



Amyloidosis
Research
Consortium

ANNUAL REPORT

2022



OUR MISSION

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

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Forging Ahead

This annual report allows us to look back at our past achievements and see how far the field of amyloidosis has come. We have made great strides in developing treatments for amyloidosis and building an increasing level of awareness about the disease, with many patients benefiting from an earlier diagnosis.

With the changing landscape we are forging ahead with programs that will ensure patients have access to the treatments of today while we work with the scientific community to speed the development of the treatments of tomorrow.

As we look toward the future, we remain focused on what needs to be done to ensure that all patients have high quality care and access to cutting edge treatments.

We would not be where we are today without your support. Together we can build on these successes and I truly believe we can conquer amyloidosis.



Isabelle
ARC Founder & CEO



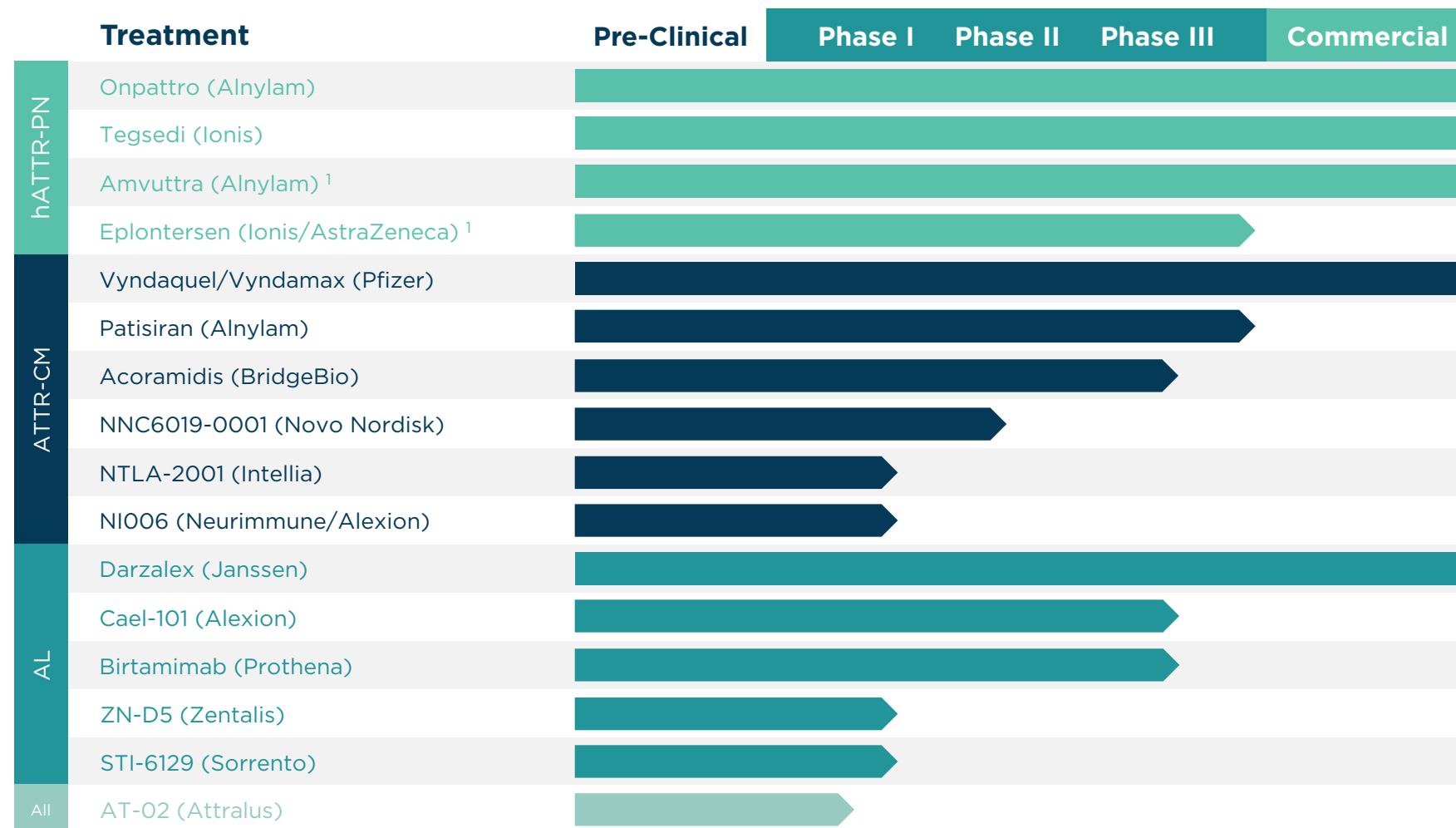
Isabelle,
AL patient

Expanding Treatments

When ARC was founded in 2015 there were no FDA approved treatments for systemic amyloidosis. We now have 5 drugs available on the market.

There is a promising drug discovery pipeline, where more pharmaceutical and biotech companies than ever before have programs committed to conducting clinical trials to evaluate novel therapies in amyloidosis.

We've highlighted a few programs in this impressive pipeline here.



