



# NAVIGATING THE PATH

AMERICAN LIVER FOUNDATION | 2019 ANNUAL REPORT



Your Liver. Your Life.

— “ —

When my son was diagnosed with liver disease, we were lost. A nurse told us to call the American Liver Foundation. It's been our compass ever since.

— Chelsea W.

— ” —



*Your Liver. Your Life.*

Founded in 1976, the American Liver Foundation (ALF) is the nation's largest patient advocacy organization for people impacted by liver disease. ALF reaches more than three million people each year with health information, education and support services via its national team, field offices, and an active online presence. Recognized as a trusted voice for those battling liver disease, ALF also operates a national toll-free HelpLine, educates patients, policymakers and the public, and provides grants to early-career researchers. For more information about ALF, please visit [www.liverfoundation.org](http://www.liverfoundation.org).





**89**

Number of elected officials ALF met with during our annual Awareness Day on Capitol Hill



**\$275,000**

Donated to cutting-edge liver research



**2.5 BILLION**

Steps taken at our Liver Life Walks



**10,000**

Inquiries received by our HelpLine Specialists

# 2019 BY THE NUMBERS



**2,000,000**

People served by our education and support services

ALF advocated for the Living Donor Protection Act (H.R. 1124/ S. 511). Key elements of this legislation were advanced by an Executive Order to enhance organ donation.



**\$5 MILLION**

Raised at our walks, challenges and culinary events to fight liver disease

We also advocated for the LIVER Act (H.R. 3016/S. 3074) which has gained cosponsors and raised awareness of the challenges and opportunities facing those impacted by liver diseases and associated conditions.



**30,000**

People connected on our online communities



**10,000**

Medical professionals viewed our educational webinars



**3 MILLION**

Individuals visited the ALF website



**367**

Community education Programs were held across the country

# A LETTER FROM LEADERSHIP

Dear Friends,

Welcome to the American Liver Foundation (ALF) 2019 Annual Report.

As we look back over the year, we're proud to be part of an organization that is singularly focused on improving the lives of people with liver disease. If you or a family member has a serious liver condition, you know the patient journey is full of twists and turns. Nobody has to travel that road alone. ALF is there at every step.

## NAVIGATING THE PATH

In 2019, our National Helpline responded to nearly 10,000 inquiries. We helped individuals with non-alcoholic steatohepatitis plan a more healthful diet. We connected those with hepatitis C and other conditions to medication assistance. We guided many on the transplant waiting list through the process of registering at two or more transplant hospitals. And we were there to listen when an exhausted mother called us because her only daughter was on at-home hospice care for end-stage liver disease. At the end of the emotional conversation, the mother told our Helpline Specialist: "You and the work you do are as important as the doctors and the nurses."

## A COMMUNITY TO LEAN ON

Approximately 30,000 people have joined one of the American Liver Foundation's online communities. There, they share their stories and connect with others who have had similar experiences. They ask questions and find answers, gain new perspectives, and support one another.

The members of ALF's National Patient Advocacy Committee share personal healthcare experiences to benefit a much broader audience. Our passionate advocates offer hope and support to others going through the challenges of liver disease.

## MAKING A DIFFERENCE IN PATIENTS' LIVES

ALF's website welcomed 3 million visitors in 2019, including Henry, who sent us the following note:

"I got my lab tests back today. My heart was pounding. I was scared. I had no idea what they meant. Then I found a video on your website called 'Understanding Your Liver Enzyme Test Results.' It was exactly the information that I needed. Thank you and God bless."

We are committed to making a difference for everyone battling liver disease and everyone at risk. Across the country, 367 community educational programs were held, often in high-risk, underserved communities. Over 300,000 people searched our comprehensive video library and viewed our informational videos and webinars.

To help empower the medical community to provide the best care for patients, professional education programs were conducted throughout the country. Additionally, almost 10,000 medical professionals viewed the webinars in our growing library of professional resources.

## YOU CAN COUNT ON THE ALF

As our country and the world continue to navigate the challenges associated with COVID-19, ALF remains committed to supporting the liver community. We have created numerous resources to help guide liver patients through the pandemic.

We also wish to acknowledge the tremendous dedication and commitment of medical professionals across the country who have been on the frontlines for liver patients during this public health crisis. You are our heroes.

