



2021

ANNUAL REPORT

ARCI.ORG

OUR MISSION

The Amyloidosis Research Consortium (ARC) is a nonprofit organization dedicated to driving advances in the awareness, science, and treatment of amyloid diseases.

CONTENTS

Letter	3
Drug Development	4
Programs	5
Accelerating Research	6
Prioritizing Patients	7
Practical Support	8
Thank You	9
Organization	10
Financials	11
Boards	12



Together we are changing the story.

We have made impressive steps forward in improving treatment and care for amyloidosis patients since ARC was founded in 2015. Four drugs have been approved and there are three times as many companies that now have drug development initiatives. The field has numerous new educational programs and several more centers with expertise in treating amyloidosis.

We won't stop until every patient has the treatment they need.

It is wonderful to see how far we have come, but we also recognize how much more there is to do. This is the time for us all to come together to double our efforts and build on our successes. I truly believe that together we can conquer amyloidosis.



Isabelle Lousada

Isabelle Lousada

ARC is working to address patients' unmet needs.

29% of hATTR patients report the disease greatly impacts emotional well-being

Only 35% of AL patients report a definite improvement after receiving treatment

35% of patients receive inaccurate treatment due to a misdiagnosis

49% of patients have little to no access to relevant clinical trial information

73% of patients are unsure how to enroll in a clinical trial

*Data from ARC patient survey

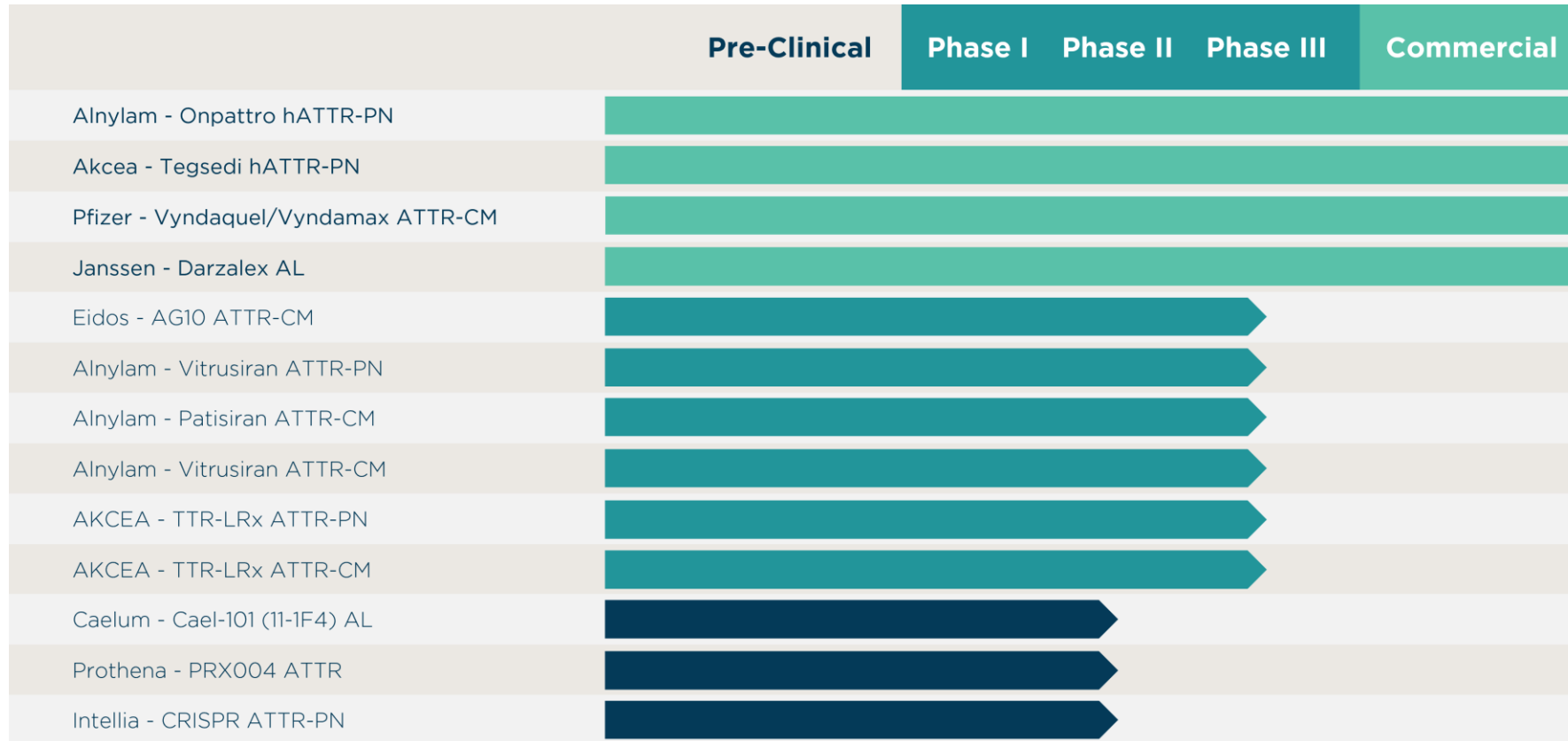
**The ARC team is
always here to
listen & support.**

