



Autoimmune  
Hepatitis  
Association

# ANNUAL REPORT 2021

A photograph of a group of people sitting around a table in a meeting or conference room. The image is overlaid with a semi-transparent teal and purple gradient. The text 'Support. Educate. Research.' is written in large, white, bold letters over the image.

**Support.  
Educate.  
Research.**

Supporting patients and families affected by  
autoimmune hepatitis.



## FROM OUR EXECUTIVE DIRECTOR

In the past year, we've truly stepped up our efforts to advance research into autoimmune hepatitis (AIH), while continuing our support and educational initiatives. We're hosting a drug development meeting in January, an event that has been over a year in the making. We're expanding our patient registry. We're supporting a clinical trial using stem cells to treat AIH. And we're offering support and our expertise to a pharmaceutical company starting their own trial for a new AIH treatment.

This important work wouldn't have happened without you, our committed donors. I hope you enjoy seeing what you made possible in this year's annual report. Thank you again.

**CRAIG LAMMERT, M.D.**

Executive Director  
Autoimmune Hepatitis Association

*"I'm especially proud of the strides the AIHA has made to advance research in the past year. None of our efforts would have been possible without our generous donors. Thank you for your support!"*

# 2021–2022 in Review

## 2022 Online Patient Conference



Due to the continued uncertainty surrounding COVID-19, we decided to once again hold a virtual conference.

It was a fantastic day filled with information on the latest research and noninvasive tests, clinical trials, transitioning from pediatric to adult care, and more. A highlight of the event was our patient panel, where patients shared their experiences living with AIH.

We were thrilled with participation in the virtual conference. Throughout the day, we consistently had more than 100 patients and family members connected at any given time.

We have already started planning our 2023 National Patient Conference and hope that it will be an in-person event.

# Drug Development Meeting for AIH



The AIHA will host an Externally-Led Patient Focused Drug Development Meeting for AIH on January 27, 2023 from 10 a.m. to 2:30 p.m. ET.

The goal of the meeting is to provide the U.S. Food and Drug Administration (FDA), drug developers, doctors, and academic researchers opportunities to hear from AIH patients about the impact the disease has on their health and daily life. It's also a chance for patients to share their views of currently available therapies and goals for treatment.

The AIHA hopes this important meeting will shine a light on the need for new treatments that work for all patients and that have fewer side effects.

We applied to hold this event nearly a year ago and have been meeting regularly with FDA staff who are generously providing advice as we work to make the event a success. We need as many people as possible to attend. [Please register here.](http://www.aihep.org/advocate)

# AIH Connect, the AIHA's Patient Registry



In 2021, we launched AIH Connect, the AIHA's Patient Registry. Our series of surveys asks patients questions about their demographics, disease history, treatment, and quality of life. Our end goal is to help researchers learn more about this disease in hopes this will one day lead to new and better treatments for patients.

To date, we have recruited 120 patients to join the registry, which is fantastic! We shifted our strategy a little bit this year. Instead of focusing on expanding recruitment with our existing registry, we decided to focus on making the registry more accessible to patients while collecting more robust information.

We've in the final stages of preparing to open the registry to pediatric patients under the age of 18. In addition, the registry surveys will soon be available in Spanish to ensure Spanish-speaking patients can participate. Finally, we're also poised to begin collecting saliva samples to make the information the registry holds more helpful to researchers. Next year, our focus will be to increase participation in the registry. Holding an in-person conference in 2023 will help us reach this goal.

# Supporting Two New Clinical Trials for AIH Treatments



The AIHA is proud to be supporting two new clinical trials for AIH treatments that will soon open to patients.

Thanks to the generosity of donors, the AIHA is providing funding to Indiana University, which is poised to begin a clinical trial using mesenchymal stem cells to treat hard-to-control AIH patients.

In addition, we are excited that Kezar Life Sciences, a corporate member of the AIHA, also [will soon open a clinical trial of a new treatment for AIH](#). The trial will target patients who haven't responded to standard treatments or who have experienced a relapse.

Standard treatments for AIH haven't advanced in more than 50 years, and these new trials are urgently needed for patients, especially those who don't respond to currently available treatments or who experience significant side effects that negatively impact their quality of life.

# The Liver Meeting: Marketing the AIHA as an Important Resource for Doctors



In early November 2022, the AIHA hosted a booth at The Liver Meeting in Washington, D.C. The annual conference held by the American Association for the Study of Liver Diseases (AASLD) draws thousands of doctors, researchers, and pharmaceutical company representatives from around the world to learn about the latest liver research.

Staffing the booth this year were AIHA Executive Director Craig Lammert, M.D. (pictured middle in the above photo), Director of Programs and Advancement Erin Anderson (left) and Registry Coordinator Kelsey Green (right).

We enjoyed sharing the resources our organization offers to patients. We distributed brochures about the AIHA in both English and Spanish, and doctors also signed up to receive additional copies in the mail to give to their patients.

