



annual report 2016

message from CEO

Dear friend,

I am pleased to present to you the 2016 Mesothelioma Applied Research Foundation's annual report, including its audited financials. All of us, including myself, our board of directors, our science advisory board, our dedicated staff, and our volunteers, can be proud of the organization we have built.

Starting with the finances, this is an organization that continues to raise over 65% of its funding from individuals. Now, more than ever, we depend on our individual donors and appreciate their investment into our work. We are proud to spend 83% of every dollar we raise on our programs: research, education, support, and advocacy. Only 5% is spent on management, and 12% on fundraising. In the nonprofit world, such numbers display exceptional fiscal responsibility as evidenced by the highest marks given to us by third-party charity evaluators such as Charity Navigator.

Over the last year, we have continued our focus into providing patients and their families with what they need most: advice, guidance, information, support, and in some cases, financial help. Our Travel Grant Program has helped 36 of our community members who needed to travel away from home to be seen and treated by mesothelioma experts.

In the field of research, the Meso Foundation continues investing into seed grants, providing researchers with the incentive to work in the field of mesothelioma and be innovative in their work. This year we funded four promising research studies bringing our total research funded to date to \$9.8 million. In addition, our advocacy work has brought another \$2.7 million to mesothelioma researchers.

Finally, I wish to extend a huge and heartfelt thank you to this community that comes together, helps one another through the difficult stages of a mesothelioma diagnosis, sometimes even through heartbreaking loss, and does so selflessly and generously. Our community members choose to participate in various ways -- by leading support groups, providing peer-to-peer support, volunteering their time in the office or on Capitol Hill, by organizing fundraisers, to name a few. In 2016, our community members organized 42 events raising over \$290,000.

We truly couldn't do this work without all of you. Thank you again from the bottom of our hearts.



Melinda Kotzian, Chief Executive Officer
Mesothelioma Applied Research Foundation

The Meso Foundation is a nationally-recognized nonprofit organization. Third-party charity evaluators have rated the Meso Foundation as a top charity for good governance, sound fiscal management and commitment to accountability and transparency. No other organization working within the field of mesothelioma has such credentials.



Charity Navigator awarded the Meso Foundation a 4-star (out of 4 stars) rating.



In 2016, as a result of 65 positive reviews, GreatNonprofits rated the Meso Foundation as a Top-Rated Nonprofit.



The Meso Foundation is also accredited by the Better Business Bureau and the Independent Charities of America. More information about our most current accreditations is available at curemeso.org/accreditations.



The Foundation has been vetted by the National Cancer Institute (NCI) and is listed on their website as a resource.

Chief Executive Officer

Melinda Kotzian

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(703) 879-3825

Executive Director

Mary Hesdorffer, Nurse Practitioner

mary@curemeso.org
(703) 879-3820

Board of Directors

Volunteer members of the board of directors of the Meso Foundation are responsible for the organization's long-term financial stability and integrity and for governing the Foundation and setting its strategic direction and broad policy directives.

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University of Maryland Medical Center

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University of Pittsburgh

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Eric Witkin, Esq.
Rye, NY

Dennis Wigle, MD
Mayo Clinic

In Memoriam
Congressman Bruce F. Vento

Science Advisory Board

Our science advisory board is comprised of clinicians and researchers who work within the mesothelioma field around the world. Members of the SAB are volunteers. They are expected to review and score the applications submitted for our research grants. They are also called upon for expert opinions and advice on scientific matters on behalf of the Meso Foundation.

Tobias Peikert, MD, Chair
Mayo Clinic

Brad Black, MD
Center for Asbestos Related Disease

Alain Borczuk, MD
Columbia University

V. Courtney Broaddus, MD
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Marc de Perrot, MD
University Health Network

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University of Vermont College of Medicine

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Vercelli/Borgosesia Hospitals

Anna Nowak, PhD
University of Western Australia

Jeremy Steele, MD
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David Sugarbaker, MD
Brigham & Womens Hospital

Anish Thomas, MD
National Cancer Institute

Anne S. Tsao, MD
MD Anderson Cancer Center

Kiran Turaga, MD
Medical College of Wisconsin

James Urbanic, MD
UCSD Moores Comprehensive Cancer Center

Haining Yang, MD, PhD
Cancer Research Center of Hawaii,
University of Hawaii

Marjorie Zauderer, MD
Memorial Sloan-Kettering Cancer Center

The Meso Foundation is the only 501(c)3 non-profit organization dedicated to eradicating mesothelioma and easing the suffering caused by this cancer. The Meso Foundation actively seeks philanthropic support to:

- Fund the highest quality and most promising mesothelioma research projects from around the world through our rigorous peer-reviewed process;
- Help mesothelioma patients connect with national mesothelioma experts and obtain the most up-to-date information on treatment options;
- Advocate in Washington, DC for federal mesothelioma research funding to stop this national tragedy.