## OUR SINCEREST THANKS

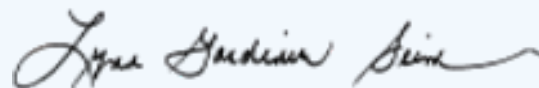
We are particularly grateful to Nicholas DeRoma, who is completing his term as National Board Chair and Thomas Nealon III, who has served as National Board Chair and then President and CEO. Thankfully, both will remain involved as Board members. You can read about them in this report.

We also admire all of you in our liver community. You have inspired us with your determination and perseverance – especially during these difficult times – and with the countless hours you've expended in support of ALF. Together, we will achieve our vision of a world without liver disease.

With great appreciation,



**Daniel E. Weil**  
National Board Chair



**Lynn Gardiner Seim, MSN, RN**  
Executive Vice President and  
Chief Operating Officer



**David Ticker**  
Executive Vice President and  
Chief Financial Officer

# NOT ALL HEROES WEAR CAPES

On his 50th birthday, Tom Nealon decided to run a marathon. Tom always dreams big. Soon he ran the New York City and Chicago marathons, and the annual Marine Corps Marathon in Washington D.C., as well as the Miami and Disney marathons. But he always hoped to run the Boston Marathon.

So, in 2002, he took a philanthropic route to the starting line. Agreeing to raise funds to help ALF end liver disease, Tom joined our Boston Marathon Team.

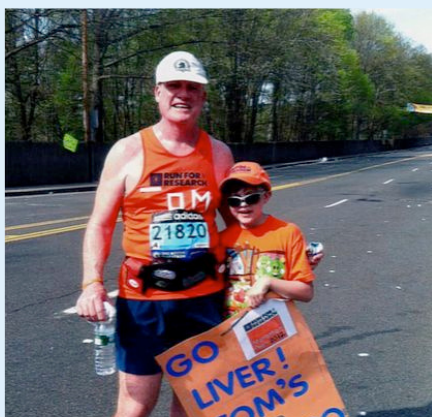
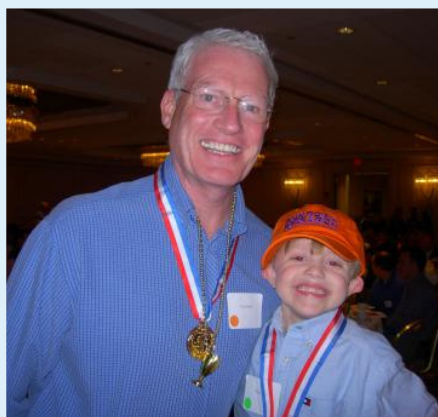
That is when he met one-year-old Zachary Rue, who was born with biliary atresia, a rare liver disease. ALF matches runners with patients. "From the moment we spoke, it was like we knew each other," Zac's mom Heather recalls of meeting Nealon. The feeling was mutual.

Zac's strength and story motivated Tom to do even more for ALF. To this day, Tom holds the record as the person who has raised the most funds for ALF by competing in marathons: over \$1,500,000.

As a lawyer and compassionate leader, Tom has helped build and shape the ALF. He has spent the last eight years in senior leadership roles, including national board chair and then President and CEO.

Under Tom's leadership, ALF broadened its education programs for medical professionals and patients, expanded its federal advocacy efforts, secured new organizational and industry partnerships, provided critical support to young researchers, shared the patient voice at national conferences and the FDA, and provided life-saving information and services to an unprecedented number of individuals with liver disease — as well as their families, friends and those at risk.

Tom recently stepped down from the position of CEO and President, however, he remains an active Board Member and mentor to 18-year-old Zac. Thank you, Tom



Tom Nealon is motivated by a desire to do good in the world. This, combined with his integrity, tenacity and intelligence, is a powerful force. ALF and those with liver disease are the beneficiaries.

David Ticker  
ALF EVP & Chief Financial Officer

Tom stepped into the CEO role during a challenging time at the Foundation. With his practical application of logic and his well-mannered temperament, he guided the organization to stability and expanded the impact of ALF both with our patients and in the medical community.

Michael Kerr  
ALF Board of Directors

# HONORING NICK DEROMA

"Nick has been an anchor for the ALF for so many years. His leadership experience coupled with his kind and caring nature has kept the ALF grounded in even the roughest of waters."