# New Patient Tool Kit and Expanded Site



Over the past year, we've spent significant time updating our website to include expanded AIH education for patients. We have many new pages under the "[What is AIH?](#)" section of our website. And we also have a new resource called the [Patient Tool Kit](#) especially for newly diagnosed patients. Both these sections of our website are now available in Spanish!

Our [Patient Tool Kit](#) helps patients quickly get up-to-date on this rare disease and navigate upcoming medical appointments. The tool kit includes information on:

- The basics of AIH
- Choosing the right doctor
- Questions to ask your doctor
- Tips for doctors visits
- Frequently asked questions (and answers)
- How to join our support group for newly diagnosed patients



# Diversity, Equity, and Inclusion Efforts



## Welcome to Our Expanded Website!

Select pages now  
available in Spanish  
[www.aihep.org](http://www.aihep.org)



Last year, the AIHA formed a Diversity, Equity, and Inclusion Committee to help us learn more about health inequity, conduct better outreach to AIH patients of color, and advance research in diverse populations.

This year, our focus has been on making our core educational materials available in Spanish so more patients can benefit from them.

We worked with a professional Spanish translator and a Spanish proofreader to help us translate the educational pages on our website into Spanish. Our organizational brochure is now available in Spanish, and our registry will soon be offered in Spanish.

In 2023, we plan to conduct a survey and a focus group to better engage with and learn from our members of color.

# Virtual Support Groups

Our virtual support groups continue to meet regularly. They allow patients and family members to connect with others living with the disease, share experiences, and give advice on questions they should ask their doctor.

We're especially proud of our support group for newly diagnosed patients. Patients tell us that the first six months after being diagnosed with AIH are the most challenging, and we aim to provide education and support during this time.

Most patients attending the newly diagnosed group have never met another person with the disease. Sitting in a virtual room with others who also have AIH is a powerful experience and often provides a sense of comfort and reassurance for patients who are usually stressed out and worried about what their future holds. AIHA Executive Director Craig Lammert, M.D., attends the newly diagnosed meetings to provide education about the disease and answer general questions, which are other important forms of support.

## Virtual Support Groups

Caregivers of pediatric patients

Midwest

Newly diagnosed patients

Northeast

Southeast

Teen mentors

West Coast

*"Thank you for offering these support groups. It's nice not to feel so alone living with this disease."*

*—a support group member*

## By the Numbers

**120** patients enrolled in AIHA Patient Registry

**9** conference videos with **2,596** views

**4,400** AIHA members

**9** new educational pages on our website to help patients learn more about the disease and better prepare for medical appointments

**7** virtual support groups

**2** new clinical trials for AIH treatments set to begin

# THANK YOU TO OUR GENEROUS 2021 AND 2022 DONORS

We greatly appreciate our members who have chosen to give a financial contribution to the AIHA. Our programs would not exist without your generosity! We'd like to extend a special thank you to the following:

## **Donors contributing \$500 or more\***

Erin Anderson	Indiana University, Division of
Adam Beaton	Gastroenterology and Hepatology
Nate Beaton	Kezar Life Sciences
Robert and Kim Beaton	Lilly Endowment
Janet Bliden	Liz LaHaye
Jan Brandt	Craig Lammert
Chan Zuckerberg Initiative DAF	Rodger and Jennifer Landau
Chris and John Browner	Robert and Barb Long
Jim Deveney	Alysoun Mahoney
Kerry and Martha Dodd	Patricia McKay
Tom and Stephanie Downey	Rachel and Kent Perkocha
Bob & Lisa Drew Charitable Fund	Gregg and Becki Russell
Andrew Eye and Kate Williams	Usama Samaan
Forward Group	Sanguine
Diane Garrett	Silicon Valley Community Foundation
Sara Hart	The Smith-Fuqua Foundation
	Dax and Cameron Williamson

\*Donors listed in this annual report for 2021 gave from January 1, 2021, to October 31, 2022.. Donors giving \$500 or more in 2022, including those who gave after October 31, 2022, will be listed in our 2022 annual report, which will be published in 2023.

# THANK YOU TO OUR GENEROUS 2021 AND 2022 DONORS

## Monthly and Quarterly Donors\*

Nate Beaton  
Janet Bliden  
Lisa Devereaux  
Kristi Feeney  
Beckie Hill  
Kent and Susan Kinkade  
Liz LaHaye  
Courtney Linville  
Brenda Milliken  
Maryann Rosenberg  
Usama Samaan  
Rachel Schmidt  
Beverly Wells  
Veronica D. Williams

\*Donors listed in this annual report for 2021 gave from January 1, 2021, to October 31, 2022.. Donors who give monthly and quarterly in 2022, including those who started a recurring gift after October 31, 2022, will be listed in our 2022 annual report, which will be published in 2023.

# AIHA LEADERSHIP

## **AIHA Board of Directors 2022**

Executive Director: Craig Lammert, M.D.

