



**American  
Autoimmune**  
Related Diseases Association, Inc.



[aarda.org](https://aarda.org)



# ANNUAL REPORT **2020**



# TABLE OF CONTENTS

Mission Statement.....	2	Independent Auditors' Report.....	9
Board of Directors.....	2	Statement of Activities.....	10
AARDA's Scientific Advisory Board.....	2	Statement of Functional Expenses.....	11
Message from President & CEO.....	3	Tribute to Dr. Noel Rose.....	12
Major Contributors.....	4-5		
Major Accomplishments:			
<i>Patient Education and Support</i> .....	6		
<i>Awareness</i> .....	7		
<i>Research</i> .....	7		
<i>Advocacy</i> .....	8		

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[www.aarda.org](http://www.aarda.org)



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Clinton Township,  
MI 48038

## OUR MISSION

The American Autoimmune Related Diseases Association (AARDA) is dedicated to the eradication of autoimmune diseases and the alleviation of suffering and the socio-economic 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 OF THE BOARD OF DIRECTORS

*Chair:* Rich Hodge

*Vice-Chair:* Lilly Stairs

*Secretary:* Michelle Ouellet

*Treasurer:* Nona Bear

*President & CEO:* Randall Rutta

## BOARD OF DIRECTORS

Stanley Finger    Mike Linn    Bob Phillips    Scott Selby

## ADVISORS TO THE BOARD OF DIRECTORS

David Bammert    Stephanie Hales    Robert Meyer, CPA

## SCIENTIFIC ADVISORY BOARD LEADERSHIP

*Chair:* Betty Diamond, M.D.



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# MESSAGE FROM PRESIDENT & CEO

As our nation rises to the extraordinary challenge of the novel coronavirus, COVID-19, the American Autoimmune Related Diseases Association wants you to know that we are in the fight. We are working to ensure that the needs of autoimmune patients and families — who are among the most vulnerable — are not forgotten or overlooked.

AARDA is meeting with key stakeholders and collaborating with partners to protect patient access to life-saving medicine and make certain that new health care policies and directives address the impact on autoimmune patients and caregivers. We also are developing alternative ways to deliver our programs, events and services to the autoimmune community.

In times of crisis, people look to their friends for support. AARDA is no different. We have relied on the generosity and kindness of friends for nearly 30 years. And now, more than ever, we need your support. With your help, AARDA can continue to be there for the autoimmune community in the difficult months ahead — driving awareness, leading patient education, pushing for more research, and advocating for the millions of Americans in need of a cure and ongoing treatment.

I am eager to continue the critical work ahead to advance AARDA's mission of eradicating autoimmune diseases and lead AARDA and our constituents through the challenging coming months. While the year has been difficult, our team at AARDA has remained resilient and dedicated, and even expanded with the addition of new staff. I'm proud of the work AARDA has accomplished, especially given the circumstances, and I look forward to the coming success of the new fiscal year.

**Randall Rutta, President & CEO**

# MAJOR CONTRIBUTORS IN FISCAL YEAR 2020

## MAJOR IN-KIND CONTRIBUTORS

Southwest Magazine  
Eli Lilly and Company  
BIO

iMD Health  
Context Strategies

Penn Quarters  
Sidley Austin

## INDIVIDUAL, CORPORATE, AND FOUNDATION DONORS

### Contributions \$20,000 & over

AbbVie Inc.  
Amgen USA  
Anonymous  
Biotechnology Innovation Organization  
Bristol-Myers Squibb Company  
Campaign for Medical Discovery  
Eli Lilly and Company  
Genentech, Inc.  
Horizon Therapeutics

Janssen Scientific Affairs, LLC  
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Merck & Co.  
Dianne Peterson  
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PhRMA  
Takeda Pharmaceuticals USA, Inc.

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

Anonymous  
Brave Dave Foundation  
Macon Callicott  
Robert A. Waller Foundation  
WABC TV

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

American Eagle Lifecare Corporation  
Anonymous  
Scott and Ann Barnhouse  
Nona Bear  
Steffi and Allan Bokser  
Marilyn Clague  
Community for Autoimmunity  
Mr. & Mrs. Nicholas Cullen  
Lori Ann Demple  
Mary Deters  
Duro Dyne National Corporation  
Linda Feist and Roger Junnila  
Akiva Flesher  
Michael Gallagher  
Elias Gottlieb-Schulze  
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Chris and Maggie Hatch  
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Immunovant, Inc.  
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Keith and Mary McJunkin  
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Phyllis Nazari  
Elizabeth Niemeyer  
Ann Pearson  
Rita and James Peterson