**ARC informational
booklets empower
patients & caregivers.**

**Our knowledge-share
programs are educating
doctors & nurses.**

**Monthly newsletters
highlight clinical trial
news to thousands.**

DRUG DEVELOPMENT



Before ARC, there were no FDA approved treatments for amyloidosis.

We now have four approved therapies for systemic amyloidosis and a portfolio of clinical trials to evaluate promising new agents.



PROGRAMS

[ARCI.ORG](https://arci.org)

ACCELERATING RESEARCH

Focusing on the development of the next generation of therapies.



The Amyloidosis Forum

Accelerating & improving drug testing and approval

Formed in 2019, the Amyloidosis Forum is a Public-Private Partnership between ARC and the U.S. Food and Drug Administration (FDA). This year's meeting of the Forum examined novel endpoint development in AL amyloidosis.

Six working groups consisting of 60 participants spent the day evaluating endpoints to determine key areas to improve.

Revolutionary Collaboration

Improving research capabilities by sharing knowledge without waiting for shared data

A novel approach called Federated Data Analytics allows us to easily ask and answer key questions across a broad group of global datasets.

This program runs standardized analytics locally and then pools results, not data, for collaborative learning without the time delaying complexities of data sharing



PRIORITIZING PATIENTS

To deliver true value to patients, ARC brings them to the forefront with our partners and network.



Evaluating Treatment Impact

Better measuring how patients are responding to treatments

Patients want to feel better, function easier, and live longer. Quality of life is vital. Amyloidosis patients have a unique set of symptoms and health challenges.

To measure the impact of treatments, ARC has developed an ATTR amyloidosis specific patient reported outcome tool to be used in clinical trials and care.



The Patients' Megaphone

Making patient needs the #1 priority for research, drug development, & doctors' offices

Patients know what patients need. ARC has built a reputation as the model patient-centered organization able to make real impact in patients lives thanks to programs including our patient panels, focus groups, community surveys, and data analysis.



PRACTICAL SUPPORT

ARC directly supports patients daily while we work towards a cure.



Comprehensive Patient Resources

Educational material in every-day language gives patients a foothold on their health

Frequently underrecognized and underdiagnosed, many patients find themselves needing to become their own amyloidosis experts. That's why ARC has developed a library of patient resources to explain disease processes and treatments for hATTR, wild-type, and AL amyloidosis in thorough and easy-to-understand language.

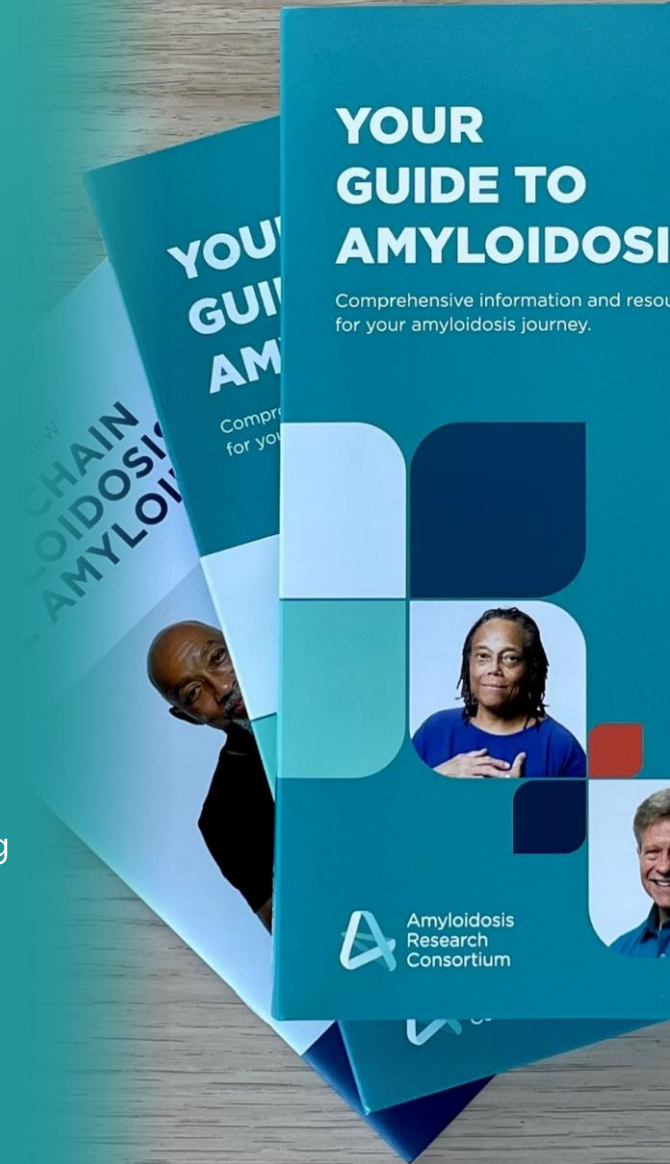
Thanks to your generous support, these resources are available to patients and caregivers free of charge.