Secretary/Treasurer: Lisa Devereaux

Board Members:

Luke Britt

Andrew Eye

Veronica D. Williams

## **AIHA Senior Staff 2022**

Director of Programs and Advancement: Erin Anderson

## **AIHA Medical Advisory Board 2022**

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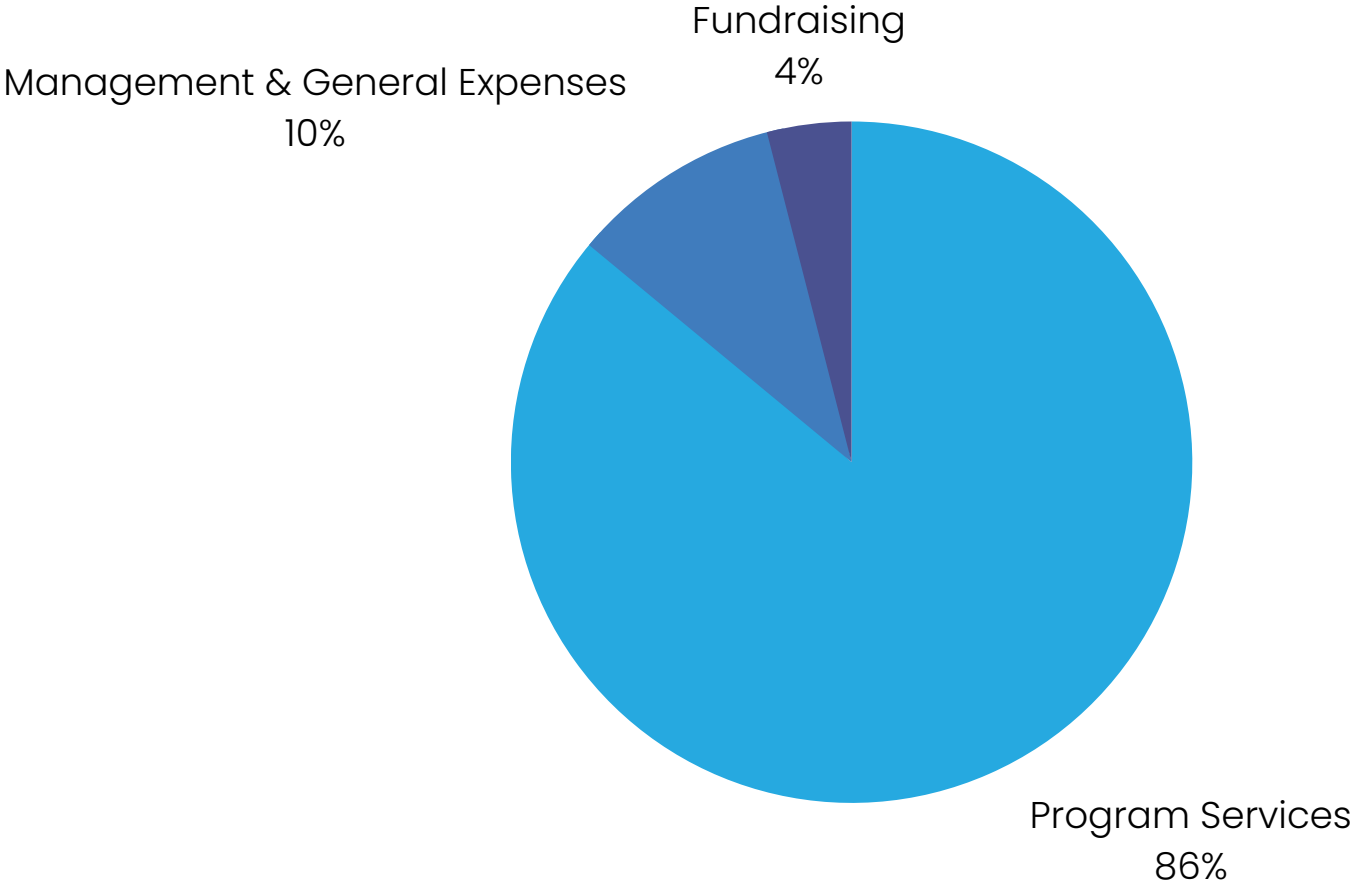
Howard Waksman, M.D., Deborah Heart and Lung Center

Ethan Weinberg, M.D., University of Pennsylvania

# 2021 FINANCIAL STATEMENT

Total revenue:	\$ 246,651
Total expenses	127,566
Revenue less expenses	119,085
Net assets, beginning of year	163,689
Net assets, end of the year	282,775

**86% of our expenses in 2021 went directly to programs that advance our mission.**



*The mission of the Autoimmune Hepatitis Association is to provide support and hope to patients and families affected by autoimmune hepatitis through disease education and research opportunities.*



*The Autoimmune Hepatitis Association, Inc., is a 501(c)(3) nonprofit organization, EIN: 81-0810579. Donations are tax deductible as allowed by law.*