



Mesothelioma Applied[®]
Research Foundation

research - education - support - advocacy

ANNUAL REPORT

2015



2015

curemeso.org[®]

MESSAGE FROM CEO

Dear supporter,

I am pleased to present to you the 2015 Mesothelioma Applied Research Foundation's annual report, including its audited financials. As we continue the life-saving work to eradicate mesothelioma, this organization, its leadership, board of directors, science advisory board, and staff are all dedicated to maintaining the highest level of accountability and transparency.

Our effort in this regard is praised through third-party charity evaluators who continue to award us the highest grades and accolades for this organization's financial responsibility. You can read more about it on page 4 of this publication.

In line with its mission, in 2015, the Foundation awarded five research grants to worthwhile projects selected by a strict peer-review process conducted by the Science Advisory Board. We also funded a portion of the staging project led by Dr. Valerie Rusch, which has resulted in updated staging beginning in 2017.

Our patient support and education program saw several areas of growth in 2015. In particular, participation in our support groups and our travel grants program has grown dramatically.

In 2015, we organized two conferences to help patients obtain up-to-date information from top experts in mesothelioma; our main Symposium was held in partnership with the National Cancer Institute on the campus of the National Institutes of Health, while the second conference was held in New York City at the Memorial Sloan Kettering Cancer Center. For the second year in a row, we also facilitated the exchange of information on a scientific level by hosting a special conference for researchers, clinicians, and other medical professionals working in the field.

In 2015, advocacy gave us much hope with the patient registry bill (more on pg. 7).

All this work, and much more that couldn't be mentioned because of space restrictions, is only possible because of donors like you, who believe that a world without mesothelioma is a much better world, and a world that we owe to our children.

From the bottom of my heart, thank you for your continued support.

With gratitude,



Melinda Kotzian, Chief Executive Officer
Mesothelioma Applied Research Foundation

Melinda Kotzian
Chief Executive Officer
mkotzian@curemeso.org
(703) 879-3825

Mary Hesdorffer, Nurse Practitioner
Executive Director
mary@curemeso.org
(703) 879-3820

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2015**

BOARD OF DIRECTORS

Volunteer members of the Meso Foundation's board of directors are responsible for the Meso Foundation'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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In Memoriam
Congressman Bruce F. Vento

SCIENCE ADVISORY BOARD

Our Science Advisory Board (SAB) 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.

H. Richard Alexander, MD, Chair
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Cancer Research Center of Hawaii,
University of Hawaii

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FINANCIALS 2015



ABOUT THE MESO FOUNDATION

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 D.C. for federal mesothelioma research funding to stop this national tragedy.

The following financial information is compiled from the Meso Foundation’s 2015 audited financial statements.

Public Support and Other Income	2015	2014
General Contributions	\$ 1,753,314.00	\$ 1,689,278
Investment Income	\$ (54,684.00)	\$ 29,419
Total	\$ 1,698,630.00	\$ 1,718,697

Expenses	2015	2014
Research	\$ 440,426	\$ 660,544
Education, Support, Awareness	\$ 962,513	\$ 906,471
Advocacy	\$ 192,936	\$ 81,697
Fundraising	\$ 329,923	\$ 129,627
Management	\$ 118,650	\$ 301,159
Total	\$ 2,044,448	\$ 2,079,498

Total Assets at end of year \$ 2,404,543.00



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.

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.

In 2014, as a result of 65 positive reviews, **GreatNonprofits** rated the Meso Foundation as a Top-Rated Nonprofit.

RESEARCH

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.

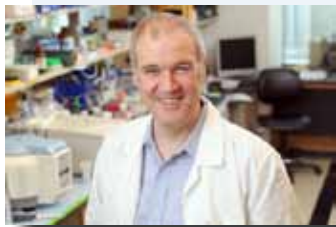
In 2015, five grants were awarded, bringing the Meso Foundation's total research funded to \$9.4 million.



Dr. Andrea McClatchey, Massachusetts General Hospital
Exploiting Nf2/Merlin as a therapeutic biomarker for mesothelioma



Dr. El Bachir Affar, Hôpital Maisonneuve-Rosemont
Identifying cellular vulnerabilities for the treatment of mesothelioma



Dr. Sean Carlin, Memorial Sloan Kettering Cancer Center
Novel CXCR4-targeted theranostic compounds for mesothelioma



Dr. Jill Ohar, Wake Forest University
Familial Mesothelioma: Beyond BAP1



Dr. Carlo Follo, University of California, San Francisco
The role of autophagy and its modulation in the treatment of mesothelioma

EDUCATION AND SUPPORT

In 2015, the Mesothelioma Applied Research Foundation continued growing its education and support services, and began the process of evaluating them and improving them as needed. To keep up with demand for services, the Foundation added a new staff member to focus specifically on patients' (and their caregivers' and families') needs. In 2015, our support groups have seen a 60% increase in participation. Another area of significant growth has been our travel grant program. In 2015, the Foundation gave out \$33,000 toward patient travel to and from clinical trials and specialist visits, increasing the number of grants given by nearly 20%.

