



# annual report 2018

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

**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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Rochester Hills, MI

*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*  
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Kiran Turaga, MD, MPH  
University of Chicago School of Medicine

Walter Weder, MD  
University Hospital Zurich

The following financial information is compiled from the Meso Foundation's 2018 audited financial statements.

Public Support and Other Income	2018		2017	
General Contributions	\$	1,185,273	\$	1,318,448
Investment Income	\$	(50,198)	\$	130,208
<b>Total</b>	<b>\$</b>	<b>1,135,075</b>	<b>\$</b>	<b>1,448,656</b>

Expenses	2018		2017	
Research	17%	\$ 242,829	30%	\$ 644,073
Education, Support, Awareness	50%	\$ 736,716	44%	\$ 962,040
Advocacy	11%	\$ 159,577	10%	\$ 211,764
Fundraising	14%	\$ 208,214	12%	\$ 257,927
Management	8%	\$ 117,675	5%	\$ 99,712
<b>Total</b>	<b>\$</b>	<b>1,465,011</b>	<b>\$</b>	<b>2,175,516</b>

Total Assets at end of year \$ 1,613,764.00

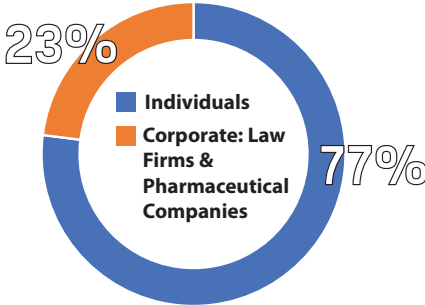
**\$10.2 million**  
in mesothelioma research grants funded

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

**\$21.7 million**  
in government funding directed to mesothelioma research

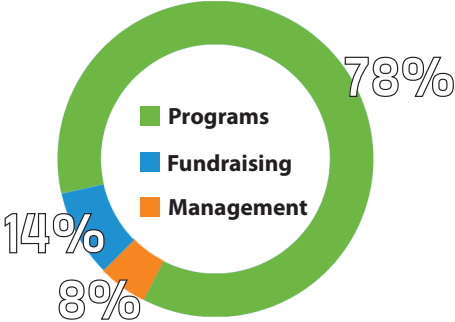
**\$0.78 cents**  
of every dollar donated goes to programs

### WHO DONATES TO THE FOUNDATION



The Meso Foundation receives 77% of its donations from individuals, and 23% from law firms and pharmaceutical companies

### HOW WE USE THE FUNDS



The Meso Foundation uses 78% of donations received to support its programs, 14% on fundraising, and 8% on management.

The Mesothelioma Applied Research Foundation funds critically-needed, peer-reviewed 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 2018, the Foundation funded two projects, one focused on pleural mesothelioma and the other on peritoneal mesothelioma.

The first project titled **"Using gene expression to predict successful responses to chemoimmunotherapy"** will look into gene expression to predict successful responses to combination treatment of chemotherapy with immunotherapy in pleural mesothelioma. The study, which seeks to identify biomarkers that will help differentiate responders from non-responders prior to the administration of treatment, is an extension of the DREAM trial, which enrolled 54 patients treated with Alimta/cisplatin (standard chemotherapy for mesothelioma) and Durvalumab (a PD-L1 inhibitor).

The second project titled **"Genetic variants, pathways, and drug targets of peritoneal mesothelioma"** will analyze three histological subtypes (epithelioid, biphasic, and sarcomatoid) in peritoneal mesothelioma to find the most significant gene mutations, thus allowing for better characterization of the genes involved, and identification of genetic variants associated with this particular type of mesothelioma.

These projects were funded by The Lance S. Ruble, Donald E. Smitley, Craig S. Kozicki, and Ferraro Law Firm Research Grant, and The Anderson Family Research Grant, respectively. The grants are funded in their entirety by these families affected by mesothelioma through personal donations and through fundraising events in their communities.

To date, the Mesothelioma Applied Research Foundation has funded \$10.2 million in cutting-edge mesothelioma research.

# 2018 RESEARCH

**Anna Nowak, MD, PhD, University of Western Australia**

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

*"Using gene expression to predict successful responses to chemoimmunotherapy"*

**Waqas Amin, MD, University of Pittsburgh**

**The Anderson Family Grant**

*"Genetic variants, pathways, and drug targets of peritoneal mesothelioma"*

## Patient Support Services

In 2018, 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 assistance

## Support Groups

This year, we hosted 39 private support group calls and three online support groups for more than 900 patients, caregivers, and those who have suffered a loss to mesothelioma.

## Conferences

In 2018, the Mesothelioma Applied Research Foundation held two separate conferences in Minneapolis, MN and New York City. These smaller conferences provided the opportunity for our community to gather and learn from experts without extensive travel and expenses.

## Meet the Mesothelioma Experts

We held three Meet the Mesothelioma Experts live broadcasts that covered the *mesothelioma patient registry bill* with Bill Franco and Julie Pawelczyk of the Conafay Group; *Aduro Biotech's pleural mesothelioma clinical trial* with Natalie Sacks, MD, the chief medical officer at Aduro Biotech and Evan Alley, MD, PhD, the chief of the Division of Hematology and Oncology at Penn Medicine; and a *front-line clinical trial for non-epithelioid mesothelioma* with Marjorie G. Zauderer, MD, of Memorial Sloan Kettering Cancer Center, and John Bomalaski, MD, of Polaris Pharmaceuticals, for nearly 250 registrants.

## Travel Grants

In 2018, the Foundation's Patient Travel Grant Program awarded 35 travel grants for travel assistance to expert consultations and cutting-edge treatment.





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

In 2018, the CDMRP's Peer-Reviewed Cancer Research Program, which houses merit-based funding for several cancers, including mesothelioma, was appropriated \$80 million to support innovative, high-impact cancer research. This is a major increase from last year's \$60 million, \$50 million the year before, and \$25 million two years prior. The upward trend, in particular, is very promising. Mesothelioma researchers were able to obtain nearly \$2.3 million, also an upward trend. This brought the total mesothelioma research funding by the DoD to \$21.7 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.

## **National Mesothelioma Patient Registry**

In September 2018, the Fiscal Year 2019 (FY19) funding bill for the U.S. Department of Health and Human Services (HHS) that Congress passed included \$100,000 for a feasibility study, the first step in the development of a National Mesothelioma Patient Registry. This funding will be provided through the Centers for Disease Control (CDC) and specifically through the National Institute for Occupational Safety and Health (NIOSH).

The Foundation is working in conjunction with the CDC to bring together stakeholders in the community to discuss issues such as approaches to establishing a registry, desired services, and to identify and address potential barriers. To this end, we've begun to assemble a task force set to meet in conjunction with our 2019 International Symposium on Malignant Mesothelioma in Bethesda, MD.

Since 2015, the Foundation and our community of patients, their families, bereaved, and others interested in eradicating mesothelioma have been advocating for a mesothelioma patient registry for mesothelioma. This development marks a huge victory for the mesothelioma community as it lays down the ground work for speedier advances in the treatment of this cancer – something mesothelioma patients desperately need.

## **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 2018 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.

## **Matter of Fact with Soledad O'Brien**

In August 2018, Mary Hesdorffer, NP, executive director, and Heather Von St James, a mesothelioma warrior and advocate, were interviewed by Soledad O'Brien on her program Matter of Fact. The interview, taped at the Newseum in Washington, DC, covered recent EPA changes to rules and regulations surrounding asbestos.



***In 2018, our community members hosted 25 events to support the Foundation.  
Thank you for all of your hard work and dedication!***





# Thank you!

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