

Our Mission: To advocate for those affected by lupus and allied diseases through awareness and research program initiatives to improve quality of life.

Lupus Communiqué

Lupus and Allied Diseases Association, Inc.

Volume 11, Annual Edition 2014-2015

ANNUAL RESEARCH DONATION



Lupus Research Institute Chairmen Jack Lavery (left) and Robert Ravitz (right) and Annie Ravitz (center right) receive our Annual Research Donation of \$20,500 which represents a little over 1/3 of our annual income for 2014 from Lupus and Allied Diseases Association President & CEO Kathleen Arntsen (center left) on October 20, 2014 at the LRI Annual Scientific Meeting. We are extremely proud that we have invested \$270,000 over the past 13 years for novel, innovative and successful lupus research at the LRI.

Lupus and Allied Diseases Association, Inc. is a tax-exempt charitable organization eligible to receive tax-deductible contributions under IRS Code Section 501(c)(3). Our federal tax identification number is 16-1083229 and a copy of our latest annual report may be obtained upon request from us or The NYS Attorney General's Charities Bureau at 120 Broadway, NY, NY 10271.

Since we are no longer collecting membership dues, please consider Memorial and Tribute contributions to our organization. It is a wonderful way to honor or remember someone special in your life while also supporting the lupus cause. If you belong to a Service or Fraternal organization, or participate in a workplace-giving program such as: SEFA, UNITED WAY, IBM or other campaign, please remember to designate our organization.

EDITOR'S NOTE

Suggestions or comments on the newsletter are always welcome. Please contact us with any address changes or other corrections to ensure accuracy in the database. If an address is incorrect the Post Office will not deliver under their revised policies and the mail piece will be returned and we will be charged a fee. Please notify us immediately of any changes to avoid extra postal fees. As Technical Director I also invite your input and assistance in improving our organization's operations, especially in maintaining our website. Thank you.

Dave Arntsen

Lupus and Allied Diseases Association, Inc. is proud to be a member of the

- National Coalition of Autoimmune Patient Groups
- Lupus Research Institute National Coalition
- NIAMS Coalition
- Lupus Agencies of New York State
- NIAMS Lupus Federal Working Group
- Coalition for Accessible Treatments—CAT
- New York BIO
- BIO NJ
- New York State Rheumatology Society—NYSRS
- Patients for Biologics Safety & Access—PBSA
- New Yorkers for Accessible Health Coverage—NYFAHC
- Health Care for all NY—HCFANY
- Coalition for Clinical Trials Awareness—CCTA
- Alliance for Access to Innovative Therapies—AAIT



Beanie Bears \$10 each

The Lupus Communiqué

Is published once a year by
Lupus and Allied Diseases Association, Inc.
PO Box 170 Verona, NY 13478
Phone: 315-829-4272 or 1-866-258-7874

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DISCLAIMER

It is the policy of the Lupus and Allied Diseases Association, Inc. to publish articles on Lupus and related diseases that have been written by physicians, nurses, and other healthcare providers and medical professionals. The opinions and statements expressed by the authors or contributors to this publication do not necessarily reflect the opinions or positions of The Lupus Communiqué, or Lupus and Allied Diseases Association, Inc.

The material published herein is provided for informational purposes only and does not imply endorsement of any specific treatment, product, clinical trial, company or organization. We oppose self-diagnosis and self-treatment and urge readers to discuss any concerns they may have regarding diagnosis and treatment with their physicians. All rights reserved. No material in this issue may be copied or published without the express written consent of Lupus and Allied Diseases Association, Inc. Thank you.

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President's Message—

I realize that I usually begin my message with a poetic comment about the weather but as it is still snowing and frigid in late April in Central New York, I am at a loss for any prose that would be appropriate other than Seriously! Since it has been over a year since our last annual newsletter I would like to share our organization overview and accomplishments with you. As we previously told you the Board voted to transition the organization to build on our advocacy and research strengths.

We are proud to say that although it took longer than expected, Lupus and Allied Diseases Association name, address, mission, purposes and bylaws have all officially been approved. We are a passion driven, patient-focused, all-volunteer charitable organization dedicated to improving quality of life for those impacted by lupus and allied diseases and conditions of unmet need by fostering collaboration among stakeholders and promoting innovative and promising advocacy, awareness and biomedical research program initiatives.

