



Mesothelioma Applied[®]
Research Foundation

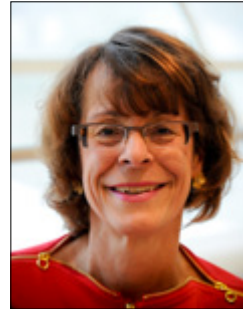
research - education - support - advocacy

ANNUAL REPORT 2013



curemeso.org[®]

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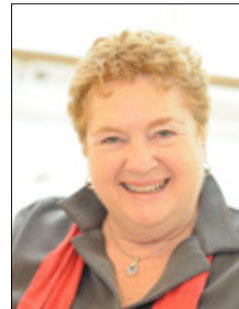
Mary Hesdorffer, Nurse Practitioner

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MISSION STATEMENT

The Mesothelioma Applied Research Foundation is the nonprofit collaboration of patients and families, physicians, advocates, and researchers dedicated to eradicating the life-ending and vicious effects of mesothelioma. We believe in a cure for meso. Given the human toll of suffering the disease causes, the compassion and energy of the meso community, the moral, legal and economic aspects of asbestos, and the benefits of meso research to cancer research generally, we believe that the resources to accomplish this cure are available and must be mobilized. We seek to marshal and utilize these resources responsibly, as effectively as possible and with financial transparency to:

- Offer hope and support to patients and families by educating them on the disease, helping them to obtain the most up-to-date information on treatment options and to connect with meso treatment specialists, and providing them assistance, emotional support and community with others;
- Fund the highest quality and most promising meso research projects from around the world through rigorous peer-review; and
- Raise awareness of meso, and advocate that the public and private sectors partner in the effort to cure it by directing the resources needed to stop this global tragedy

MESSAGE FROM THE CHIEF EXECUTIVE OFFICER

It is my pleasure to present to you the 2013 Mesothelioma Applied Research Foundation's financials. I am proud to share these, as they help exemplify how the Meso Foundation lives up to high standards both fiscally and programmatically.

As a result of the Foundation's fiscal responsibility, we have been recognized as a four-star charity through Charity Navigator, named an accredited charity by the Better Business Bureau, and awarded the prestigious 2013 Top-Rated Award for Great Nonprofits. We are also listed through the National Cancer Institute as a mesothelioma support service organization, an honor awarded to a very few select charities.

The Meso Foundation strives to keep costs to a minimum. As a result, I am proud to announce that 86 cents of every dollar goes directly to research, education, patient support, and advocacy.

In 2013, alongside our established one-on-one patient consultations, we continued providing the crucially-informative "Meet the Mesothelioma Experts" live broadcasts, featuring top experts in the field. We re-designed our website to make it easier to navigate and more user-friendly, and we added to it sections on complementary and alternative medicine, as well as information for caregivers, veterans, and bereaved. Through these changes, we also held "town hall" meetings to keep you, our community, informed about these new programs.

In 2013, the Meso Foundation continued funding the most promising research, bring our total research funded to \$8.7 million. As always, all submitted research projects were reviewed through our rigorous peer-review process, which so far has yielded an impressive 190 published works in over 90 prestigious scientific journals.

In the following pages we outlined the details of our work and impact this organization continues to have on mesothelioma – an impact that wouldn't be possible without your support. Thank you!

Melinda Kotzian, Chief Executive Officer
Mesothelioma Applied Research Foundation

FINANCIALS

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

Public Support and Other Income	2013	2012
General Contributions	\$ 2,550,426	\$ 2,140,966
Investment Income	\$ 99,214	\$ 79,717
Total	\$ 2,649,640	\$ 2,220,683

Expenses	2013	2012
Research	\$ 987,213	\$ 783,294
Education, Support, Awareness	\$ 540,912	\$ 531,179
Advocacy	\$ 195,035	\$ 211,178
Fundraising	\$ 202,244	\$ 202,950
Management	\$ 117,730	\$ 169,016
Total	\$ 2,043,134	\$ 1,897,617

Total Assets: \$3,065,546

ACCREDITATIONS



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. Its Accountability & Transparency metrics, which account for 50 percent of a charity's overall rating, reveal which charities have "best practices" that minimize the chance of unethical activities and whether they freely share basic information about their organization with their donors and other stakeholders.