Lynn Seim  
ALF EVP & Chief Operating Officer

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All of us at ALF owe Nick a tremendous debt of gratitude. His dedication, compassion, mentorship and extensive attention to detail have immeasurably benefitted the ALF and liver patients everywhere."

Daniel Weil, Chair  
ALF Board of Directors

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Nick DeRoma has great leadership talents. With corporate experience in executive positions, he brings both practical application of proven solutions and wisdom to ALF. As a student of knowledge, his plain-spoken manner and anecdotes help make his points. He sees problems clearly and can fashion solutions which enable him to motivate others to action and to focus on the goal.

Michael Kerr  
ALF Board of Directors

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To describe Nick in one sentence is an insurmountable task - so instead - I thank you for all you have done for liver patients, their families, caregivers and me. Over the years, you have mentored me, guided me and encouraged me to become the best version of myself.

Alicia Eppich  
Director, CT Division



We thank Nick DeRoma for serving as Board Chair from 2018 – 2020 and continuing to remain a vital part of our Board of Directors.

Nick is an attorney and retired from the practice of law. During his extensive international legal career as in-house counsel, he served as Executive Vice President and Chief Legal Officer, Alcoa, Inc.; Senior Vice President and Chief Legal Officer, Nortel Networks Corp.; Vice President & General Counsel, IBM Europe, Middle East, Africa; General Counsel, IBM North America; General Counsel, IBM Asia; and Managing Attorney, IBM Corp.

He is a graduate of William & Mary Law School and the University of Connecticut, and has been awarded an Executive MBA from the Harvard Business School.

Nick has been a powerful force for assisting people with liver disease. Always humble, Nick seldom praises himself. So today, we want to do it ourselves.

# FUNDING RESEARCH

Every year, the American Liver Foundation supports early-career researchers whose efforts bring us closer to finding cures for liver disease.

This year, we awarded five incredibly talented early-career scientists who are raising the bar on cutting-edge liver research.

## 2019 POSTDOCTORAL RESEARCH FELLOWSHIP AWARDS:



### **BILIARY ATRESIA FUND FOR THE CURE AWARD**

Jessica Llewellyn, PhD - University of Pennsylvania  
Project: Identification and characterization of fibrogenic cell of the extrahepatic bile duct  
Mentor: Rebecca G. Wells, MD



### **HANS POPPER MEMORIAL AWARD**

Omar Haque, MD - Massachusetts General Hospital, Harvard Medical School  
Project: Ex-Vivo Liver Graft Regeneration via Normothermic Machine Perfusion in a Two-Thirds Partial Hepatectomy Model  
Mentors: Korkut Uygun, PhD & James F. Markmann, MD, PhD



### **ALEXANDER M. WHITE, III MEMORIAL AWARD**

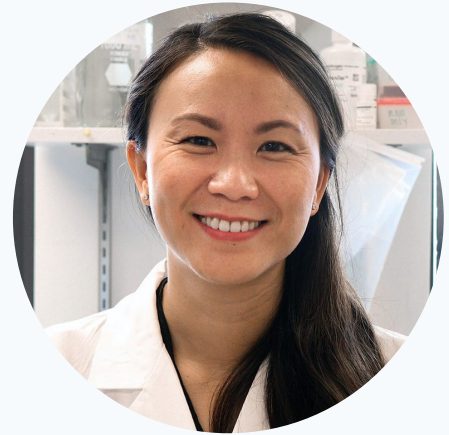
Debanjali Dasgupta, PhD - Mayo Clinic, Rochester  
Project: Hepatic IRE1alpha activation induces EV release, leading to hepatic injury  
Mentor: Harmeet Malhi, MBBS



### **IRWIN M. ARIAS, MD AWARD**

Taylor M. Coe, MD - Massachusetts General Hospital  
Project: Role of IdeS in Depletion of IgG to Reduce Antibody Mediated Graft Damage in Non-Human Primate Liver Xenotransplantation  
Mentor: James F. Markmann, MD, PhD

## **CHARLES TREY, MD MEMORIAL LIVER SCHOLAR AWARD**



### **Hien Dang, PhD**

Thomas Jefferson University

Project: Genome-wide CRISPR/Cas9 screening for synthetic lethal targets in NELFE/MYC HCC.

Mentor: Jonathan Brody, PhD

—“

This is my first research award as an independent thinker! I'm so honored and excited!