Our organization believes it is critical for all health care stakeholders to collaborate on advocacy and research initiatives and that the patient voice must be included. We are very active on both the state and national level regarding health care reform and access issues that impact all Americans especially by providing stronger patient protections. Because lupus is a multi-system autoimmune disease and is unpredictable and highly individualized, having access to the full array of treatments is important to us. We are passionately committed to ensuring that all Americans receive the most appropriate therapies as directed by their treating providers and that drug development and discoveries continue to progress rapidly to improve quality of life. We are also expanding our collaborative efforts with other biopharmaceutical stakeholders to promote patient-centered care and to ensure public policy keeps pace with biomedical research innovation. We believe that medical research and development needs to be encouraged; not stifled by bureaucracies so that all individuals, regardless of race or socioeconomic status can live longer and healthier lives.

Now that we are a national organization and recognized as a strong grassroots collaborative group, we were invited to join several advocacy coalitions and provide public comments regarding important research initiatives. We have been and will continue to boldly insert ourselves into the research and development communities whenever possible to make sure a patient perspective is included. We are proud to say that organizations like BIO, NY BIO, BIO NJ, NYS Rheumatology and the American College of Rheumatology are visionaries and have welcomed patient advocates with open arms, but most organizations do not see patients as equal stakeholders. Patients like me who take nearly 40 drugs a day and deal with our complicated healthcare system daily have a wealth of information to share. "The patient perspective is powerful, passionate, persistent, persuasive and non-proprietary."

We are thrilled that we are in an era of patient-centric and patient-engaged initiatives. For decades the patient perspective was not welcome nor appreciated and basically ignored. Advocates like me fought tenaciously for the patient voice to be present and have an equal say in health care, research and development. Bearing witness to these achievements has brought a sense of pride and fulfillment to those of us who have been a catalyst of change in pushing for these endeavors. But things move far too slow and get lost in the politics and bureaucracy while individuals struggling to manage complicated, debilitating, volatile, and potentially fatal diseases of unmet need like Lupus and those who love, advocate for, and treat them continue to wait; we are impatient.

We may be a small organization but we are mighty. We are the lead group organizing The Lupus Agencies of NYS 6th Annual Awareness Day in May in both houses and have lupus education and research bills introduced. We just collaborated with the NYS Rare Disease Alliance, NORD and NY BIO for the 2nd Annual Rare Disease Day and helped procure legislative sponsors for a NYS Resolution and the entire group was recognized in both houses. We are a member of both NY BIO and BIO NJ now; attending both the NY BIO Advocacy Day and the BIO Fly-In in DC annually. We have attended NY BIO's Annual Scientific Meeting for 5 years now and participated as panelists and were honored to be guests at the BIO NJ Annual Meeting & Dinner. We just attended the American Autoimmune Related Diseases Association's Summit and I participated as a panelist in their Congressional Briefing on Biosimilars as well as the LRI Coalition's Annual Advocacy Event and the Reintroduction of the Patients' Access to Treatments Act in Washington, DC.

Advocacy has been and will continue to be a major part of our program services. We not only advocate for people affected by lupus and other diseases of unmet need but also for health care reform and patient access to care issues which affect each and every American including: the ACA implementation, protecting Medicare and Medicaid programs, ensuring strong patient protections exist, supporting NIH and biomedical research programs, commenting on FDA guidance for Biosimilars and other relevant issues, and advancing health information technology. If you have a personal story about a health care access issue that has impacted you or someone else then please share it with us.

We address access to care issues as they arise, often taking the lead to organize grassroots efforts within the state or nation. We are a lead group on advocacy efforts in NYS and have helped to coalesce 60 patient and professional groups to unite on these important efforts. We have also supported access issues in various states and have led and collaborated on national efforts. We sent comments on the 21st Century Cures and Senate Healthier Americans Initiative and led the effort for the entire lupus community to submit comments to the FDA on Patient-Focused Drug Development. I recently returned from the CDC Public Health Agenda for Lupus as a steering committee member. It has been a busy time but we remain committed to improving access to treatments and driving research and development forward with the patient as an equal stakeholder.