Caleb Powers  
Douglas and Linda Robinson  
Diana and Ronald Shepard  
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Robert Spofford  
Gregory Svorinich  
Vicki Tolari  
Alex Turner  
Raymond Welsh  
Jennifer and Bryan West  
Brian Williams  
David Zehnpfennig

### Contributions \$250 through \$999

Cheryl Akey  
Emily Alter  
Joanne Altes  
Anonymous  
Hazel Aquino  
Paige Bahloul  
Kassidy Baum  
Elaine Belter  
James Bookhamer  
Dr. John Bornhofen  
Nathaniel Bride  
Ann Brouse  
Susan Butler  
Stanley and Jeanne Cavitt  
Richard Chiburis and Alyson Tom  
Helen Chien  
Ed and Judy Christian  
Althea and Simon Cices  
Emma Coffey  
Jane Cogswell  
Shelia Cruz  
Jeffrey Davenhall  
Anthony and Julie Del Santo  
Joan De Milt Boddie  
William DeRousse  
Justine Devlin  
Donovan Family Charitable Fund  
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Andrew and Maryan Dunnet  
Penny and Phil Ehrlich  
Josh and Julie Einiger  
Robert Field  
Christy Frantz  
Eric Friedman  
Connie Goetzl  
David, Flora, Ali and Shlomo Goldsmith  
Greatest Commandments Foundation, Inc



# MAJOR CONTRIBUTORS IN FISCAL YEAR 2020

## INDIVIDUAL, CORPORATE, AND FOUNDATION DONORS

### Contributions \$250 through \$999

Christine Grindler	Cecelia Lance	Gretchen Schmidt
John and Mary Sue Gunzburger	Sarah Linhardt	Susan Smith
Anne Hammell	Helen Lopez	Pamela Stewart
Dr. Edward Hecker	John and Gail Maloney	Ashley Stipes
David Heleniak	Steve Martin	Craig and Nicolette Straley
Jan Hewlett	Eileen and Ward McCarthy	Maria and Tabettha Steiner
Randy and Dru Hickman	Richard McGrath	Vicki Summers
Ellen Hipsky	Carolyn Merryman	Jane Taft
Richard Hodge	Lynn Moloney	Marie Taylor
Jonathan Howard	Patrick Niemeyer	Valrie Thomas
Indie Lee & Co.	Debra O'Connell	Kathleen and Daniel Thornberry
Iota Elementary School 4-H Club	Richard Olson	Lauren Torres
Sharon Jacobs and David Cohan	Michelle Ouellet	Jeff and Joanne Urbanowski
Beth Johnson	William Padnos and Margery Kaye	Darin Wacs
Betty Jordan	Nisha Parikh	Lindsay Wagner
Gregory Kahles	Jinah Parker	Johnny Walylko
Geoffrey Karny	Lucille Parreno	Petra Weakley
Steve and Lynn Kieffer	Michael Reed	Marcie Weil
Kevin Kitze	Janis Reinschmidt	Adele Welty
Suzanne Klein	Anne Remington	Carol Lynn White
Brian and Amy Kobishop	Kim Rodriguez	Shirley Wisner
Rita Konetzka	Randall Rutta	Michele Wornow
Kurt Knight	James Ryan	Karen Yager-Rizzo
Phyllis Krattenmaker	Sarangan Sampath	ZS Associates
Ashley Krokowski and James Acierno	Linda Schafer	

### Payroll Campaigns, Matching Gifts & Online Giving

AbbVie Foundation Employee Engagement Fund	KPMG Gives
Aetna Foundation	Kroger Community Rewards Program
American Express	Medtronic Foundation Volunteer Grant Program
America's Charities	Merck
Applied Materials Foundation	New York Life
AT & T Corporate Employee Giving Programs	Pepsico Foundation Employee Giving Program
Bank of America Employee Giving Campaign	Pfizer Foundation Matching Gifts Program
Bank of America Matching Gifts	Pricewaterhouse Coopers LLP.
Battelle Foundation Fund of The Columbus Foundation	Shell Oil Company Foundation
Best Buy Employee Giving Program	The Capital Group Companies, Inc. Charitable Foundation
Blackbaud, Inc.	The Carlyle Group
Bright Funds Foundation	TIAA Serves
Charities Aid Foundation of America	TisBest Philanthropy
Chevron Matching Employee Funds	United Way California Capital Region
City of Seattle	United Way of Central and Northeastern Connecticut
Exelon Corporation	United Way of Central New Mexico
Fossil Group	United Way of Central New York
IBM	United Way of Greater Philadelphia & Southern New Jersey
JP Morgan Chase	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.