”—

In 2019, our Liver Scholar Award went to Hien Dang, PhD, who is making a difference in the battle against liver cancer - one of the fastest-rising cancers in the U.S.

Dr. Dang is part of a research team that discovered a mechanism that affects the DNA of more than one-third of liver cancer patients. With her ALF grant, she is working to develop a biomarker that will help identify tumors driven by this mechanism. Ultimately, her goal is to create more precise therapies for liver cancer and save lives.

When you donate to ALF, your gift supports our research program and helps ensure that bright minds remain in the field of liver research.

By doing your part, you help scientists do theirs.

# YOU'RE NEVER ALONE



## “ THE AMERICAN LIVER FOUNDATION HELPED ME WIN THE FIGHT OF MY LIFE. ”

**I am one of over 40,000 people diagnosed with liver cancer each year.**

Cancer makes you take stock of your life and what matters most to you. I always tell people: “There will be challenges and bad days. But your inner strength will surprise you.”

When I learned I needed a transplant, I thought, “Okay, I can get through this”. But the transplant team didn’t agree. It wasn’t because of my general health. It was because I’m single with no kids and my relatives live too far away.

The team said I wouldn’t have enough support post-transplant. I was scared. But I wasn’t ready to give up. Neither was the American Liver Foundation. Reaching out to them was one of the smartest things I ever did. ALF staff helped to identify hospitals that might be open to my situation. I traveled by car, train and plane to meet with those medical centers. After every appointment, ALF staff talked to me. And they lifted my spirits every time I was told: “You aren’t a viable transplant candidate.”

**Five hospitals and 4,000 miles later, I found my transplant team!**

When my surgery was over, the ALF staff were the first people I called. Thanks to the American Liver Foundation, I never had to carry the burden of liver cancer alone.

The American Liver Foundation was my advocate. They are a voice for all of us - every adult and child - living with liver disease. We need that voice now more than ever because liver disease is on the rise. Liver cancer is the fastest-increasing cause of cancer death in the United States. And - because so many of us eat too much and don’t exercise enough - as many as 100 million Americans are at risk for unhealthy fat build-up in their livers.

I like that ALF is there for people who are living with liver disease now and supports research and policies that will one day end liver disease. Please join me in supporting ALF so they can continue to provide a brighter future for all those impacted by liver disease.



# CONTRIBUTORS

Our efforts were made possible because of the generosity of the individuals, foundations and corporations listed here.\* For the millions of people served by ALF, we thank you.

## **\$100,000 & ABOVE**

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AbbVie, Inc.  
Bayer Pharmaceuticals, Inc.  
CVS Health  
Eisai Inc  
Gilead Sciences, Inc.  
Intercept Pharmaceuticals, Inc.  
Michael and Susan Kerr  
Salix Pharmaceuticals, Inc.  
Scripps Family Foundation  
University of Pittsburgh Medical Center  
Estate of Kevin James Wolff

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Alexion Pharmaceuticals, Inc.  
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Pfizer, Inc.

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Centene Management Company LLC  
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Dova Pharmaceuticals, Inc.  
Genfit Corporation  
Jeannie M. and James M. Goldberg  
Integritas Communications LLC  
Jackson Health System  
Lucile Salter Packard Children's Hospital at Stanford  
Mayo Clinic Arizona  
Marjie and Thomas F. Nealon, III  
New York Presbyterian Hospital  
Octapharma USA  
Estate of Margaret G. Picarelli  
The Institute For Liver Health LLC  
The Lee and Aidan McMahon Foundation, Inc.  
Yale-New Haven Hospital

## **\$12,500 - \$24,999**

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Michael Braunstein  
Catholic Health Initiatives  
Children's Hospital, Los Angeles  
Connecticut GI, PC  
Dynavax Technologies  
Fairview Health Services  
Fujifilm Wako Diagnostics U.S.A. Corporation  
Hartford Healthcare  
Estate of Mark B. Landau  
Loma Linda University Health  
MedStar Georgetown Transplant Institute  
Memorial Hermann Health System  
Neudesic  
Northwestern Memorial Healthcare  
Novartis Pharmaceuticals Corporation  
OneLegacy Foundation  
Pharmaceutical Research and Manufacturers of America  
PNC Wealth Management  
Robert and Gina Pollichino  
Retrophin, Inc.  
Walter and Joyce Senney  
Shionogi Inc.  
Sutter Bay Hospitals  
Texas Children's Hospital  
The Allergan Foundation  
The Kellner Family Pediatric Liver Disease Foundation  
UCSD Medical Center  
University Hospitals Transplant Institute  
UT Physicians  
Rick and Susan Zehetner