Our various community education programs are designed to empower people to become more proactive in their own health care and to become engaged in the public policy process. We continue to promote our "The Power of Advocacy—Promoting Participation to Improve Care" an informative presentation on how to become an effective personal and public advocate with an overview of current access and health policy initiatives and "Hope is on the Horizon" program to educate consumers on the importance of clinical research trials in getting new treatments to patients.

Our organization strongly supports innovative research initiatives that include cross-sector collaborations, public-private partnerships and robust basic, clinical and translational projects that enable scientists to: investigate disease pathogenesis and physiology, design better clinical trial methodologies, improve diagnostic tests, identify biomarkers, develop safer, more effective treatments, prevent complications, and ultimately, discover cures. We invite you to partner with us to accelerate biomedical research and development to ensure the next generation of lupus and autoimmune patients has a better quality of life and the opportunity to pursue their dreams.

On a sad note, Annie Ravitz passed away in January after courageously battling lupus for decades. The lovely daughter of Francine and Robert Ravitz, co-chairman of the LRI, Annie was an inspiration to all who knew her. David and I had the extreme honor of attending her celebration of life, surrounded by her beautiful family and loved ones. May her legacy live on through the tremendous research advances at the Lupus Research Institute.

We would like to recognize our Board Members who retired this past year: 1st Vice President and former Secretary Stephanie Darwak, and Directors Jaime Venditti and Julie Miner. We thank them for their support, dedication and volunteerism. Their input was vital in helping our organization grow into the advocacy powerhouse it is today. We wish them the best of luck in their endeavors. Thank you Ladies!

2014 was another record breaking year for the annual Golf Classic proceeds raising over \$74,000 with a net of \$57,000. We are very proud of the fact that we donate one-third of our revenue each year to lupus and autoimmune research. In the past 13 years we have donated \$270,000 to the Lupus Research Institute for novel research. We at The Lupus and Allied Diseases Association, Inc. are proud to play an active role and honored to represent you during these thrilling times. We are extremely thankful for your ongoing support; afterall, Lupus ends with US!

Hope for Warmer Weather and Be Well—Kathleen

LRI: Celebrating the 15 Years that Changed the Face of Lupus Research

"Every great advance in science has issued from a new audacity of the imagination."

John Dewey, philosopher

That guiding principle is what brings the Lupus Research Institute (LRI) to our 15th anniversary – a milestone in our history and in our future. To encourage scientists to take risks; to take away constraints to creativity; to fund the most novel and audacious research to understand, treat, prevent and cure lupus – that is what the Lupus Research Institute set out to do. And with all of your help – our scientists, our advisors, our donors, our patients and their dedicated families – we have turned lupus research upside down.

- \$200 million delivered for innovative, groundbreaking research. With an investment of \$50 million in original ideas, LRI leveraged over \$150 million in additional funding from the NIH and others to continue the novel research initiated with our grants.
- New talent and ideas to lead the field. LRI funded over 150 investigators from diverse disciplines, many working in lupus for the first time. Their new perspectives and expertise expanded the scope and ambition of lupus research.
- Deep understanding of human lupus. LRI pushed forward the scientific agenda by championing investigations in human lupus. Over half of LRI research focuses on cells and tissues from patients, generating deep knowledge of the human disease that directly informs the development of new medicines.
- Breakthrough discoveries to propel new treatments. LRI-funded discoveries on the immune system in lupus and how it damages vital organs such as the heart, kidney and brain have spurred the development of new treatments like belimumab. LRI advances in understanding lupus propel innovative targeted therapies now being tested in patients and even more following in the pipeline.
- Driving to prevention and cure. LRI's \$1 million Distinguished Innovator Awards, launched in 2012, challenge the global scientific community to uncover the root causes of lupus that drive to prevention and a cure.

Read more about how LRI's cornerstone strategy of funding innovative scientific ideas in lupus has more than demonstrated its power to make significant breakthroughs in understanding a complex disease. We now have the knowledge and tools to innovate across the full spectrum of lupus research – fundamental, human, translational and clinical research – to propel the delivery of new treatments and diagnostics to patients. At the LRI we will continue to turn lupus research upside down and push for the ultimate goals of prevention and cure. And at the same time, drive creative, new practical solutions so patients can be identified earlier, and treated with safer and more effective medicines to protect them from life-threatening organ damage.

