boxes allowing participants to cook alongside one of two professional chefs, live!

### LIVER LIFE WALK >> COAST2COAST



On June 5, 2021 ALF broadcast a live virtual walk across the country. The event included participation from Team Captains, sponsors and top fundraisers. Despite being a virtual walk, we were joined nationally by 274 teams who raised over \$360,000.

### LIVER LIFE CHALLENGE >>



ALF's endurance program, Liver Life Challenge, offered three new events this year: 45 in 45, 20-day cycling challenge and El Tour de Tucson. Collectively, the program engaged over 150 individuals and raised over \$700,000.

## Impact Through Understanding

In early 2021, ALF took a closer look at its community to better understand who our followers are, where they are, how they are interacting with us and what are they interested in. The findings were not only impressive but insightful.

### Key Findings:

- ALF's database is made up of primarily Baby Boomers, but our online resources are frequented mainly by Millennials and GenX users.
- The primary topics of interest are health, wellness and disease prevention
- We added two new questions to every registration form as a way to customize individual communications and resources and improve the user experience.
- Over 65% of donations received are made online.

### Outcomes:

- In December 2021, ALF created a dedicated Marketing and Communications team with the hire of a Chief Marketing & Communications Officer.
- Changes implemented from our analysis helped increase email engagement by 50% over the course of six-months.
- We are optimizing our website for a better mobile experience.
- We are focusing on liver health and wellness rather than liver disease.
- Improvements were made to simplify and optimize the online donation experience.

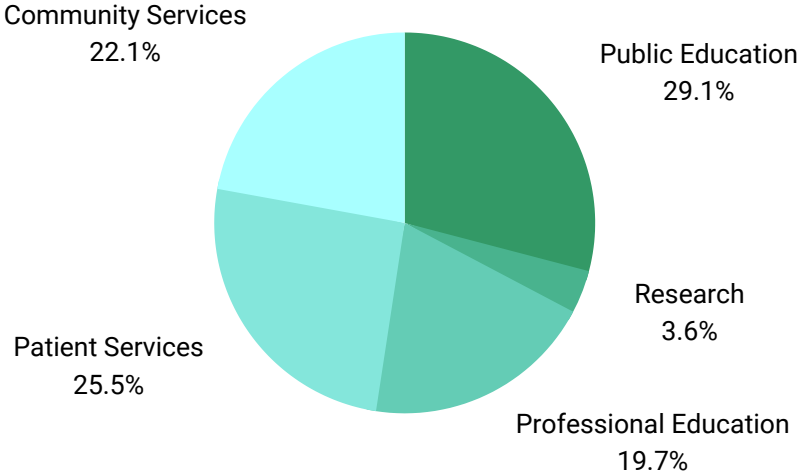


# Financials

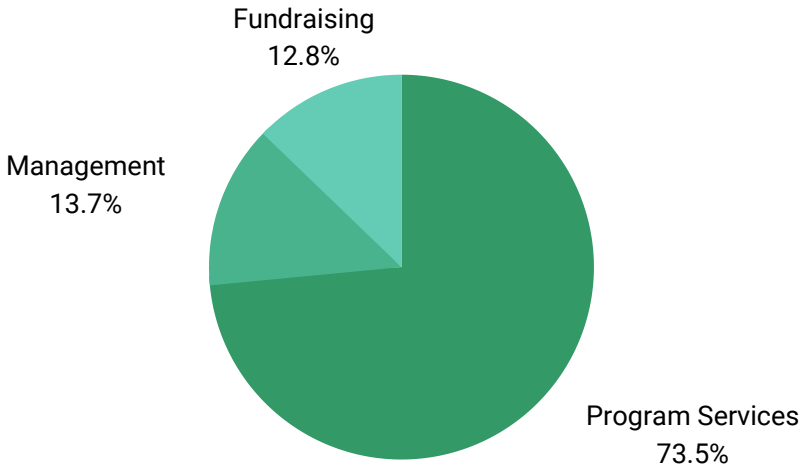
Total Revenue & Public Support  
\$7,126,651

Total Assets  
\$8,459,237

Program Services  
\$2,874,303



Support & Program Expenses  
\$3,911,508





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Digestive Disease Institute  
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**Terry Box, MD**

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