## **\$5,000 - \$12,499**

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Abbott Laboratories  
AbbVie Foundation Employee Engagement Fund  
AcariaHealth Pharmacy, Inc.  
Abound Affi, MD  
Albert Brothers, Inc. and Cornerstone Realty  
Estate of Rita Alexander

Aligos Therapeutic  
Arizona Transplant Associates, PC  
Assembly Biosciences, Inc.  
Shahzad Bashir  
Bausch Health  
Lee Becker  
Christopher J. and Katherine A. Berman  
BioPlus Specialty Pharmacy Services, Inc.  
BlueCross BlueShield of Arizona  
Blum Shapiro  
Carol L. Brosgart, MD  
Eric Brown  
Dr. John Stevenson and Nancy Bynon  
Canyon Surgical Associates  
William A. and Sonya T. Carpenter  
Casino Arizona Talking Stick Resort  
Centura Health Corporation  
Michael Chen  
Chicago Wolves Charities  
Children's Hospital of Philadelphia  
Cincinnati Children's Hospital Medical Center  
Clinical Care Options, LLC  
Community Bank on the Bay  
Connecticut Gastroenterology Consultants, PC  
CPMC  
Peter L. Cullen  
CVS Health Foundation  
Cymbay Therapeutics  
Denver Region Toyota  
Mr. and Mrs. Nicholas DeRoma  
Dignity Health, St. Joseph's Center for Liver Disease and Transplantation  
Allan J. and Kathy F. Doerr  
Donor Alliance, Inc.  
Donor Network of Arizona  
Dr. and Mrs. David Douglas  
Michael and Anne Doyen  
Echosens North America  
Eiger Biopharmaceuticals, Inc.  
Emory University  
Enanta Pharmaceuticals, Inc.  
Raymond and Kathleen Epes  
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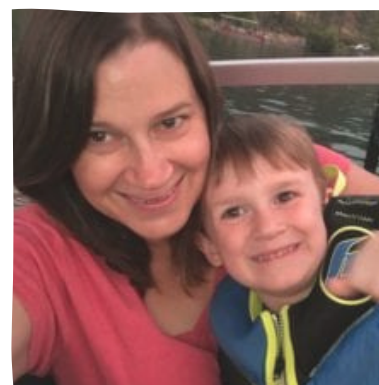
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The John J. McDonnell Margaret T. O'Brien Foundation  
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Lahey Health Shared Services  
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Landry's Management, L.P.  
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Loma Linda Mercantile  
Lissa and Jeffrey Longacre  
Jay R. Luly  
Timo Makkonen  
Marcus Hotels and Resorts  
Jill V. Marmorek  
Tim Marshall  
Mayo Foundation for Medical Education and Research  
McCarter & English, LLP  
MedHealth  
Merck & Co., Inc.  
Mid-America Transplant Foundation  
Minnesota Gastroenterology, PA  
Montefiore Medical Center  
Mount Sinai Recanati/Miller Transplantation Institute  
MSG Networks  
Naugatuck Valley Gastroenterology Consultants, LLC  
Nemours Children's Health System  
NIC - USA

North Shore Gastroenterology and Endoscopy Centers  
Northwell Health  
Kenneth O'Connor and Deedee Rowe  
Old Lyme Gourmet Company  
Optimum Solutions Corporation  
Partners Healthcare System  
Dr. Pratik Patel  
Patient Access Network Foundation  
Larry Patrick  
Edward F. Pergiovanni, DMD, PC and Mary L. Pergiovanni, DDS  
Peter Fogliano & Hal Lester Foundation, Inc.  
Phoenix Children's Hospital  
P-SL Medical Center  
Quest Diagnostics Incorporated  
Raymond F. Schinzai and Family Foundation, Inc.  
Dr.'s Rajeev Puri and Nancy Reau  
Reddy GI Associates, PLLC  
Rocky Mountain Gastroenterology Associates, PLLC  
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Rx Abuse Leadership Initiative  
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Southern California Liver Centers  
Sparks Exhibits & Environments Corporation  
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State Street Foundation, Inc.  
Susan and Joseph Stone  
The Children's Hospital Association  
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Walgreens Specialty Pharmacy  
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Daniel and Elizabeth Weil  
Valentine S. Welman  
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Winstead PC  
Kelly M. Wrenn  
Thomas J. and Jane F. Wulf  
Yale University