Thank you for your support as we work to transform the lives of those with lupus today and to prevent and cure lupus tomorrow.

Investment in novel research

\$50 Million invested by LRI in novel research.

168 grants awarded to date—161 Novel Research Grants and 7 Distinguished Innovator Awards.

Leverage

Generated over \$200 Million for lupus research. LRI's investment of \$50 Million multiplied four-fold. LRI investigators have been awarded \$151 Million in extended funding, primarily from the National Institutes of Health.

Discoveries with impact

84% of investigators confirmed novel hypotheses, winning substantial follow-on funding or publishing in thought-leading scientific journals.

Over 350 published research papers credit LRI funding.

(LRI Article-continued)

Expanding the field

Over one-third of investigators come from other disciplines to work in lupus for the first time; 80% of those new-comers remain in the field long term.

LRI funded investigators at 75 institutions across 25 states, United Kingdom and Australia – an integrated, international network of investigators from diverse disciplines, all dedicated to novel research in lupus.

Sustained success

88% of projects remain active after the completion of the grant and continue to influence the field; even a decade after the original LRI investment, the majority of projects continue to deliver new insights and propel new therapies.

Human lupus biology

50% of LRI grants involve investigation of human tissue, blood or genetic material. These novel studies of human lupus biology provide new understanding directly relevant to the human disease that can be translated rapidly to new clinical applications.

- Source Lupus Research Institute February 26, 2015

See more at: http://lupusresearchinstitute.org/lupus-news/2015/02/26/2015-lri-%E2%80%93-impact-researchinnovation#sthash.4ZT9JAXf.dpuf

First Biosimilar Approved

Lupus and Allied Diseases Association President & CEO and National Patient Advocate Kathleen Arntsen gave public comments from a patient perspective regarding the difficulties of treating complex autoimmune disease patients on January 7th at the FDA Advisory Committee meeting reviewing the application for the first proposed biosimilar to NEUPOGEN, a biologic treatment for neutropenia.

Biologics are complex large molecule medicines manufactured from living organisms. Biosimilars are follow-on biologics and unlike generic copies of traditional small molecule drugs, biosimilars will be therapies that are similar to, but not the same as, the original product.

Among 18 public speakers, Kathleen expressed a prevailing viewpoint among patient stakeholders urging the FDA to require additional clinical trials, especially in subpopulations and post-marketing surveillance to be conducted to ensure safety, efficacy and tolerability. At the end of the meeting the Advisory Committee recommended that the FDA approve EP2006, as a lower-cost biosimilar to Neupogen, a biologic drug used to help cancer and autoimmune patients fight off infection while taking immunosuppressive drugs because of neutropenia.

On March 6, 2015 the U.S. Food and Drug Administration approved the first biosimilar drug Zarxio – a close copy of the existing biologic medication Neupogen. The approval of Zarxio has implications for lupus because it poses the possibility of FDA approving other biosimilars for biologic drugs used to treat lupus.

Our organization remains very vigilant in following the pathway to develop and regulate biosimilars and considers it a priority issue for all impacted by diseases of unmet need like lupus.

14TH ANNUAL LUPUS CHARITY GOLF CLASSIC

























GOLF CLASSIC WINNERS







What a day to break a record! The 14th Annual Lupus Charity Golf Classic was held on August 21st, 2014 -- an intermittently rainy day at Shenendoah Golf Club at Turning Stone Resort in Verona, NY. More than \$57,000 net and a new fundraising record was set to support our program services.

Closest to the Pin













Longest Drive









Shenandoah Golf Course at Turning Stone Resort

Thursday, August 20, 2015

Proceeds Benefit:

Lupus and Allied Diseases
Association, Inc.