### 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 2020



## EDUCATION AND SUPPORT

At the beginning of the fiscal year, AARDA revamped and **expanded its Education Modules by launching a video library online**. Videos include a revised Basic Autoimmunity Module and four specialty categories: Dermatology, Gastroenterology, Neurology, and Rheumatic Autoimmune Diseases. To date, the new resources have been viewed over 20,000 times and served especially useful once the world pivoted to a virtual setting.

For people living with one or more autoimmune diseases, simply managing diagnosed conditions is often challenging. With the spread of COVID-19, new layers of difficulty compounded as patients struggled to access current, accurate information – especially guidance that addresses their unique health care circumstances and needs. Early on in the pandemic, AARDA recognized the need for timely, accurate information. The [COVID-19 resource page](#) launched in March 2020 with curated information on the COVID-19 coronavirus for the autoimmune community on steps to take to avoid contagion and, if infected, to manage the illness.

In April 2020, AARDA hosted a **National Briefing with the Centers for Disease Control and Prevention** and leading medical experts on the coronavirus and how it's impacting individuals with autoimmune diseases. The briefing resulted in a combined view of over 10,000 people touched by autoimmune disease. Due to the overwhelming response, AARDA created additional resources and FAQs to address the thousands of questions submitted through the event registration page.

AARDA also conducted a **National Webinar on Managing Stress and Promoting Well-Being in the Midst of a Pandemic**, featuring Board Member Dr. Bob Phillips as keynote speaker, expert patient and clinician presenters, and Board Vice-Chair Lilly Stairs moderating. The speakers provided empathy, hope, and practical coping strategies that are critical to this moment in time.



## AWARENESS

Throughout the last year AARDA received significant media coverage and was featured in several television, print and online channels, including two international televised segments. Topics spanned COVID-19 and autoimmunity, clinical trials, philanthropy, and pain management for people with autoimmune diseases. In March, AARDA also drove awareness through Autoimmune Disease Awareness Month with a special emphasis on advocacy.



## RESEARCH

For 50 million Americans living with autoimmune diseases, the focus on research and innovation is critical and potentially life-changing. The COVID-19 pandemic added a new level of urgency. Scientists are racing to develop a COVID-19 vaccine as well as transforming facilities to focus on testing and treatment options for people infected by the virus. Therapies to treat and prevent the novel coronavirus can't come soon enough.

Yet, research at companies, academic institutions, and health systems are supporting clinical trials of promising treatments that, due to the COVID-19 pandemic, have been interrupted, suspended, and otherwise challenged. This is a serious concern. Safely restarting this critical drug development pipeline will help deliver lifesaving medicines to some of our nation's most vulnerable patients. Read more about this urgency and the importance of continued forward progress on research in a recent op-ed in The Buffalo News.

AARDA remains committed to research through the Virginia T. Ladd Young Investigators Program which offers awards to support young researchers in basic autoimmune disease discovery. Currently, AARDA is supporting five dedicated researchers with two-year grants of \$20,000 each. In addition, Autoimmune Research Network – ARNet – supports patients in learning about and participating in clinical trial design and trials that may lead to breakthrough treatments. More than 18,000 individuals with one or more diagnosed autoimmune conditions are part of this network and that number continues to grow – nearly 100 new patients each month. These individuals are matched to researchers and given the opportunity to participate in trial design and/or clinical trials themselves, often receiving a stipend to take part. To participate, access: [www.aarda.org/who-we-help/patients/arnet/](http://www.aarda.org/who-we-help/patients/arnet/).

Our commitment is particularly relevant in the last year as we mourned the loss of Dr. Noel Rose, the “father of autoimmunity,” founding member of AARDA, and long-time Chair of AARDA's Scientific Advisory Board. He championed the AARDA mission and led the renowned Scientific Colloquia.



## ADVOCACY

### Let My Doctors Decide

AARDA continues to lead [Let My Doctors Decide](#), a national partnership of leadership organizations across health care working to ensure that treatment decisions will be made by patients and trusted health care professionals. Since its inception, Let My Doctors Decide has proven effective in helping consumers understand and navigate PBM practices. We especially aim to protect the patient and physician relationship from the damaging consequences of step therapy.