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J. Allison  
American Fundraising Foundation  
Ann & Robert H. Lurie Children's Hospital of Chicago  
Jerome Arenas  
Lourdes Arriola  
Associates in Gastroenterology, P.C.  
Aurora Health Care  
Barbera & Watkins, LLC  
BD Matching Gift Program  
John M. Beard, Jr.  
Boeing Employee Good Neighbor Fund  
Maria Teresa Borja  
Boston Children's Hospital



Going through the testing and diagnosis process can be just as frightening as getting used to a new diagnosis, but, we are not alone!

- Julie M.  
Autoimmune Hepatitis



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Kristina Botti  
Dr. and Mrs. James L. Boyer  
Broward Health  
Julie and Lawrence Burgart  
Ron and Sally Burns  
Allene Cashmore  
Celerion  
Sing Chan, MD, FACC  
CharterCare Health Partners  
Amy Chenault  
Christ Church United  
Colorado Gastroenterology Prof.  
LLC  
Janet Conley  
Jordana Connor  
Consulting Radiologists, Ltd.  
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Geoffrey Emerick  
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Anthony E. and Kathleen H. Madrid  
James Malatack, MD  
Derek and Brenda Marcou  
Dr. Christopher L. Marsh and Mrs.  
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Karen Beth Mashkin, PhD  
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Aronas Commercial Services, Inc.  
Gina Baixauli, RN, BSN

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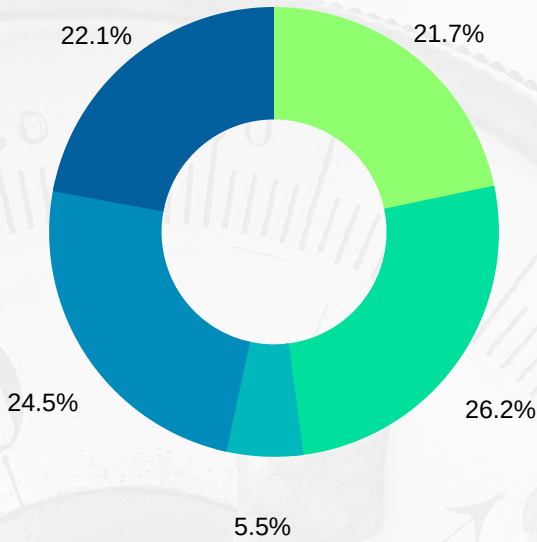
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\*If we inadvertently omitted a contributor, we sincerely apologize and would like to know. Kindly call us at (646) 737-9405.

# WHERE YOUR MONEY GOES

Gifts to the American Liver Foundation help improve life for people with liver disease through advocacy, education, support services and research. We are committed to being the best possible stewards of donated funds, honoring donor intent and practicing financial transparency.

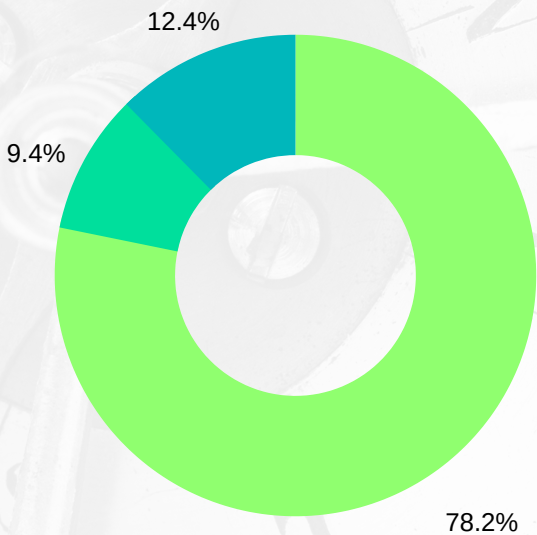
## PROGRAM SERVICES



<span style="color: #00FF00;">●</span> PUBLIC EDUCATION	\$1,790,670	26.20%
<span style="color: #00B0F0;">●</span> RESEARCH	\$377,122	5.50%
<span style="color: #004A87;">●</span> PROFESSIONAL EDUCATION	\$1,507,357	22.10%
<span style="color: #0072BC;">●</span> PATIENT SERVICES	\$1,677,847	24.50%
<span style="color: #90EE90;">●</span> COMMUNITY SERVICES	\$1,480,641	21.70%

