



annual report 2019

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.

Marjorie G. Zauderer, MD, *Chair*
Memorial Sloan Kettering Cancer Center

Shelly Kozicki
Waunakee, WI

Antoinette Wozniak, MD
UPMC Hillman Cancer Center

Keith Cengel, MD, PhD
University of Pennsylvania

Kristen L. Lofgren, *Treasurer*
New York, NY

William N. Ziegler ("Bill")
Rochester Hills, MI

Richard A. DeAugustinis ("Rich")
Peachtree Corners, GA

Aaron S. Mansfield, MD
Mayo Clinic

In Memoriam
Congressman Bruce F. Vento

Patrick Forde, MD
Johns Hopkins University School of
Medicine

R. Taylor Ripley, MD
Baylor College of Medicine

Sandy Robb
Blue Springs, MO

Jason Foster, MD
University of Nebraska

Buerkley Rose, MSN, RN
The University of Chicago

Ross A. Kellman
Charlotte, NC

Daniel Sterman, MD
NYU Lagone Health

Eric D. Witkin, Esq.
Rye, NY



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

Arnaud Scherpereel, MD
Thoracique Hopital Calmette

Brad Black, MD
Center for Asbestos Related Disease

Jamie Stevenson, MD
Cleveland Clinic

Andrea Cercek, MD
Memorial Sloan Kettering Cancer Center

Peter Szlosarek, MD
St. Bartholomew's Hospital

Marc de Perrot, MD
University Health Network

Anish Thomas, MD
National Cancer Institute

Assunta De Rienzo, MD
Brigham and Women's Hospital

Anne S. Tsao, MD
MD Anderson Cancer Center

Richard Lake, PhD
University of Western Australia

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

Edward K. Moon, MD
University of Pennsylvania

Walter Weder, MD
University Hospital Zurich

Anna Nowak, MD, PhD
University of Western Australia

Sanjay Popat, MD
The Royal Marsden Hospital



The following financial information is compiled from the Meso Foundation's 2019 audited financial statements.

Public Support and Other Income	2019	2018
General Contributions	\$ 2,002,903	\$ 1,185,273
Investment Income	\$ 163,918	\$ (50,198)
Total	\$ 2,166,821	Total \$ 1,135,075

Expenses	2019	2018
Research	22% \$ 262,152	17% \$ 242,829
Education, Support, Awareness	58% \$ 705,507	50% \$ 736,716
Advocacy	2% \$ 24,301	11% \$ 159,577
Fundraising	11% \$ 139,330	14% \$ 208,214
Management	7% \$ 87,440	8% \$ 117,675
Total	\$ 1,218,730	Total \$ 1,465,011

Total Assets at end of year 2019 \$ 2,561,855.00

Patient Support Services

In 2019, 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

There were 39 private support group calls and three online support groups for more than 1,000 patients, caregivers, and those who have suffered a loss to mesothelioma.

Conferences

Our three-day International Symposium on Malignant Mesothelioma took place at the Hyatt Regency Bethesda outside of Washington, D.C. Attendees gathered to socialize with community members and mesothelioma experts and researchers while learning about the latest in treatment options. The conference ended with an Advocacy Day on Capitol Hill, where attendees requested that their elected officials support including \$400,000 in the Fiscal Year 2020 (FY20) Appropriations bill for funding through the Centers for Disease Control and Prevention (CDC) to establish a National Mesothelioma Patient Registry.

Meet the Mesothelioma Experts

Over 200 registrants joined the Foundation for three Meet the Mesothelioma Experts live broadcasts that covered: a breath test for early detection of mesothelioma with Dr. Michael Harbut, a discussion of a Phase 3 gene therapy clinical trial evaluating the efficacy and safety of intrapleural administration of adenovirus-delivered interferon Alpha-2b (rAd-IFN) in combination with celecoxib and gemcitabine in patients with malignant pleural mesothelioma with Drs. Dan Sterman and Steve Albelda, and a special Veterans Day installment focused on the mesothelioma program at the VA Medical Center in Houston, TX.

Travel Grants

In 2019, the Foundation's Patient Travel Grant Program awarded 88 travel grants for travel assistance to expert consultations and cutting-edge treatment.



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 \$10.2 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 2018, the Foundation funded two projects, will look into gene expression to predict successful responses to combination treatment of chemotherapy with immunotherapy in pleural mesothelioma. The other 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.



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 renewed at \$80 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.

2018 RESEARCH

(The Anderson Family Grant)

Amin, Waqas

University of Pittsburgh

Genetic variants, pathways and drug targets of peritoneal mesothelioma

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

Nowak, Anna

University of Western Australia

Using gene expression to predict successful responses to chemoimmunotherapy

Mesothelioma Patient Registry

In 2019, the Mesothelioma Applied Research Foundation continued its work to make the mesothelioma patient registry a reality. A white paper documenting presentations and discussions from the Mesothelioma Patient Registry workshop, which was convened by the Mesothelioma Applied Research Foundation in March of 2019 in Bethesda, MD, was recently published in the American Journal of Industrial Medicine.

The paper, "Workshop summary: Potential usefulness and feasibility of a US National Mesothelioma Registry," addresses the current state of mesothelioma research from epidemiological and clinical perspectives, and discusses ways to bridge research gaps through the development of a national mesothelioma patient registry. Furthermore, the paper outlines examples of currently existing registries in other diseases and their impact on research for those diseases, as well as currently existing tools in mesothelioma, such as the mesothelioma tissue bank.

In authors' own words, "The workshop began with formal presentations by subject matter experts, which were followed by a moderated group discussion. Workshop participants reviewed the epidemiology of mesothelioma and clinical and research needs; the strengths and limitations of existing databases, including cancer surveillance programs and the National Mesothelioma Virtual Bank (NMVB); and the lessons learned from a national registry for amyotrophic lateral sclerosis (ALS) and from mesothelioma registries in other countries."

One of the primary benefits discussed in terms of a Mesothelioma Patient Registry would be the ability to connect patients with available clinical trials. This would present patients with access to novel therapies, while simultaneously helping researchers obtain critically important data to move the field forward.

Another distinct benefit of a patient registry is the support it would provide for research into detection, prevention and treatment of this cancer, all crucial to the task of alleviating the deadly effects of mesothelioma.

A Mesothelioma Patient Registry would be a reliable step toward gaining this understanding.