The following financial information is compiled from the Meso Foundation's 2016 audited financial statements.

Public Support and Other Income	2016	2015
General Contributions	\$ 1,888,337.00	\$ 1,753,314.00
Investment Income	\$ 43,505.00	\$ (54,684.00)
Total	\$ 1,931,842.00	\$ 1,698,630.00

Expenses	2016	2015
Research	\$ 573,344	\$ 440,426
Education, Support, Awareness	\$ 883,308	\$ 962,513
Advocacy	\$ 228,903	\$ 192,936
Fundraising	\$ 241,626	\$ 329,923
Management	\$ 98,891	\$ 118,650
Total	\$ 2,026,072	\$ 2,044,448

Total Assets at end of year \$ 2,459,767.00

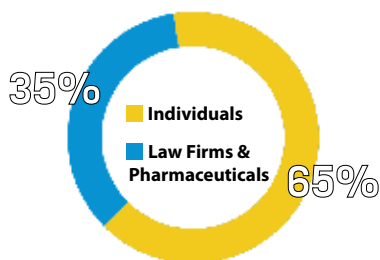
\$9.8 million
in mesothelioma research grants funded

103 studies
funded through the research grant program

\$12.4 million
in government funding directed to mesothelioma research

\$0.83 cents
of every dollar donated goes to programs

WHERE THE MONEY COMES FROM



The Meso Foundation receives 65% of its donations from individual donors and 35% from law firms and pharmaceutical companies.

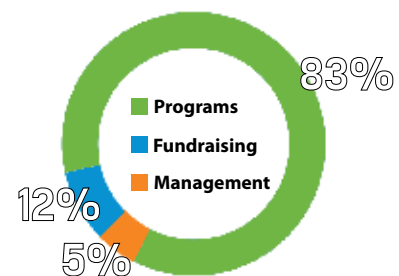
600 people
helped every month, including patients, caregivers, and bereaved

527 proposals
submitted to the research grant program

240 articles
resulted from Meso Foundation funding

83 journals
published research funded by the Meso Foundation

HOW THE MONEY IS USED



The Meso Foundation uses 86% of donations received to support its programs, 9% on fundraising, and 5% on management.



The Mesothelioma Applied Research Foundation funds critically-needed research to eradicate mesothelioma as a life-ending disease. The Foundation's Science Advisory Board (SAB) members, comprised of leading mesothelioma physicians and researchers from around the world, use their expertise to review and rank grant proposals submitted by their peers. Based on the funds generously donated to the Meso Foundation, the Board of Directors awards grants to the most promising projects.

In 2016, four grants were awarded, bringing the Meso Foundation's total research funded to \$9.8 million.



Dr. Prasad Adusumilli, Memorial Sloan Kettering Cancer Center

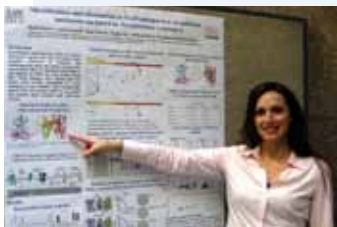
Craig Kozicki Memorial Grant

CAR T cells with TGF- β resistant cell-intrinsic strategies for mesothelioma



Dr. Antonio Giordano, Temple University

PRMT5 as two-in-one strategy for mesothelioma treatment



Dr. Ronit Mazor, National Cancer Institute

Improving Immunotoxin therapy of mesothelioma



Dr. Dan Sterman, New York University School of Medicine

The Lance S. Ruble, Donald E. Smitley, Craig S. Kozicki & Ferraro Law Firm Research Grant

Lymph Node Immunophenotyping In Malignant Pleural Mesothelioma

Patient Support Services

In 2016, our patient support services were the cornerstone of our Education and Support Program. Our on-staff experts provided patients with personalized consultations to:

- Identify a mesothelioma specialist if needed
- Review your treatment options to choose the best one for you
- Advise you regarding symptom-management and side-effects
- Understand the basics of the disease and the complex medical terms
- Connect with other mesothelioma patients
- Obtain financial aid

Support Groups

Our support groups, provided monthly by telephone for patients, caregivers, and those who have lost a loved one to mesothelioma, were complemented by our online groups.