**TOTAL PROGRAM SERVICES**      **\$6,833,637**      **100.00%**

## SUPPORT & PROGRAM EXPENSES



<span style="color: #90EE90;">●</span> PROGRAM SERVICES	\$6,833,637	78.2%
<span style="color: #00FF00;">●</span> MANAGEMENT	\$823,259	9.4%
<span style="color: #00B0F0;">●</span> FUNDRAISING	\$1,080,670	12.4%

**TOTAL EXPENSES**      **\$8,737,566**      **100.00%**

# FINANCIAL STATEMENTS

## BALANCE SHEET

ASSETS	2019	2018
CASH & CASH EQUIVALENTS	\$1,791,670	\$1,570,520
INVESTMENTS	\$3,039,894	\$2,274,611
CONTRIBUTIONS RECEIVABLE	\$196,618	\$1,117,480
PREPAID EXPENSES & OTHER ASSETS	\$191,894	\$219,161
PROPERTY & EQUIPMENT, NET	\$47,121	\$78,556
<b>TOTAL ASSETS</b>	<b>\$5,267,197</b>	<b>\$5,260,328</b>

LIABILITIES & NET ASSETS	2019	2018
LIABILITIES:		
ACCRUED EXPENSES	\$264,817	\$364,152
PAYROLL & RELATED LIABILITIES	\$308,085	\$304,462
FUNDS HELD ON BEHALF OF OTHERS	\$774,204	\$793,980
AWARDS AND GRANTS PAYABLE	\$137,500	\$237,500
DEFERRED RENT PAYABLE	\$81,638	\$133,507
LOAN PAYABLE	---	\$99,509
<b>TOTAL LIABILITIES</b>	<b>\$1,566,244</b>	<b>\$1,933,110</b>

NET ASSETS SURPLUS (DEFICIT)	2019	2018
WITHOUT DONOR RESTRICTION	\$614,131	\$(474,617)
WITH DONOR RESTRICTION	\$3,086,822	3,801,835
<b>TOTAL NET ASSETS</b>	<b>\$3,700,953</b>	<b>\$3,327,218</b>
<b>TOTAL LIABILITIES &amp; NET ASSETS</b>	<b>\$5,267,197</b>	<b>\$5,260,328</b>

## STATEMENT OF ACTIVITIES

PUBLIC SUPPORT & REVENUES	2019	2018
CONTRIBUTIONS	\$4,141,294	\$4,317,775
CONTRIBUTED SERVICES	\$525,462	\$268,000
INVESTMENT INCOME NET	\$349,305	\$(121,217)
OTHER	\$35,890	\$25,653
SPECIAL EVENTS (NET OF DIRECT EXPENSES)	\$4,570,320	\$4,739,542
<b>TOTAL PUBLIC SUPPORT &amp; REVENUES</b>	<b>\$9,622,271</b>	<b>\$9,229,753</b>

PROGRAM SERVICES	2019	2018
PUBLIC EDUCATION	\$1,790,670	\$1,859,566
RESEARCH	\$377,122	\$587,528
PROFESSIONAL EDUCATION	\$1,507,357	\$1,374,807
PATIENT SERVICES	\$1,677,847	\$1,725,794
COMMUNITY SERVICES	\$1,480,641	\$1,844,091
<b>TOTAL PROGRAM SERVICES</b>	<b>\$6,833,637</b>	<b>\$7,391,786</b>

SUPPORTING SERVICES	2019	2018
MANAGEMENT & GENERAL	\$1,334,229	\$1,197,107
FUNDRAISING	\$1,080,670	\$959,680
TOTAL SUPPORT SERVICES	\$2,414,899	\$2,156,787
<b>TOTAL COST OF PROGRAM &amp; SUPPORTING SERVICES</b>	<b>\$9,248,536</b>	<b>\$9,548,573</b>

CHANGE IN NET ASSETS	\$373,735	\$(318,820)
NET ASSETS, BEGINNING OF YEAR	\$3,327,218	\$3,646,038
<b>NET ASSETS, END OF YEAR</b>	<b>\$3,700,953</b>	<b>\$3,327,218</b>

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