A Premier Charity Golf Tournament

Registration - 11:30 AM Shotgun Start - 1:00 PM

Tournament Format: Captain & Crew 4-Person Scramble

LUNCH - GOLF - AWARDS BANQUET - PRIZES

Accepting Registration for:

Teams - Pairs - Individual Golfers Men, Women, Senior and Co-Ed Categories

Early Registration by July 17th \$175 per golfer

Registration after July 17th \$200 per golfer

Sponsorship Opportunities Available



Help to Make a Difference for those Affected by Lupus While enjoying a great round of golf

Honorary Chairman - Donald A. Raddatz, MD

Bassett Healthcare Rheumatologist

For more information on Registration, Sponsorships or Prize Donations
Call 315-829-4272 or e-mail lupusinnovators@aol.com
or visit our website www.nolupus.org

LUPUS ALLIED DISEASES Association, Inc.

FIFTEENTH ANNUAL LUPUS CHARITY GOLF CLASSIC AUGUST 20, 2015

Shenendoah Golf Course Turning Stone Resort Casino



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Other Donation – Please list
*All foursomes include 18 holes of golf w/cart, lunch, and dinner for four
For additional information call: 315-829-4272 or 1-866-2-LUPUS-4 or E-mail <u>LupusInnovators@aol.com</u>

Please make checks payable to: Lupus and Allied Diseases Association PO Box 170 Verona, NY 13478

An Invitation to Celebrate World Lupus Day

WHAT: Victorian Tea

WHERE: Your Home

WHEN: May 10, 2015

Recipe for a successful tea party:

1. Dust off the stove

- 2. Find the teapot (a mug & microwave will also work)
- 3. Cookies Optional
- 4. Turn off all phones and electronic devices
- 5. Kick off your shoes
- 6. Play your favorite music
- 7. Write out your donation check

Please consider supporting the Lupus cause this Spring by participating in our World Lupus Day Victorian Tea. Proceeds from this non-event will be used to fund our Organization's Program Services:

Newsletter Printing & Postage Lupus Awareness, Advocacy and Public Education Programs Continued Training to update our leaders on current information Distribution of lupus materials for awareness events Telephone hotline and website

Please make checks payable to:

Lupus and Allied Diseases Association PO Box 170 Verona, New York 13478



Thank you for your Consideration and Support!!!

The Lupus and Allied Diseases Association, Inc. is a tax-exempt charitable organization eligible to receive tax-deductible contributions under IRS Code Section 501(c)(3). Our federal tax identification number is 16-1083229 and a copy of our latest annual report may be obtained upon request from us or The NYS Attorney General's Charities Bureau at 120 Broadway, NY, NY 10271. For more information on our event please contact us by phone at 315-829-4272 or e-mail lupusinnovators@aol.com.

Memorials, Tributes, and Donations

Memorials

In Loving Memory of...

Bernie Carter-Bob & Cathy Walseman Isabel Woolshlager Jeffrey & Susan Virkler & Family Larry & Karen Woolshlager & Family

> Ethel Clark-Isabel Woolshlager

Wellington Walseman-Bob & Cathy Walseman

Douglas Kerr-Bob & Cathy Walseman

James McCarthy-Larry & Karen Woolshlager

> Eleanore Iglesias-Lisabeth Iglesias

Louis Smith Christine Marie Smith-Dave & Kathleen Arntsen

Marguerite Curri
Peter & Dorothy Curri
Angela "Aya" Lo Conti
Michael P. Jones
Elizabeth Jones
Rosemary FranklinDavid & Kathleen Arntsen

The Reverend S. Kenneth Arntsen-David & Kathleen Arntsen Marian J. Arntsen

Richard W. & Penny L. Cassin-Helen E. Cassin

> Barbara M. Porter-Helen E. Cassin John Zeock Bill & Sandi Frear

> > Joseph Jupin-Victoria Jupin

Bonnie J. Martin-Kay J. Falcone Memorials
In Loving Memory of...

Lorna E. Relf
Louis A. Relf
Sam Relf
Elva Fox
Arthur A. Relf
John & Alberta Bagley
Elmer & Alice BagleyJames & Patricia Mitchell
David & Kathleen Arntsen

Shawna Lynn Mitchell
James E. Mitchell
Mary Alice Mitchell
Harold Leach
Catherine Leach
James E. Mitchell
Elizabeth Mitchell
Thomas P. MitchellJames & Patricia Mitchell
David & Kathleen Arntsen

Isabell Zeock-John Zeock

Harold F. Woolshlager-Bob & Cathy Walseman Isabel Woolshlager Jeffrey & Susan Virkler & Family Larry & Karen Woolshlager & Family

