

Mobilizing for a Mesothelioma Cure



Who We Are

Mission Statement

The Meso Foundation is the only national non-profit dedicated to eradicating mesothelioma as a life-ending disease. We :

- **Fund peer reviewed research**
- **Advocate to secure federal funds for mesothelioma research and raise awareness of mesothelioma**
- **Provide education and support for patients**

Leadership

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Science Advisory Board, Chair
Dr. Lee Krug

Executive Director
Mary Hesdorffer, NP

Chief Operating Officer
Melinda Kotzian

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* personally impacted by Mesothelioma

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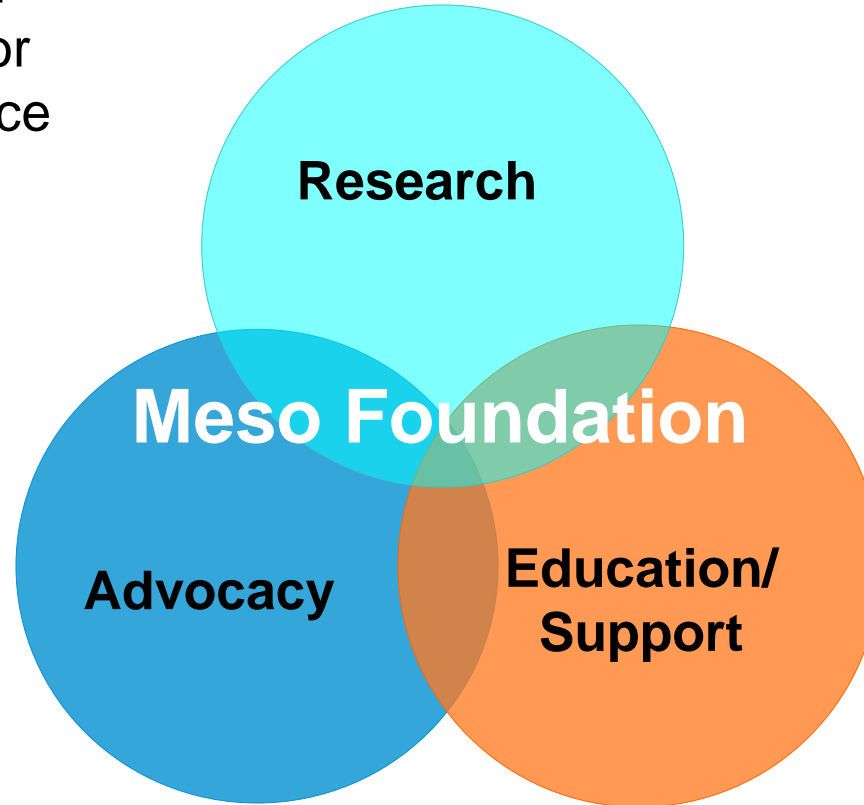
The Meso Community

- Patients
- Family and Friends
- Caregivers
- Doctors and RN's
- Scientists/Researchers/Pharmaceutical Companies
- Advocates (for Congress and for Public Awareness)
- Law Firms representing patients

What We Do

Awarded over
\$8.2 Million for
Research since
2000

Advocate to
raise
awareness
and
influenced
\$8.8 million in
federal
research
funding to
date



Educate tens of
thousands
about
mesothelioma

Provide
medical
guidance to
thousands of
meso patients,
families, and
caregivers

Social Media



follow us on
twitter

Public Facebook

- **Page**
 - Mesothelioma Applied Research Foundation (1,368 Likes)
facebook.com/curemesothelioma
- **Group**
 - Cure Mesothelioma (2,087 members)

Online Support Groups

- Mesothelioma Survivors and Caregivers Group (275)
- Mesothelioma Q& A Group (148)
- Mesothelioma Warriors Caregivers Group (48)
- Caregiver Conversations (132)
- Mesothelioma Loss Group (72)

Research

- Over the last twelve years, the Meso Foundation has awarded 86 peer-reviewed research grants totaling \$8.2 million through our grant program
- National Institute of Health SPORE
“Specialized Programs of Research Excellence”

Meso Foundation Collaborating with:

University of Hawaii
University of Pennsylvania
New York University
Mayo Clinic
University of Minnesota

Research Grant Program

- \$8.2 million to 86 projects from 7 countries
- At the end of our peer-review process, an approved application will have moved through three review cycles, be assessed by no less than 6 SAB members, be scrutinized by at least one expert in their particular field and approved by the two governing bodies of the funding organization.

