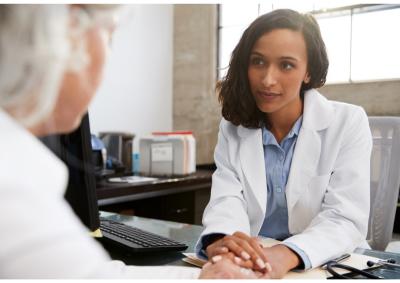




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ANNUAL REPORT 2021

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#### **CONTACT AARDA**



www.aarda.org



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## **FOLLOW AARDA**



/autoimmunity



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## **OUR MISSION**

The American Autoimmune Related Diseases Association (AARDA) is dedicated to the eradication of autoimmune diseases and the alleviation of suffering and the socioeconomic impact of autoimmunity through initiating, fostering, and facilitating collaboration in the areas of education, public awareness, research, and patient services in an effective, ethical, and efficient manner.

## **OFFICERS**

Chair: Rich Hodge Vice-Chair: Lilly Stairs

Secretary: Michelle Ouellet

Treasurer: Nona Bear

President & CEO: Molly Murray

## **BOARD OF DIRECTORS**

Mirta Avila Santos Ouardricos Driskell

Indie Lee
Anna Legassie
Dr. Robert Phillips
Linda J. Roelans
Michael Linn
Sloane Salzburg
Scott Selby
Scott Williams



## ADVISORS TO THE BOARD OF DIRECTORS

David Bammert Stephanie Hales Artie Shelton

## SCIENTIFIC ADVISORY BOARD LEADERSHIP

Chair: Betty Diamond, M.D.

# **MESSAGE FROM MOLLY MURRAY**

I am grateful for the collective autoimmune community and all that is being done for people living with autoimmune disease, their families and care team, and the scientific and medical teams who are working to find better treatments, and ultimately, cures. Despite this year's significant challenges brought on by the pandemic, this community has come together to support patients and families like never before. I am proud of what we are accomplishing together and the constant innovation taking place across autoimmune awareness, advocacy, education, and research. We look forward to continued collaboration to create a better tomorrow for the autoimmune patients we serve.

**Molly Murray, President & CEO** 

# MAJOR CONTRIBUTORS IN FISCAL YEAR 2021

## INDIVIDUAL, CORPORATE, AND FOUNDATION DONORS

#### Contributions \$20,000 & over

Anonymous

AbbVie Inc.

Bristol-Myers Squibb Foundation INC

Eli Lilly and Company

Facebook Fundraisers

Genetech, Inc.

Gilead Sciences Inc.

Horizon Therapeutics

Johnson & Johnson Health Care Systems

Momenta Pharmaceuticals, Inc.

Patient-Centered Outcomes Research Institute

Pfizer, Inc.

**PhRMA** 

Silicon Valley Community Foundation

Takeda Pharmaceuticals USA. Inc.

#### Contributions \$5,000 through \$19,999

Todd and Kathy Baker Charitable Fund

Biotechnology Innovation Organization

Indie Lee & Co.

Larry and Catalina Koch

Dr. Nat and Jill Linhardt

Robert A. Waller Foundation

The Park Foundation

Raising money for a Cure - Gracie Reed fundraiser

#### Contributions \$1,000 through \$4,999

**Anonymous** 

Ann and Scott Barnhouse

Dr. James D. Barrie and Dr. Leslie Ann Momoda

Nona Bear

Judith Bellin

**BLR Fund** 

Jennifer Carmichael

Lori Ann Demple

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Fraser Family Foundation

**Great Lakes Center of Rheumatology** 

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Lynn and Steve Kieffer

Mary Kimball

Ashley Krokowski and James Acierno

Casaundra Lindsey

Kellie Martin and Keith Christian

Kathryn Mayer

Diane Moss

Nancy Munis

Victoria Murray

Mythical Entertainment

Phyllis Nazari

Elizabeth Niemeyer

Raising awareness in honor of Cara Lian Lebedda fundraiser

James and Rita Peterson

**Caleb Powers** 

Purple Butterfly Gift Fund

Quad Cities Community Foundation

William and Terri Reid

Anne Remington

#### Contributions \$1,000 through \$4,999 Cont'd

Linda and Douglas Robinson

Steven Robinson

Ben Thomas

Linda and Dan Wilhelms

Women of Health Occupations Promoting Education

#### Contributions \$250 through \$999

Aizaz Akram

Chris Alford

Anonymous

William Arnett

Joy Berenfield

Darci Berkovich

Jerianne Berman

Steffi Bokser

James Bookhamer

Dr. John Bornhofen

Teena Cadwell

Christopher Calabia and Suzanne Brown

Janel Carroll

Eli Cheung

Ed and Judy Christian

Katie Cleary

Rachel Coffman

Edward Connolly

Natasha Corrigan Jeffrey Davenhall

Joan de Milt Boddie

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William DeRousse

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Valerie Forstman Charitable Fund