In November 2019, LMDD debuted [Escape the System: Stop the Madness of Step Therapy](#), an interactive exhibit that demonstrates the origins and negative consequences of step therapy for patients and practitioners through stories, quotes, facts and statistics, and a maze of step therapy obstacles all too familiar to patients, care partners, and advocates. The exhibit's Action Center engaged participants onsite and long-term, inviting them to endorse our principles, sign our petition, and opt-in to staying connected to collectively Stop the Madness of Step Therapy.

In May 2020, AARDA completed an [interactive virtual](#) component to our outreach, focusing on the Dermatology community, in part motivated by the cancellation in March of the American Academy of Dermatology national conference due to COVID-19. A comparable effort is underway to reach the Gastroenterology community. These efforts featured compelling stories and insights of AARDA Board members, patient advocates, clinicians, and LMDD member organizations.



## 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, 2020, 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

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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

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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

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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, 2020, 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.*

January 25, 2021

# STATEMENT OF ACTIVITIES



**American  
Autoimmune**

Related Diseases Association, Inc.

For the Year Ended September 30, 2020

	WITHOUT DONOR RESTRICTIONS	WITH DONOR RESTRICTIONS	2020 TOTAL
<b>Revenue and Other Support</b>			
Contributions	\$ 1,849,397	\$ 458,000	\$ 2,307,397
In-kind goods and services	962,556	0	962,556
Fundraising income - net of expenses of \$4,672	17,993	0	17,993
Loss on disposal of asset	14,387	0	14,387
Other income	1,187	0	1,187
Interest income	13,237	0	13,237
	<b>2,858,757</b>	<b>458,000</b>	<b>3,316,757</b>
Net assets released from restrictions	413,846	(413,846)	0
<b>Total Revenue and Other Support</b>	<b>3,272,603</b>	<b>44,154</b>	<b>3,316,757</b>
<b>Expenses</b>			
<i>Program services</i>			
Education	1,513,003	0	1,513,003
Public awareness	1,288,423	0	1,288,423
Research	274,457	0	274,457
<b>Total program services</b>	<b>3,075,883</b>	<b>0</b>	<b>3,075,883</b>
<i>Supporting services</i>			
Management and general	96,415	0	96,415
Fundraising	102,896	0	102,896
<b>Total supporting services</b>	<b>199,311</b>	<b>0</b>	<b>199,311</b>
<b>Total Expenses</b>	<b>3,275,194</b>	<b>0</b>	<b>3,275,194</b>
<b>Change in net assets</b>	(2,591)	44,154	41,563
<b>Net assets, beginning of year</b>	<b>\$ 914,671</b>	<b>\$ 320,632</b>	<b>\$ 1,235,303</b>
<b>Net assets, end of year</b>	<b>\$ 912,080</b>	<b>\$ 364,786</b>	<b>\$ 1,276,866</b>

# STATEMENT OF FUNCTIONAL EXPENSES



For the Year Ended September 30, 2020

	PROGRAM SERVICES			TOTAL PROGRAM SERVICES	SUPPORTING SERVICES		TOTAL
	Education	Public Awareness	Research		Management and General	Fundraising	
Wages	\$ 313,966	\$207,267	\$39,135	\$560,368	\$22,084	\$60,623	\$643,075
Professional fees	819,192	697,973	55,854	1,573,019	43,569	12,378	1,628,966
Postage/shipping	7,223	4,585	71	11,879	531	1,658	14,068
Public relations	10,000	15,000	0	25,000	0	0	25,000
Printing/stationery	11,624	6,592	46	18,262	54	2,904	21,220
Office supplies	1,408	1,401	0	2,809	469	60	3,338
Operating supplies	2,678	2,530	68	5,276	204	1,329	6,809
Dues/subscriptions	14,953	18,638	8,508	42,099	4,627	4,370	51,096
Filing fees	1,067	1,072	0	2,139	1,097	1,067	4,303
Rent	861	861	862	2,584	861	861	4,306
Equipment maintenance	1,916	1,548	268	3,732	111	843	4,686
Telephone	2,973	2,973	0	5,946	249	175	6,370
Insurance	1,544	1,544	0	3,088	1,478	1,544	6,110
State/national meetings	16,875	2,216	10,942	30,033	325	1,180	31,538
Travel	9,941	3,580	17,507	31,028	592	1,149	32,769
Depreciation	1,769	1,769	1,769	5,307	1,769	1,769	8,845
Payroll taxes	22,221	15,602	3,309	41,132	1,891	4,255	47,278
Insurance - Health	16,261	10,675	2,535	29,471	1,269	4,710	35,450
Fundraising -							
Bound by a Common Thread	0	0	0	0	0	4,672	4,672
Other	0	0	0	0	0	0	0
Board expenses	0	0	0	0	13,565	0	13,565
Professional training	23	23	0	46	99	82	227
Grants	1,500	1,500	130,000	133,000	0	0	133,000
Repairs/maintenance	7,164	4,559	0	11,723	651	651	13,025
Utilities	1,785	1,785	0	3,570	152	76	3,798
Miscellaneous	16	398	0	414	9	9	432
Retirement plan contributions	773	1,781	3,568	6,122	90	706	6,918
Website	7,067	4,488	0	11,555	236	236	12,027
Advertising/development	238,203	278,063	15	516,281	433	261	516,975
<b>Total Expenses by Function</b>	<b>\$ 1,513,003</b>	<b>\$ 1,288,423</b>	<b>\$ 274,457</b>	<b>\$3,075,883</b>	<b>\$ 96,415</b>	<b>\$ 107,568</b>	<b>\$3,279,866</b>
Less expenses included with revenues on the statement of activities	0	0	0	0	0	(4,672)	(4,672)
<b>Total expenses included in the expense section on the statement of activities</b>	<b>\$ 1,513,003</b>	<b>\$ 1,288,423</b>	<b>\$ 274,457</b>	<b>\$ 3,075,883</b>	<b>\$ 96,415</b>	<b>\$ 102,896</b>	<b>\$3,275,194</b>