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 2013, as a result of 65 positive reviews, **GreatNonprofits** rated the Meso Foundation as a Top-Rated Nonprofit.

RESEARCH



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 2013, five grants were awarded, bringing the Meso Foundation's total research funded to **\$8.7 million**.

Tao Dao, MD, PhD
Memorial Sloan-Kettering Cancer Center
Specific immunotherapy for mesothelioma by use of a bi-specific TCR-like antibody

Marc De Perrot, MD
University Health Network
Optimizing the radiation approach to mesothelioma with immunotherapy

Elisa Giovannetti, MD, PhD
VU University Medical Center
Novel lactate dehydrogenase inhibitors for the treatment of mesothelioma
 The Law Offices of Peter G Angelos Grant

Christian Ottensmeier
University of Southampton
Evaluating the effect of immunity on outcomes of patients with mesothelioma
 The Lance S. Ruble, Janelle Bedel and Ferraro Law Firm Grant

Usha Pendurthi, PhD
The University of Texas Health Science Center at Tyler
Endothelial Cell Protein C Receptor Attenuates Mesothelioma Progression

\$8.7 MILLION
 in research funding

180 ARTICLES
 resulting from Foundation's
 research funding

83 JOURNALS
 published Foundation-funded
 research

91 STUDIES
 funded



The 2013 International Symposium on Malignant Mesothelioma was held in Las Vegas, NV.



New website was launched in the summer of 2013.



In 2013, patients, caregivers, and bereaved were encouraged to participate in Foundation-led support groups (in person, online, and over the phone).

EDUCATION

INFO PACKETS The Meso Foundation sends out **informational packets** to every person who reaches out for help. This includes information on our programs; information about mesothelioma, its treatments, and clinical trials; and other resources of interest to someone dealing with a mesothelioma diagnosis.

MEET THE MESOTHELIOMA EXPERTS SERIES This series of informational live interviews (broadcast over the phone) continued in 2013. All recordings are available on the Meso Foundation's website.

INTERNATIONAL SYMPOSIUM ON MALIGNANT MESOTHELIOMA The Meso Foundation hosts an annual Symposium, which is a conference geared to attendees from all walks of life, including patients and their families, advocates, medical professionals, and those who have lost loved ones to mesothelioma. The Symposium provides a setting for everyone in the meso community to come together and take part in both scientific sessions and community conversations. The video feed of the event is broadcast live, free of charge, on the Foundation's website, and its recordings are published on YouTube shortly after the event.

REGIONAL CONFERENCES In 2013, the Meso Foundation held a regional conference in New York.

WEBSITE/BLOG The Meso Foundation's website, curemeso.org, is a comprehensive source of treatment and research information, but also community resources such as events, advocacy, social media, and news articles. In 2013, the Meso Foundation re-designed its website to make it more user-friendly and easier to navigate. The new website features several new sections, including one specifically for caregivers, veterans, complementary and alternative medicine, and clinical trials.

NEWSLETTERS AND E-NEWSLETTERS Each year, the Foundation publishes 1 - 2 print newsletters, such as this one. In addition, every three weeks, the Foundation sends out a *What's New* email to its entire email database, featuring all articles, news and information published within that period.

PRESS RELEASES The Meso Foundation is often the source of treatment and research news about mesothelioma. Such news is disseminated through press releases to local and national media outlets.

SUPPORT

MARY HESDORFFER is the first point of contact for patients and family members that reach out to the Meso Foundation. Mary Hesdorffer, MS, APRN-BC, is a nurse practitioner with over 16 years of experience in mesothelioma treatment. She is an expert in clinical trials for mesothelioma and her work has been published in a variety of scientific journals.

ONLINE SUPPORT Five private, by-invitation-only, moderated, online support groups for patients, caregivers, and bereaved provide community members with 24/7 support, whenever they need it.

TELEPHONE SUPPORT The Meso Foundation hosts four support groups that meet via telephone once a month. These include a patient, caregiver, spousal loss and a Christian prayer group.

PATIENT TRAVEL GRANT PROGRAM The Meso Foundation believes that every patient should have the chance to consult a mesothelioma expert. The Patient Travel Grant covers expenses related to travel, lodging and meals incurred while traveling for a consult.