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**Greatest Commandments Foundation** 

Mary Sue and John Gunzburger

Nancy Harris

Karen and Jeffrey Hays

Ellen Hipsky

Sharon Jacobs and David Cohen

John and Myrna's Charitable Fund

Betty Jordan

Geoffrey Karny

**Charity Kates** 

Patrick Kinlan Suzanne Klein

Amy and Brian Kobishop

Rita Konetzka

Phyllis Krattenmaker

Cecelia Lance

Michael Lebednik

# MAJOR CONTRIBUTORS IN FISCAL YEAR 2021

#### Contributions \$250 through \$999 Cont'd

Naomi M. and Marc D. Levenson Charitable Fund

Jeremy Levine

Lighthouse Financial LLC

Gail and John Maloney

Shannon Marold

Steve Martin

James McGrath

Richard McGrath

Logan McGruder

Cameron and Kelli McPhee

Patrick Milnes

Bruno Moschetta

Patrick Niemever

Orkand Family Foundation

William Pace

William Padnos and Margery Kaye

Jinah Parker

U.S. Japan Communications fundraiser

Sravan Reddy-Bezwada

Robin Reich

Janis Reinschmidt

Lori Richardson

Madeline, Melissa and Samantha Ross

RTU Charitable Fund

Jeanne Russell

Randall Rutta

James Ryan

Tamar Rydzinski

Sean Sanders

Marci and Fred Schwartz

Jaclyn and Scott Selby

Jean Paul Sevilla

**Christine Smith** 

Nicolette and Craig Straley

Thomas Surgent

Marie Taylor

Kathleen and Daniel Thornberry

Joanne and Jeff Urbanowski

Lindsay Wagner

Jerry Wald

Joel Wald

Gail and Lois Warden

Barbara and John Wehling

Jennifer Whipple

Carol Lvnn White

David Witherspoon

Charles Wofford

Michele Wornow

#### **Major In-Kind Contributors**

Ally Financial Inc. Corporate Citizenship

Bank of America Matching Gifts

Charity on Top Foundation Inc.

Charities Aid Foundation of America

Kroger Community Rewards Program

Context Strategies iMD Health

River Ridge Corporate Center

Sidley Austin

Amazon Smile

Charityvest Inc.

Good Today

**Exelon Corporation** 

Give inLieu Foundation

Make My Donation Inc.

**Graham Holdings Company** 

**American Express** 

America's Charities

**Battelle Always Giving** 

My Tribute Gift Foundation, Inc.

Network for Good

Onehope Foundation

Shell Oil Company Foundation

The Blackbaud Giving Fund

The Wonderful Company Foundation Inc.

Trustees of American Express Foundation

United Way of Central and Northeastern Connecticut

United Way of Central New Mexico

United Way of Greater Philadelphia & Southern New

Jersey

Verizon Matching Gifts

Walt Disney Company Foundation Employee Matching

Gifts Program

#### Other Contributors and Friends

Space does not allow us to include the names of all persons and organizations who gave their financial support to AARDA, but we say "Thank You" again as we give this recognition in honor of their generosity.

Payroll Campaigns, Matching Gifts & Online Giving

#### **Memorials and Tributes**

Since it is our policy not to release amounts given for these contributions, we take this opportunity to express our appreciation again to all the kind donors. Every contribution has been acknowledged to the donors, to those persons honored, and to the families of those held in memory.

# MAJOR ACCOMPLISHMENTS DURING FISCAL YEAR 2021



## Let My Doctors Decide

AARDA continues to lead <u>Let My Doctors Decide</u> (LMDD), a national partnership of leaders across health care working in support of a simple goal: treatment decisions should always be made by patients and trusted health care professionals, not insurance companies or pharmacy benefit managers. LMDD launched a <u>Drop the Barriers</u> campaign that calls out the top 10 barriers to care that patients experience, including a patient-focused <u>explainer video</u>. AARDA and LMDD continues to leverage this unique message, driven by a task force of patient and provider groups, to shine a spotlight on the barriers patients face daily.

## **National Briefing**

In July, AARDA hosted *Barriers to Improved Health In the Era of COVID-19: Advocates and Providers Speak Out*, where patient advocates, providers and health care experts discussed the harm posed by access restrictions.