# TRIBUTE TO DR. NOEL ROSE, “THE FATHER OF AUTOIMMUNITY”

We are so grateful for the outpouring of support received as we mourned the loss of Dr. Noel Rose (December 3, 1927 – July 30, 2020). Among his peers, Noel R. Rose, M.D. was a giant. To AARDA, he was a friend, mentor, advisor, leader and champion for nearly 30 years.

A prominent figure at Board of Directors meetings, public forums and Congressional briefings, in webinars and national and international conferences, Dr. Rose shared his vast knowledge and expertise with millions, always with great charm, clarity and his signature bow tie.

Dr. Rose was a founding member and served as chair of AARDA's Scientific Advisory Board. He led the renowned Scientific Colloquia; headed the AARDA-supported Center for Autoimmune Disease Research at the Johns Hopkins University Bloomberg School of Public Health; and championed the AARDA mission.

For his incomparable and dedicated service, AARDA presented Dr. Rose with its first Champion Award in 2016, named him an Autoimmune Hero in 2017, and last year renamed the series of scientific meetings he established and convened, the Noel R. Rose Scientific Colloquia. Dr. Rose received dozens of other honors and awards from prestigious institutions throughout his career. He was once nominated for a Nobel Prize, and was awarded the American Association for the Advancement of Science Golden Goose Award in 2019 for his pioneering work in autoimmunity.

“Words cannot express the magnitude of my feelings for this man who was both intellectually and in his personhood a giant,” says Virginia T. Ladd, AARDA founder, immediate past president, and current advisor to the president. “Noel Rose leaves an incredible legacy and will be remembered by AARDA and the autoimmune community. His willingness to always take time to respond to patient calls and emails, which he continued to do until last week, is a tribute to his respect for patients and their need for information.”

Dr. Rose was recognized as the “father of autoimmunity” for his groundbreaking discovery of thyroid autoimmunity in 1956. With this discovery, he would effectively establish the field of autoimmunology and usher in a new era of autoimmune disease research that today impacts one in every five Americans.

“Our patients with autoimmune diseases of the skin will remember [Dr. Rose] and will be forever grateful for his contributions in understanding their illnesses,” says Luis A. Diaz, M.D., UNC School of Medicine.

“He was one of those giants on whose shoulders we have all stood,” says Robert Eisenberg, M.D., professor emeritus, University of Pennsylvania, Division of Rheumatology.

“We have decided to name a session in the Congress of Autoimmunity after Noel R. Rose,” says Yehuda Shoenfeld, M.D., FRCP, MaACR, professor emeritus of the Zabludowicz Center for Autoimmune Diseases, Sheba Medical Center, Tel-Aviv University. “We will all remember and memorialize him.”

Noel R. Rose, M.D., Ph.D., was editor or co-editor of 23 books, most notably, “The Autoimmune Diseases”, a classic textbook, and published more than 880 articles and chapters in the fields of immunology, immunopathology, autoimmunity and autoimmune diseases. In addition, he authored several AARDA patient education brochures. He was 92.