NATIONAL INSTITUTES OF HEALTH

In 2013, the Meso Foundation dealt with the devastating effects of the sequester and a two week government shutdown. The National Institutes of Health (NIH), which house the National Cancer Institute, saw a budget reduction of 5.5% this year, to \$29.15 billion. As a result, NIH expects to fund about 650 fewer grants than it did the previous year. In 2012, the NIH funded 23 grants to mesothelioma research. Theoretically, this cut would mean 2 less grants would be made to mesothelioma research in 2013, and two less in 2014. The Meso Foundation advocated for a balanced approach to budget cuts with several coalitions, cosponsored the Rally for Medical Research and its' Hill Day.

CDMRP

The Meso Foundation advocated in 2013 for the creation of a mesothelioma research program within the CDMRP. We submitted written testimony to both chambers of Congress, and wrote a white paper in support of the program at the request of the Senate Appropriations Subcommittee on Defense. The House and Senate versions of the DoD Appropriations bill did include mesothelioma as a topic of interest in the Peer Reviewed Cancer Research Program in the CDMRP, funded at \$15 million. The Fiscal Year 2014 (FY14) Defense Appropriations Act provided \$25 million to the Department of Defense Peer Reviewed Cancer Research Program (PRCRP) to support innovative, high-impact cancer research for select cancers, mesothelioma included.

RECALCITRANT CANCER ACT

In January, the Recalcitrant Cancer Act was signed into law by President Obama. This legislation directs the NCI to develop scientific frameworks for addressing deadly cancers that fit certain criteria, starting with pancreatic and lung cancers. Once those are established, the NCI has the authority to add additional deadly cancers at the discretion of the director, Dr. Harold Varmus.

The new law will provide strategic direction for the nation's deadliest cancers. We believe mesothelioma should be included, and have written a letter to Dr. Varmus urging him to do so. As part of our advocacy efforts, the following actions took place:

- Congresswoman Betty McCollum (D-MN) joined by Congresswoman Chellie Pingree (D-ME) wrote a *Dear Colleague* letter circulated to all members of the House.
- Senator Collins sent an individual letter in support of this effort to Dr. Varmus.
- We set up a community letter to Dr. Varmus that we circulated to gather signatures.

OTHER ACTIVITIES

In 2013, the Foundation joined the Coalition for Health Funding, One Voice Against Cancer and the National Organization for Rare Diseases. We also continued our involvement with the Ad Hoc Group of Medical Research and the Friends of the CDC.

The Meso Foundation also held a Capitol Hill briefing for staffers on *Mesothelioma Awareness Day*, featuring speakers Melinda Kotzian, CEO of the Mesothelioma Applied Research Foundation; Richard Alexander, MD, Mesothelioma Surgeon and Chair of our Scientific Advisory Board; and Mesothelioma Warrior Lisa Gonneville. The briefing resulted in Congresswomen Betty McCollum and Chellie Pingree circulating the aforementioned 'Dear Colleague' letter.



COMMUNITY



The 2013 International Symposium on Malignant Mesothelioma took place in Las Vegas, Nevada, bringing together top experts in the field of mesothelioma, with patients, their families, caregivers and the bereaved community.

Meso Foundation's community events cater to all generations. Featured here is a photo from the 2013 ROD's Benefit for Meso, organized by Missy Bowles in memory of her father.



Meso Foundation advocates and supporters have made their annual appearance on the Today show a tradition.



The Meso Fighters Band (consisting of community members), instituted officially for the first time at the Las Vegas Symposium, is now a staple during the entertainment portions of the Symposium.



During Meso Awareness Day, hundreds of community members organized or participated in grassroots events raising awareness and funding. Above are some community members who attended the Rockefeller Plaza Today show event, the New York conference, and the dinner that followed.



The 2013 regional conference was in its second year, and took place in New York, NY.



The Symposium continued to be the only event of its kind, where scientific information is shared directly from researchers and physicians and delivered to patients and their families. The Foundation understands the importance of this information in the hands of patients, so most Symposium presentations are recorded, live broadcast during the event, and then posted on the Foundation's website.

Thank you!

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