Always Here To Help

With ARC's team of staff ready to help, patients are never alone

Many patients don't know where to turn after receiving a diagnosis. ARC's patient navigators are here to support patients and caregivers throughout their journey from their first suspicions, to diagnosis, through to finding an amyloidosis treatment center. ARC offers valuable support to patients when they are faced with making decisions about their treatment, ongoing care, and beyond.



THANK YOU

Your support drives our work toward a cure
and a world where each and every patient can
access the treatment they need when they need it.



ORGANIZATION

[ARCI.ORG](https://arci.org)

FINANCIALS

ARC 2021 Statement of Activities



ARC 2021 Source of Funds

- Contributions
- In-Kind Contributions, et al.



ARC 2021 Spending Allocation

- Programs
- Administrative
- Fundraising

Support Revenue 2021

Contributions	\$	1,472,339
Other		172,651
In-Kind Contributions		20,000
Honorariums & Consulting		2,258
Investment Income		724
Total Support		1,667,972

Expenses 2021

Programs	\$	1,429,655
Administrative		111,612
Fundraising		160,864
Total Expenses		1,702,131

Change in net assets (34,159)

Net assets, beg. of year 2,230,101

Net assets, end of year 2,195,942

BOARDS

Board of Directors

Sarah Cairns-Smith

Board Chairman

Senior Partner & Managing Director,
Boston Consulting Group

Isabelle Lousada

Founder and CEO,
Amyloidosis Research Consortium

Dena Heath

Board Secretary Facilitator,
Northern California Amyloidosis Support Group

Jason Shore

Board Treasurer
CEO,
Patient Discovery

Raymond Comenzo, MD

Director, Transfusion Services;
Director, John C. Davis Myeloma & Amyloid Program,
Tufts Medical Center

Professor,
Tufts University School of Medicine

Giampaolo Merlini, MD

Director, Center for Research and Treatment of
Systemic Amyloidosis, and of the Biotechnology
Research Laboratories, Scientific Institute Policlinico,
San Matteo
University of Pavia, Italy

Scientific Advisory Board

Raymond Comenzo, MD

Tufts Medical Center

Mathew Maurer, MD

New York-Presbyterian Hospital
Columbia University Medical Center

Angela Dispenzieri, MD

Mayo Clinic

Giampaolo Merlini, MD

University of Pavia

Jeffery Kelly, PhD

The Scripps Research Institute

Vaishali Sanchrawala, MD

Boston Medical Center

Ashutosh Wechalekar, MD

Royal Free Hospital

Nurse Advisory Board

Lisa Mendelson

Boston University
Amyloidosis Center,
Boston, MA

Johana Fajardo

MedStar Washington Hospital,
Washington, DC

Janell Grazzini Frantz

Mayo Clinic,
Rochester, MN

Katharina Ganapathi

UCSF,
San Francisco, CA

Patient Advisory Board

Eric Eckerstrom

Dawn Gimbel-Myers

Nancy Verel

David Antonaitis

Cordelia Maloney

Kathleen Burda



**Accelerating the development of and access to
new and innovative treatments for amyloidosis.**

Amyloidosis Research Consortium

320 Nevada Street, Suite 210
Newton, MA 02460

T 617.467.5170

E arc@arci.org

ARCI.ORG