Amyloidosis Research Consortium

2020 ANNUAL REPORT

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OUR MISSION

The Amyloidosis Research Consortium is a nonprofit accelerating the development of and access to new and innovative treatments. We are driving the research that will have the greatest impact on length and quality of life for patients.

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MESSAGE FROM OUR CEO

Dear Friends,

2020 will forever be etched in our memories as the year of the pandemic. It is a year that reshaped the world.

One can only marvel at the power of science and the pace of discovery that occurred, as 2020 was marked by the race for an effective vaccine for COVID 19, harnessing the power of researchers across the globe. The pandemic also framed for us all the challenges and opportunities that exist in medicine today. For many with pre-existing conditions like amyloidosis it was an extremely difficult time, there was an added level of anxiety, disruption to care, while, novel approaches, including, for many, virtual visits became the new normal.

At ARC, we were able to quickly adapt our initiatives this year in order to meet the changing needs of the community; we led the way in supporting and keeping the patients informed about how best to manage their amyloidosis during the pandemic.

Despite the disruptions of a global pandemic, we also successfully advanced and grew our research programs. Moving into the virtual arena, has increased the opportunities for global collaboration, which the logistics of face-to-face meetings did not allow. In the rare disease space, international collaboration is vitally important, and virtual tools have provided new ways to facilitate that. Nowhere was this more clearly demonstrated than through the work that is being done within the Amyloidosis Forum, which is creating a unique, rigorous and truly international approach to improving the pathways for drug development and review.

Despite the challenges we all faced, I could not be prouder of the ARC team, who rose to the occasion, supported patients and drove our portfolio of research initiatives forward. Thanks to all of you we have continued to grow our programs, to advance the mission of ARC and together with your support we can make a difference and change the lives of those affected by amyloidosis.

Isabelle Lousada

BUILDING A BETTER FUTURE

Because ARC was **founded by a patient**, we have a razor-sharp focus on the patient. It is the reason we relentlessly pursue our goal of improving treatments and the lives of amyloidosis patients.

A LOOK BACK

ARC has grown rapidly since its inception in 2015. Our approach has delivered high impact programs focused on patients' needs and has positioned ARC as a leader in the field of rare disease research.

2015

FDA Drug Development Meeting
Our Patient Focused Drug Development Meeting with FDA generated data and reports about patient experiences — this first-of-its-kind meeting was so successful that a pathway has been established for other rare diseases.

Patient Experience Study
First-of-its-kind study to define the amyloidosis patient journey from diagnosis through treatment, and impact on quality of life.

Research Roundtable
First meeting of researchers, FDA and industry to address challenges of drug development in amyloidosis.

2016

Draft Guidance for Drug Development
Created extensive guidance for industry on drug development in both AL and ATTR amyloidosis.

Biomarker Publication
Landmark paper on the importance of the biomarker NT-proBNP in AL amyloidosis.

Patient Voice Publication
A unique publication that was developed to be shared with the FDA and contains a valuable benefit/risk framework for use in product review.

2017

Research Landscape White Paper
ARC convened leading experts across academia, industry regulatory and other areas for a two-day workshop. Resulting in the identification and publication of the most pressing needs in research across the drug development continuum, to focus research initiatives.

MAP
My Amyloidosis Pathfinder (MAP) was developed to enable patients to stay informed about research and clinical trials opportunities, and connect them with amyloidosis treatment centers.

Clinical Resources App
Developed an interactive app to support clinicians in diagnosing and treatment patients. It has been associated with an increase in the diagnosis of amyloidosis.

2018

September 2018
Onpattro approved for ATTR-PN

October 2018
Tegsedi approved for ATTR-PN

Cardiac Awareness Campaign
Misdiagnosis and delays are common in amyloidosis. This campaign was aimed at physicians who had missed the diagnosis and featured an Olympic champion diagnosed with amyloidosis.

International Cardiac Study
This international study was the first to evaluate patient's experiences with cardiac amyloidosis, and identify challenges in practices that need to be addressed.

2019

June 2019
Vyndaqel approved for ATTR-CM

Guidelines for suspicion and diagnosis of ATTR amyloidosis
Led on the publication of guidelines to support earlier diagnosis across multiple medical disciplines.

Patient Preference Study
Conducted a pioneering patient preference elicitation study to highlight patients' and caregivers' perspectives on potential benefits and risk of treatment options.

Amyloidosis Forum
Formed a Public Private Partnership with FDA to advance and accelerate the science of drug development through multi-stakeholder collaboration.

2020

Masterclass
In 2020, we established these physician masterclasses, which are held regionally, and focus on building expertise in centers in areas that are underserved.

AAC
The Amyloidosis Appointment Companion (AAC), a digital tool, was developed and provides a framework for patients to share information and concerns with their physician. The tool was integrated into virtual visits during COVID.

PRO Development
Initiated the development of a tool to capture all the aspects of ATTR amyloidosis that matter to patients, to be used in both clinical trials and clinical care.

January 2021
Darzalex Faspro approved for AL

Amyloidosis Research Consortium

DRUG DEVELOPMENT PIPELINE

ADVANCING TREATMENTS

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.

WHAT WE DO

We enable pioneering research to better understand the factors responsible for the onset and progression of amyloidosis.

We accelerate the discovery and development of new and effective treatments and support their approval, reimbursement, adoption and diffusion into health systems across the world.

We raise awareness and provide education for physicians about the signs, symptoms and care of amyloidosis to raise the level of suspicion, improve the speed of diagnosis, and standards of care.

We provide information and support for patients and their families to help them cope with everything an amyloidosis diagnosis brings and to empower them to make informed decisions about treatment and care.

URGENCY

Patients needs drive us with a focus and determination to speed discovery and improve lives.

INNOVATION

We believe in finding transformative solutions to increase knowledge and advance research.