¹ Commercial treatments seeking secondary approval

Securing the Future

In 2022 ARC made an important step towards securing the future of amyloidosis research. Thanks to the generosity of Dr. Peter Ruehlman and Debra Chisolm Ruehlman we established our first endowment to advance treatments and improve the quality of life of patients with amyloidosis.

ARC Legacy Funds will ensure amyloidosis research has a reliable source of funding year after year.

ARC Legacy Funds like the Ruehlman Fund for Amyloidosis Research will ensure amyloidosis research has a reliable source of funding year after year. In addition to other sources of funding like individual donors and government grants, these legacy funds will continue to drive our work pushing research forward and building a better future for amyloidosis patients and families.

[Learn More](#)





PROGRAMS

2022

Accelerating Research

Transforming the next generation of amyloidosis therapies.

The Amyloidosis Forum

arci.org/forum

This public private partnership with FDA brings together international experts from regulatory, scientific, clinical care and research and aims to identify and address knowledge gaps to improve trial design and ultimately drive faster, patient-centric research. In November 2022 we convened a hybrid in-person and virtual meeting to explore how imaging can be used in both AL and ATTR amyloidosis.

Driving Innovation with Collaborative Data

arci.org/research

Scientifically rigorous data is critical to advancing research in rare disease. Many datasets are still stonewalled behind organizational barriers. ARC's unique federated data analytics platform allows centers of excellence, single-staff clinics, and contributors of all sizes to collaborate. By analyzing combined datasets, we can accelerate progress and create opportunities to improve clinical trial design and therapeutic development.



November 2022,
Amyloidosis Forum

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Prioritizing Patients

Measuring what matters to patients and caregivers.

ATTR Quality of Life Tool

arci.org/attr-qol

Improving care and advancing research requires understanding the complex impacts of amyloidosis on patients' lives.

We developed a unique patient reported outcome (PRO) tool to provide the research field with a standard questionnaire that is appropriate for use for any ATTR patient. Use of the ATTR-QOL will expand our understanding of the benefits of treatment, while making sure what matter most to patients is measured.

Patient Centered Research

arci.org/surveys

Our research and advocacy work is deeply informed by the patient and caregiver experience. Our scientifically rigorous patient surveys have been cited in over 300 publications and are a cornerstone for global clinical insight. In 2022 we launched an annual community survey, explored the impact of high cost therapies on patients and caregivers, and investigated the value of imaging to AL & ATTR patients.



Ralph,
Wild-Type patient

Practical Support

Walking alongside patients in their journey.

Patient Education Without Jargon

arci.org/patients

Educational material in every-day language gives patients a foothold on their health. Available to patients, caregivers, and clinicians free of charge, ARC's library of resources explain disease processes and treatments for hATTR, Wild-Type, and AL amyloidosis. Our booklets and guides are continuously updated with the latest information, making them some of the most appreciated materials we produce.

Always Here to Help

arci.org/contact

ARC's team of patient navigators are always ready to help. Whether they reach out by email, phone call, or online, patients are never alone. We're always here to support patients facing decisions about treatment, ongoing care, and beyond.



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ORGANIZATION

2022

Financials



Source of Funds

- Contributions
- In-Kind Contributions, et. al.



Spending Allocation

- Programs
- Administrative
- Fundraising

Support Revenue 2022

Contributions	\$ 2,219,649
In-Kind contributions	10,500
Honorariums & Consulting	1,913
Investment Income	38,693
Total Support	2,270,755

Expenses 2022

Programs	\$ 1,461,902
Administrative	278,120
Fundraising	400,410
Total Expenses	2,140,432

Change in net assets	19,408
Net assets, beg. of year	2,195,942
Net assets, end of year	2,215,350

Board and Committees

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;
Professor, Tufts University School of Medicine

Ashutosh Wechalekar, MD

Professor of Medicine and Haematology,
University College London

Giampaolo Merlini, MD

Emeritus Board Member

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

Scientific Advisory Committee

Raymond Comenzo, MD

Director, Transfusion Services;
Director, John C. Davis Myeloma & Amyloid Program;
Professor, Tufts University School of Medicine

Mathew Maurer, MD

Arnold and Arlene Goldstein Professor of Cardiology;
Professor of Medicine, New York-Presbyterian
Hospital/Columbia University Medical Center

Angela Dispenzieri, MD

Consultant, Division of Hematology;
Serene M. and Frances C. During Professor of
Medicine and of Laboratory Medicine and Pathology;
Hematology Research Chair,
Mayo Clinic

Giampaolo Merlini, MD

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

Jeffery Kelly, PhD

Lita Annenberg Hazen Professor of Chemistry,
Scripps Research Institute

Vaishali Sanchorawala, MD

Professor of Medicine;
Director, Amyloidosis Center,
Boston University School of Medicine
Boston Medical Center

Ashutosh Wechalekar, MD

Senior Lecturer; Honorary Consultant Haematologist,
Royal Free Hospital

Patient Advisory Committee

Cordelia Maloney

David Antonaitis

Dawn Gimbel-Myers

Dena Heath

Eric Eckerstrom

Kathleen Burda

Nancy Verel



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

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ARCI.ORG