Elwood Virkler-Jeffrey & Susan Virkler & Family

Anita Curtiss-Larry & Karen Woolshlager & Family

Jim, Mary Alice & Tom Mitchell-Jane Williams

Brooke N. Walseman-Bob & Cathy Walseman Isabel Woolshlager Jeffrey & Susan Virkler & Family Larry & Karen Woolshlager & Family Jack & Marcia Flint & Family

> Angelo J. "Joe" Marotta-Frank & Lyn Soja

Memorials, Tributes, and Donations

Memorials

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Brooke N. Walseman-Bob & Cathy Walseman Isabel Woolshlager Jeffrey & Susan Virkler & Family Larry & Karen Woolshlager & Family Linda Walseman

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Thomas & Sheila Sullivan
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Betty C. Fitzgerald-Bob & Cathy Walseman Larry & Karen Woolshlager

Mary Ellen DeCarlo-Peter DeCarlo & Family

Memorials

In Loving Memory of...

Christine M. Maziarz-Ed & Jennifer Ciecko Mr. & Mrs. Gregory Kaspiowicz Betty Frank Gregory Maziarz

> Erin Dewjea-Bill & Cecilia Sparks Michael Farkas

Christine A. MaddenStrategic Financial Services;
Alan & Connie Leist and
Alan & Nina Leist
Jay-K Independent Lumber Corp.
Mary Kazanjian
Alfred & Ruth Schulz
Joan F. Madden & Family

Oscar Mclain-Ellen C. Gloo

Bernice Birnbaum-Irene Fried

Tributes

In Loving Honor of...

Geri Lemke-Friends & Family, Virginia Merola

Monica & Rocco Falitico-Virginia Merola

Patricia Mitchell's Birthday-David & Kathleen Arntsen

James Mitchell's Birthday-David & Kathleen Arntsen

> Shane Perry-Marion Brooks

Memorials, Tributes, and Donations

Donations

CFC, SEFA, United Way, IBM, GE, Amex, United Health and Pfizer Employee Donor Plans Pfizer, Inc., Pharmaceutical Research & Manufacturers of America (PhRMA) Carnival Cruise Foundation PWR Strategies, Inc. Lupus Research Institute National Coalition GE Foundation Astellas Pharma US **AstraZeneca** Biotechnology Industry Organization NY State Correctional Officers & PBA— Marcy Sector Carbone **ΒΣφ** Alpha Iota Oneonta Chapter DTM^2 James & Patricia Mitchell Utica Professional Fire Fighters IAFF Local 32 Walmart Stores #1677 & #2285 & #6038 Family & Friends of Geri Lemke David & Kathleen Arntsen Buyer of Gold & Silver Coins & Jewelry Teague Accounting Xperts UFCW District Union Local ONE Americu Credit Union, Commercial Drive Branch Ellen Gloo Presto Print, LLC **Putnam Pest Control** Raquel Rosen, MD Scharf Plumbing & Heating Arthritis Health Associates Assemblyman Anthony Brindisi Rocco & Monica Falitico in Honor of Roxanne Rick & Kathryn Voskuil Rick Devulio Gates-Cole Insurance Edward B. Lee, MD

Tony & Anna Maria Maritato

MCORP—Dan & Lisa Mitchell

NY State Iron Workers

Pierce Auto Parts

Sea Shell Inn Waterfront Restaurant

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Brigiette Williams
Bob Walseman & Isabel Woolshlager

World Lupus Day Tea

David & Kathleen Arntsen Rocco & Monica Falitico Tom & Jackie Taylor Larry & Kathy Scharf Richard & Helen Lenart **Donald & Sharon Lust** Laurie Domanico Jack & Marcia Flint & Family in honor of Cathy Walseman Bill & Sandi Frear Robert & Jennifer Porter James & Patricia Mitchell Phil & Kathy Teague Ellen Gloo Frank & Stephanie Darwak Dale & Maryrose Bullock Frank, Mary & Carl Della Posta Frances S. Eck Cvnthia Donaldson Elisabeth Hawkins John & Anne McQuaid Jane Williams Victoria Jupin Jerry & Georgie Porter Helen Cassin



























AWARENESS AND ADVOCACY IN ACTION