## **National Coalition of Autoimmune Patient Groups (NCAPG)**

The NCAPG has significantly grown the past year, adding over 10 new organizations that increase representation of autoimmune disease states across the globe. This year, the NCAPG met with congressional offices, members of the CDC COVID-19 Response Team, and leading researchers in Long COVID. The growth and impact of the NCAPG magnifies the voice of patients living with autoimmune disease and addresses key issues of importance to people living with autoimmune disease and their families.

## **AWARENESS**

AARDA continues to lead the way in public awareness for autoimmune and related diseases. In March, we celebrated Autoimmune Disease Awareness Month. This year, we were honored to team up with clean beauty maven Indie Lee and patient influencers to raise widespread awareness about what it means to live with an autoimmune disease. The grassroots campaign, Faces of Autoimmunity, featured the journeys of people living with autoimmune disease. We are grateful to Indie's team and the inspiring patients, partners, and contributors that emphasized the message that no patient is alone on their journey.

## **EDUCATION**

The long-anticipated approval of the first COVID-19 vaccines brought hope to many people living with autoimmune disease across the globe. At the same time, with misinformation and feelings of uncertainty ever rising, AARDA mobilized a team of experts to ensure that autoimmune patients and their families had access to the latest information on COVID-19 vaccines. In February, AARDA debuted a first-of-its-kind newscast, COVID-19 Vaccines and Autoimmunity, featuring perspectives from the CDC's COVID-19 Vaccine Task Force, patient advocates, and renowned physicians and researchers. The urgent need for real-time information was clear by the thousands of individuals that tuned in from across the globe. As new information on the COVID-19 vaccine became available, AARDA kept the autoimmune community up to date through speaking engagements, publications, social media, and our COVID-19 Resource Page.



## RESEARCH

## **Noel Rose Scientific Colloquium**

AARDA hosted the 15th Noel Rose Scientific Colloquium on May 1, 2021, bringing together high-level researchers from different specialties to discuss the intersection of COVID-19 and autoimmunity. Participants heard directly from leading autoimmune experts, who shared how their past work on autoimmune diseases helped them pivot to study, understand, and generate hypotheses on how to combat the novel coronavirus. Experts agreed that there is a high degree of overlap between the study of autoimmune diseases and COVID-19 and affirmed their commitment to both a collaborative and holistic approach to the study of autoimmune diseases and COVID-19. As a direct result of the colloquium, a research paper was published in the Journal of Clinical Investigation (JCI), The intersection of COVID-19 and autoimmunity.

## Inflammation & Immunophysiology: An Exploration of Pathophysiology Webinar Series

AARDA partnered with the American Physiological Society (APS) and InsideScientific to bring a series of six webinars to thousands of global participants in the scientific community, covering fundamental principles, late-breaking research, and novel discoveries in the field of inflammation and immunophysiology. The series included live lectures from leading researchers around the world and "Technology & Methods" sessions focused on laboratory innovations and fundamental methods central to immunology and inflammation research and related models of disease.

## RA Research Results Funded by the Virginia T. Ladd Young Investigator Program

Dr. Tarun Sharma, a rheumatologist from the Allegheny Health Network in Pittsburgh, is a recipient of a research grant from the Virginia T. Ladd Young Investigator Program. Dr. Sharma's research looked at the best strategy for tapering treatment with biologics and non-biological RA medications to treatments with less risk in well-controlled RA patients to maximize the wellbeing of the patient has been a long-standing concern for both physician and patient. The practice-based study was conducted over a two-year period. The study shed light on the chances of a flare of RA with different tapering strategies and attempts to predict which patients might be good candidates for medication tapering. The study results concluded that tapering of both biologics and non-biologics together led to higher odds of flares. However, Dr. Sharma found that in cases where a flare occurred, resuming the previous treatment regimen led to disease control within 2-3 months. The findings help both physician and patient decision making by being better informed and able to participate in shared decisions regarding what is the most suitable long-term therapy strategy for individual patients with RA.

We congratulate Dr. Sharma and all Virginia T. Ladd Young Investigator Program awardees for their excellent investigation in autoimmune disease, and we encourage other young investigators to focus their research in this growing area where there is much opportunity and new discoveries waiting to be explored.



# INDEPENDENT AUDITORS' REPORT



#### The Board of Directors.

## American Autoimmune Related Diseases Association

Clinton Township, Michigan

We have audited the accompanying financial statements of American Autoimmune Related Diseases Association (a nonprofit organization) which comprise the statement of financial position as of September 30, 2021, and the related statements of activities, functional expenses and cash flows for the year then ended, and the related notes to the financial statements.

# Management's Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

## **Auditor's Responsibility**

Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements. whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

#### **Opinion**

In our opinion, based on our audit, the financial statements referred to above present fairly, in all material respects, the financial position of American Autoimmune Related Diseases Association as of September 30, 2021, and the changes in its net assets and its cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

Gordon advisors, P.C.

