



# annual report 2017

**The Mesothelioma Applied Research Foundation is the only 501(c)(3) nonprofit charity organization dedicated to ending mesothelioma, and the suffering this cancer causes, through:**

- **funding research to improve treatment options;**
- **providing treatment support and education for patients and their families;**
- **advocating for federal funding of research.**

## **Chief Executive Officer**

**Melinda Kotzian**

[mkotzian@curemeso.org](mailto:mkotzian@curemeso.org)

(703) 879-3825

## **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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*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.

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The following financial information is compiled from the Meso Foundation's 2017 audited financial statements.

Public Support and Other Income	2017	2016
General Contributions	\$ 1,318,448	\$ 1,888,337
Investment Income	\$ 130,208	\$ 43,505
<b>Total</b>	<b>\$ 1,448,656</b>	<b>\$ 1,931,842.00</b>

Expenses	2017	2016
Research	30% \$ 644,073	\$ 573,344
Education, Support, Awareness	44% \$ 962,040	\$ 883,308
Advocacy	10% \$ 211,764	\$ 228,903
Fundraising	12% \$ 257,927	\$ 241,626
Management	5% \$ 99,712	\$ 98,891
<b>Total</b>	<b>\$ 2,175,516</b>	<b>\$ 2,026,072</b>

**Total Assets at end of year \$ 1,943,700.00**

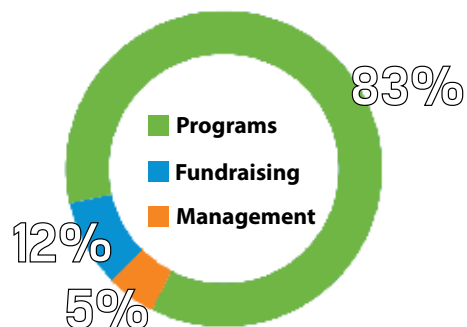
**\$10 million**  
in mesothelioma research grants funded

**106 studies**  
funded through the research grant program

**\$15.1 million**  
in government funding directed to mesothelioma research

**\$0.83 cents**  
of every dollar donated goes to programs

### 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.

With the conclusion of its latest funding cycle, the Mesothelioma Applied Research Foundation has reached the milestone of \$10 million in grant funding awarded to the most promising mesothelioma research projects across the globe. This Foundation is the only non-governmental institution to fund mesothelioma research through a transparent, merit-based process modeled after the National Institutes of Health.

The research funded so far spans across most areas of mesothelioma science covering topics such as validation of biomarkers, development of tools for objective measurement of mesothelioma tumors, immunotherapy, gene therapy, radiation therapy, genetics, mesothelioma prevention, and much more.

In 2017, the Foundation funded two projects, one looking into the efficacy of a cancer blocking agent specifically for mesothelioma, and the other consists of pre-clinical testing of a new target for mesothelioma treatment.

The two projects titled 'Blocking post-translational modifications of p27 for mesothelioma therapy' and 'gC1qR/HABP1/p32: A novel therapeutic target for mesothelioma (The Mary Hesdorffer Research Fund)' will be investigated by researchers at the New York University School of Medicine and Memorial Sloan Kettering Cancer Center, respectively.

# 2017 RESEARCH

## **Manzanares, Miguel**

New York University School of Medicine

*Blocking post-translational modifications of p27 for mesothelioma therapy*

The Mary Hesdorffer Research Fund

## **Peerschke, Ellinor**

Memorial Sloan Kettering Cancer Center

*gC1qR/HABP1/p32: A novel therapeutic target for mesothelioma*

## Patient Support Services

In 2017, our patient support services included personalized one-on-one 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 online and by telephone, served 886 patients, caregivers, and those who have lost loved ones.

## Conferences

In 2017, the Mesothelioma Applied Research Foundation held its signature 3-day conference in Bethesda, MD, in conjunction with the National Cancer Institute, on the campus of the National Institutes of Health.

## Meet the Mesothelioma Experts

The Meso Foundation held two Meet the Mesothelioma Experts live broadcasts featuring Dr. Dan Sterman of NYU and Aduro Biotech, a pharmaceutical company with a new clinical trial.

## Travel Grants

In 2017, the Foundation awarded nearly \$40,000 in travel assistance to 35 grant recipients to help them access expert consultations and cutting-edge treatment.



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

In 2017, 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. Mesothelioma researchers were able to obtain a total of \$1.57 million among four investigators. This brought the total mesothelioma research funding by the DoD to \$19.4 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 2017**

The Mary Jo Lawyer Spano Mesothelioma Patient Registry Act of 2015 was re-introduced by Representative Katko of New York in 2017 changing its name to the Mary Jo Lawyer Spano Mesothelioma Patient Registry Act of 2017.

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 2017, our community members hosted 46 events. Thank you for all of your hard work and dedication! Below, we included some event photos along with a few from the Symposium.***





# Thank you!

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