Conferences

In 2016, the Mesothelioma Applied Research Foundation took its signature Symposium on the road. As such, we held three conferences in three distinct parts of the country: Houston, San Francisco, Chicago. The main purpose was to provide patients and their families the opportunity to learn from experts in the field, without the requirement of extensive travel and expenses. The conferences were very successful with a total of nearly 300 attendees.

Meet the Mesothelioma Experts

The Meso Foundation held two Meet the Mesothelioma Experts live broadcasts with Dr. Raphael Bueno and Dr. Marjorie Zauderer. They attracted 670 listeners between the live audience and on-demand listeners.

Travel Grants

In 2016, the Foundation awarded 36 grants to help patients with travel to receive treatment.

Tribute Ceremonies for Bereaved Communities

Tribute to Life Ceremonies were held in Baltimore and San Francisco and saw 80 community members in attendance.



Congressionally Directed Medical Research Program (CDMRP), through the Department of Defense (DoD)

In 2016, the CDMRP's Peer-Reviewed Cancer Research Program, which houses merit-based funding for several cancers, including mesothelioma, was once again renewed at \$50 million. The program had seen a 50% increase just a year prior, from \$25 to \$50 million. Mesothelioma researchers were able to obtain a total of \$2.67 million among four investigators. This brought the total mesothelioma research funding by the DoD to \$12.4 million. This funding was made possible by the Mesothelioma Applied Research Foundation's advocacy, which in 2008 facilitated the addition of mesothelioma as an eligible condition for funding.

Coalitions and Partnerships

Mesothelioma is this organization's sole focus. However, in the grand scheme of things, we realize that this cancer is categorized as a rare cancer. As such, we have focused much energy on fostering and expanding important coalitions and partnerships to help us achieve our common goals. Some of our collaborators in 2016 have been: the Deadliest Cancers Coalition, the National Organization for Rare Disorders, the International Association for the Study of Lung Cancer, One Voice Against Cancer, Sheet Metal Occupational Health Institute Trust, International Association of Heat and Frost Insulators and Allied Workers, International Mesothelioma Interest Group, National Health Council, Friends of Cancer Research, National Comprehensive Cancer Network, Coalition for Health Funding, American Society of Clinical Oncology, International Thoracic Oncology Nursing Forum, National Patient Advocate Foundation.

Mary Jo Lawyer Spano Mesothelioma Patient Registry Act of 2015

The Mary Jo Lawyer Spano Mesothelioma Patient Registry Act of 2015 was introduced by Representative Katko of New York in 2015. In 2016, we continued promoting the bill among congressional representatives in order to drum up support for it. Although we successfully signed on almost 40 co-sponsors, the bill ultimately ended along with the 2016 congressional term. The nature of the 2016 election was such that no energy was left within the political system to focus on this bill. Representative Katko promised to re-introduce it in the subsequent Congress.

The Mary Jo Lawyer-Spano Patient Registry Act of 2015 became reality as a result of a meeting two years earlier between Rep. Katko and a community member of the Mesothelioma Applied Research Foundation, Ms. Meg Meccariello. At that time, Ms. Meccariello was herself a mesothelioma patient, had a sister just diagnosed with mesothelioma, and had already lost her father and another sister, Mary Jo Lawyer Spano, to mesothelioma a few years prior. Needless to say, her story and the urgent need for life-saving treatments resonated with Congressman Katko.

Currently, there is no formal federal registry to keep track of mesothelioma patients' demographics or other important information that could help identify gaps in current mesothelioma treatment. The SEER registry isn't useful for mesothelioma patients, as they die before data is fully captured by the Centers for Disease Control and Prevention (CDC).

The profound impact of patient registries has been demonstrated in other diseases (such as gastrointestinal stromal tumors, Gaucher's disease, newborn screening for inborn errors of metabolism, interstitial pulmonary fibrosis, and muscular dystrophy) which, following their implementation, have seen an acceleration in treatment development and acceleration toward cures.

In 2016, our community members hosted 42 events raising over \$290,000 for the Meso Foundation. Thank you for all of your hard work and dedication!



Thank you!

\$100,000 +

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