COLLABORATION

We build unique partnerships between patients, the scientific community regulators and other stakeholders to break down the barriers that slow research.

PROGRAMS

2020 was a year of many achievements for the Amyloidosis Research Consortium. These highlights showcase some of our many areas of impact.

Amyloidosis The FORUM

Amyloidosis Research Consortium

FDA U.S. FOOD & DRUG ADMINISTRATION

ACCELERATING DRUG DEVELOPMENT

★ HIGHLIGHT

The Amyloidosis Forum

The Amyloidosis Forum, formed in 2019, is a Public Private Partnership between ARC and the US Food and Drug Administration (FDA). The goal of the Forum is to leverage expertise and resources from all stakeholders to advance rigorous science to bridge the gaps in drug discovery and development in AL amyloidosis.

The Forum has taken full advantage of the increased capabilities of virtual meetings to expand international representation with the Medicine and Healthcare products Regulatory Agency (MHRA) in the UK joining as well as disease experts from around the globe.

In 2020 the Forum focused on novel endpoint development. Specialized working groups were established consisting of leading physicians, patient representatives, statisticians, regulators, and pharmaceutical company researchers, and statisticians to address the complex and multi systemic nature of AL amyloidosis, and ensure this was reflected in endpoint choice and clinical trial design.

We are pleased to share that the National Institute of Health (NIH) saw the importance of this initiative and provided funding to support Forum meetings.

Attendees at the first Masterclass, Dallas, Texas, January 2020

ARC Amyloidosis MASTERCLASS

Amyloidosis Research Consortium

IMPROVING CARE

★ HIGHLIGHT

ARC Masterclass

In both AL and ATTR amyloidosis, the treatment and clinical trial landscape has been fast evolving. It has never been more important to ensure that patients are quickly and correctly diagnosed and have access to the appropriate and best treatment. With the complexities associated with treating amyloidosis in its many forms, up-to-date knowledge of treatment options and management are crucial to improving patient outcomes.

ARC Masterclass, launched in January 2020, are led by a nationally/internationally renowned faculty team of amyloidosis experts, and aim to provide education and share established best practices to increase knowledge about amyloidosis, in all its forms, with the healthcare practitioners at these one-day specialized masterclass. These practitioners learn to identify, correctly diagnose, and treat amyloidosis patients in their clinical practice, as well as when and how to refer to specialty centers. The masterclass additionally supports the development of building an amyloidosis program, and the role of a multidisciplinary team to best support patients.

WE ARE STRONGER TOGETHER

"I picked up the phone, and the Consortium was there and it meant the world to me, just knowing that I wasn't alone in this fight."

—Greg, AL amyloidosis

Amyloidosis Research Consortium

SUPPORTING PATIENTS

★ HIGHLIGHT

Community Programs

Receiving a diagnosis of amyloidosis is frightening, very few people have heard the word amyloidosis before they are diagnosed or know where to turn for help. Patients and families need support, education, and access to specialized care during this difficult time. In 2020, this need for support and resources expanded to include COVID-19 in the ways in which it impacts healthcare and day-to-day life.

ARC provides patients with the comprehensive, unbiased information they need to better understand their disease and the new treatment and care options available in a rapidly changing landscape. ARC has a strong track record of producing scientifically accurate, up-to-date, and relevant information in a patient-friendly format; these include disease-specific guides, webinars, videos, and patient stories to support patients, both those newly diagnosed and those more familiar with their disease. In 2020, ARC's covid resources became some of the most accessed information to date.

Along with these tangible materials our patient support staff are available daily to speak to patients, and the My Amyloidosis Pathfinder (MAP) tool helps patients navigate finding amyloidosis treatment centers and clinical trials. We believe in empowering patients with the skills to navigate their diagnosis of amyloidosis.

ORGANIZATION

Thanks to the hard work and generosity of our supporters, **2020 was our most impactful year yet.** We were able to build unique collaborations and programs to accelerate the research **that will change lives of those affected by amyloidosis.**

FINANCIALS

ARC 2020 Statement of Activities

ARC 2020 Source of Funds

- CONTRIBUTIONS
- IN-KIND CONTRIBUTIONS & OTHER

ARC 2020 Spending Allocation

- PROGRAMS
- ADMINISTRATIVE
- FUNDRAISING

Support & Revenue		2020
Contributions	$	1,783,523
Other		215,472
In-kind contributions		930
Interest		827
Total Support & Revenue		**2,134,759**
Expenses		
Programs		
Research/Awareness/ Education		1,025,685
Supporting Services		
Administrative		95,252
Fundraising		122,311
Total Expenses		**1,243,248**
Change in net assets		**891,511**
Net assets, beginning of year		**1,094,804**
Net assets, end of year		**1,986,315**

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MAKING GREAT STRIDES

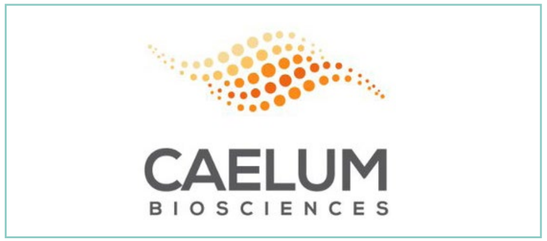
The ARC board and steering committees are comprised of a diverse group of exceptional individuals dedicated to the ARC mission. Together with the ARC staff, they identify areas of opportunity to inform our programs.

WITH GRATITUDE

We thank every **supporter, donor, corporate partner,** and **foundation** for their **commitment to helping us accelerate research** and **move closer to a cure**.

Amyloidosis Research Consortium

THANK YOU TO OUR SUPPORTERS



We are **working in partnership** with today's leading companies and research institutions to address the unmet need for all types of amyloidosis.

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

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