Mary Hesdorffer, APRN, Meso Foundation's executive director and expert nurse practitioner, provides one-on-one medical 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

The Meso Foundation also provides:

- support groups, including in-person, telephonic, and online
- national and regional conferences covering malignant mesothelioma
- 'Meet the Mesothelioma Experts' Live Interview Series
- online and printed materials providing both education and support
- support services for the bereaved community



MARY JO LAWYER-SPANO PATIENT REGISTRY ACT OF 2015

In March of 2015, a Meso Foundation advocate, Meg Meccariello, met with her member of Congress, John Katko. Being a mesothelioma patient herself, having a sister with mesothelioma, and having lost her father and another sister, Mary Jo Lawyer Spano, to mesothelioma, Meg immediately caught Congressman Katko's attention. It so happened that the Congressman knew Mary Jo well, and even attended her funeral. As a result of this meeting, Meg worked with Congressman Katko's office to introduce the Mary Jo Lawyer-Spano Patient Registry Act of 2015, a bill meant to provide a national mesothelioma patient registry.

Currently, there is no formal federal registry to keep track of mesothelioma patients, their demographics, and other important information that could help identify gaps in current mesothelioma treatment. 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, muscular dystrophy and many others; which, following their implementation, have seen an acceleration in treatment development and acceleration toward cures.

Though Meg Meccariello died in November of 2015, the bill that started out of her advocacy, continued its path through Congress.

By the end of 2015, the bill was supported by in Congress by John Katko (NY), Jan Schakowsky (IL), Chris Collins (NY), Betty McCollum (MN), Pete King (NY), Joe Kennedy (MA), Leonard Lance (NJ), Mark Pocan (WI), Nita Lowey (NY), Pete Visclosky (IN). Outside of Congress, dozens of scientists and organizations signed on as official supporters, including: International Association of Heat and Frost Insulators and Allied Workers, Lung Cancer Foundation, American Federation of Labor and Congress of Industrial Organizations (AFL-CIO), The Life Raft Group, Cedars-Sinai Medical Center, University of Pittsburg School of Medicine, American Lung Association, NYU Langone Medical Center, Queens College, Icahn School of Medicine, Lung Cancer Alliance, Wayne State University School of Medicine, Lung Cancer Association, Mesothelioma Applied Research Foundation, University of Pittsburgh School of Medicine, University of Pittsburgh Medical Center, International Association for the Study on Lung Cancer (IASLC), The Cleveland Clinic, H. Richard Alexander, MD, Chair, University of Maryland School of Medicine, Francine Baumann, PhD, University of Hawaii, Michael Becich, MD, University of Pittsburgh, Brad Black, MD, Center for Asbestos Related Disease, Alain Borczuk, MD, Weill Cornell University Medical Center, Helen Clayson, MD, University of Strathclyde and Glasgow Caledonian University, V. Courtney Broaddus, MD, University of California San Francisco, Marc de Perrot, MD, University Health Network, Margaret Huflejt, PhD, New York University, School of Medicine, Brooke Mossman, PhD, University of Vermont College of Medicine, Luciano Mutti, MD, PhD, Salford University, Anna Nowak, PhD, University of Western Australia, Jeremy Steele, MD, St. Bartholomew's Hospital, David Sugarbaker, MD, Baylor School of Medicine, 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, Dennis A. Wigle, MD, PhD, Mayo Clinic, Haining Yang, MD, PhD, Cancer Research Center of Hawaii, University of Hawaii, Marjorie Zauderer, MD, Memorial Sloan Kettering Cancer Center, Steve Albelda, University of Pennsylvania Medicine, Paul Baas, University of Amsterdam, Courtney Broaddus, University of California, San Francisco, Dean Fennell, University of Leicester, Rabab Gaafar, Cairo University, Marie-Claude Jaurand, Institut National de la Santé et de la Recherche Médicale (INSERM), Hedy Lee Kindler, University of Chicago, Sakari Knuutila, University of Helsinki, Steven Mutsaers, University of Western Australia, Luciano Mutti, Salford University, Takashi Nakano, Hyogo College of Medicine, Japan, Harvey Pass, NYU Langone Medical Center, Bruce Robinson, National Centre for Asbestos Related Diseases, Australia, Jeremy Steele, St Bartholomew's Hospital, London, Daniel Serman, NYU Langone Medical Center, Jim teWaterNaude, University of Cape Town, Walter Weder, University Hospital Zurich, Sam Armato, University of Chicago, Arnaud Scherpereel, University Hospital of Lille

AWARDS 2015



Bruce Vento Hope Builder Award honored President James Grogan of the Insulators and Allied Workers Union



Miriam Ratner received the Klaus Brauch Volunteer of the Year Award



Dr. Valerie Rusch was the recipient of the Pioneer Award.



Joanne Redondo was the recipient of the June Breit and Jocelyn Farrar Outstanding Nurse Award.



Reverend George Winchester received the Compassion Award.

COMMUNITY





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