Research Grant Program

- 148 resulting publications in scientific journals such as:
 - Cancer Research
 - Clinical Cancer Research
 - Lung Cancer
 - International Journal of Oncology
 - European Journal of Cancer
 - Journal of Thoracic Oncology
 - International Journal of Cancer
 - Journal of Molecular Medicine

Example of research funded

- **Cecilia Camacho-Hubner, MD**
St. Bartholomews Hospital, William Harvey
Research Institute, University of London,
England

Title: Development of Novel Therapeutic
Strategies for Malignant Pleural
Mesothelioma: Targeting the IGF System

Specialized Programs of Research Excellence (SPORE)

- The Foundation is actively engaged in the process of submitting for a SPORE grant
- The program will fund 5-year grants to support state-of-the-art investigator-initiated translational research that will contribute to improved prevention, early detection, diagnosis, and treatment of mesothelioma

SPORE

- SPOREs are expected not only to conduct a wide spectrum of research activities, but also to contribute significantly to the development of specialized shared resource core facilities (cores), improved research model systems, and collaborative research projects with other institutions.

SPORE

- The research supported through this program must be translational in nature and must always be focused upon knowledge of human biology stemming from research using cellular, molecular, structural, biochemical, and/or genetic experimental approaches with the goal of a translational human endpoint within the 5 year term of the grant.

SPORE

- Must include both a Developmental Research Program for pilot studies and a Career Development Program to foster careers in mesothelioma translational science.

Collaborators SPORE

- University of Hawaii
- New York University
- University of Pennsylvania
- University of Pittsburgh
- University of Minnesota
- Mayo Clinic
- National Cancer Institute

Achieving our Mutual Goals

- A TISSUE BANK: Develop the best annotated tissue, serum, plasma, etc. bank using surgical and clinical based specimens
- PROTOCOLS TO GROW THE BANK: Get specimens from every patient available

Achieving our Mutual Goals

- NEW PLATFORMS: Collaborate with experts in the field in novel technologies and absorb these technologies in the lab to build a varied portfolio for the technologies under investigation
- FIND COHORTS YOU DON'T HAVE: Reach out and collaborate with groups that have cohorts that are “pre-disease” in order to study early detection as well as carcinogenesis

Achieving our Mutual Goals

- FOCUS THE RESEARCH: Concentrate on biomarkers of different kind which could be validated
 - Prognostic
 - Early Detection
 - Monitoring

Achieving our Mutual Goals

- BUILD CONSORTIUMS FOR FUTURE VALIDATION AND DATA SHARING: Share specimens with everybody and anybody who asks for them including other academicians and industry, and whether they are in the US or in Australia, UK, Italy, etc.

Survivorship

- Wouldn't it be nice to begin a conversation about survivorship
- What would it look like?
- The platform for surviving this disease is increased funding for research, access to clinical trials and mounting more international trials with lab correlates

Trials of Interest in the UK

- HSV1716 is a mutated herpes simplex virus cell
- Infects tumour cells causing them to burst
- Delivered directly into the pleural space
- Strategy of intrapleural delivery using attenuated virus is a new strategy that appears to hold much promise

Vinorelbine

- Vinorelbine has been widely used in the second line setting in mesothelioma despite the lack of a formalized trial in this setting
- Activity of vinorelbine has been reported in several small trials

Ganetespib With Pemetrexed-cisplatin

- Ganetespib is a heat shock protein 90 inhibitor
- It is thought that this agent will reduce some of the resistance to Pemetrexed

Tremelimumab

- actively stimulates the immune system by enhancing the activity of the patient's T lymphocyte effector cells
- inhibits the activity of the T regulatory cells which physiologically “switch off” the response of the immune system, preventing a prolonged state of activation.

VS-6063

- VS-6063 is an orally-available, small molecule inhibitor of focal adhesion kinase (FAK). Research on the FAK signaling pathway has revealed a critical role for cancer stem cell survival and disease progression.
- Merlin will be assessed prior to randomization

Advocacy

- Advocated for Department of Defense grants totaling \$8.8 million to date.
- Advocated for the Centers for Disease Control and Prevention to fund a Meso Tissue Bank for \$10 million.



Senator Max Baucus, MT, and Past Chair Nicholas J. Vogelzang, MD



Senators Barbara Boxer, Pat Murray, and Johnny Isakson

Advocacy: Current Initiatives

- Advocate for a federally funded Mesothelioma Research Program.
- Mobilize stakeholders including unions, industry and health advocates in this effort.

Advocacy: Meso Awareness Day

- National Visibility on the Today Show
- Proclamations in states, counties and cities
- Community events around the country



Education and Support

- 24/7, one-on-one consultations with our nurse practitioner, Mary Hesdorffer
- 6 moderated support groups for our patients, their families and caregivers
- Medical expert teleconferences
- New Patient Packets
- curemeso.org



Annual Symposium

- Annual Symposium - in its tenth year in 2013
- Three Day Event:
 - Community
 - Advocacy
 - Science
- All sessions available online following Symposium.
- Live-stream



Mary Hesdorffer, Nurse
Practitioner

Executive Director

Mesothelioma Applied Research Foundation

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