April 25, 2022

# STATEMENT OF ACTIVITIES



## For the Year Ended September 30, 2021

	WITHOUT DONOR RESTRICTIONS		WITH DONOR RESTRICTIONS		2020 TOTAL	
Revenue and Other Support						
Contributions	\$	2,645,294	\$	634,124	\$	3,279,418
Paycheck Protection Program grant		123,400		0		123,400
In-kind goods and services Fundraising income - net of		482,143		0		482,143
expenses of \$0		3,398		0		3,398
Other income		2,285		0		2,285
Interest income		2,463		0		2,463
		3,258,983		634,124		3,893,107
Net assets released from restrictions		586,924		(586,924)		0
Total Revenue and Other Support		3,845,907		47,200		3,893,107
Expenses  Program services		066.007		0		066 057
Education Public awareness		966,873 2,217,156		0		966,873 2,217,156
Research		191,194		0		191,194
Total program services		3,375,222		0		3,375,222
Supporting services						
Management and general		104,058		0		104,058
Fundraising		61,708		0		61,708
Total supporting services		165,766		0		165,766
Total Expenses		3,540,988		0		3,540,988
Change in Net Assets		304,919		47,200		352,119
Net Assets, Beginning of Year	\$	912,080	\$	364,786	\$	1,276,866
Net Assets, End of Year	\$	1,216,999	\$	411,986	\$	1,628,985

# STATEMENT OF FUNCTIONAL EXPENSES



## For the Year Ended September 30, 2021

	PROGRAM SERVICES			TOTAL	SUPPORTING		
	Education	Public Awareness	Research	PROGRAM SERVICES	Management and General	Fundraising	TOTAL
Wages	\$ 265,002	\$ 347,709	\$87,757	\$700,468	\$31,018	\$25,740	\$757,226
Professional fees	28,646	21,914	7,097	57,657	10,916	1,755	70,328
Postage/shipping	4,877	1,131	277	6,285	195	620	7,100
Public relations	92,117	1,603,883	0	1,696,000	0	0	1,696,000
Legal	95,383	0	29,348	124,731	28,840	0	153,571
Consulting services	52,841	32,325	18,530	103,696	5,483	5,483	114,662
Grant writing	4,486	2,941	9,354	16,781	0	0	16,781
Printing/stationery	3,919	2,815	0	6,734	619	778	8,131
Office supplies	1,590	1,586	0	3,176	145	51	3,372
Operating supplies	7,530	4,697	88	12,315	285	246	12,846
Dues/subscriptions	14,360	30,711	16,779	61,850	2,997	2,030	66,877
Filing fees	1,454	1,454	0	2,908	1,418	1,454	5,780
Planned giving	6,432	6,348	0	12,780	1,456	6,197	20,433
Rent	51,157	38,757	861	90,775	5,340	4,651	100,766
Equipment maintenance	1,545	983	0	2,528	140	140	2,808
Telephone	4,613	4,661	292	9,566	360	237	10,163
Insurance	1,212	1,212	367	2,791	1,312	1,212	5,315
State/national meetings	0	1,258	985	2,243	245	0	2,488
Travel	0	1,777	0	1,777	380	0	2,157
Depreciation	1,301	1,301	1,301	3,903	1,301	1,301	6,505
Payroll taxes	20,898	23,098	5,499	49,495	2,199	3,300	54,994
Insurance - Health	18,191	15,118	3,342	36,651	1,806	1,594	40,051
Fundraising - Other	0	0	0	0	0	0	0
Board expenses	622	216	76	914	4,494	0	5,408
Events	333	333	0	666	1, 13 1	333	999
Professional training	1,473	2,318	261	4,051	153	226	4,430
Grants	0		5,000	5,000	0	0	5,000
Repairs/maintenance	500	0	500	1,500	500	500	2,500
Utilities	1,023	500	0	2,046	87	44	
Miscellaneous	•	1,023	67				2,177
Retirement plan contribution	64 ns 067	68		199	188	62	449
Website	907	2,232	3,413	6,612	93	559	7,264
Advertising/development	284,337	34,787	0	319,124	1,198	3,195	323,517
	0	30,000	0	30,000	890	0	30,890
Total Expenses by Function	\$ 966,873	\$ 2,217,156	\$ 191,194	\$ 3,375,222	\$104,058	\$ 61,708	\$ 3,540,988
Less expenses included with revenues on the statement of activities	0	0	0	0	0	0	0
Total expenses included in the expense section on the statement of activities	\$ 966,873	\$ 2,217,156	\$ 191,194	\$ 3,375,222	\$104,058	\$ 61,708	\$ 3,540,988