



Mesothelioma Applied<sup>®</sup>  
Research Foundation

research - education - support - advocacy

# ANNUAL REPORT



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IT ALWAYS SEEMS IMPOSSIBLE  
UNTIL IT'S DONE  
NELSON MANDELA

## MESSAGE FROM THE CHIEF EXECUTIVE OFFICER

Dear supporter,

I am pleased to present to you the 2014 Mesothelioma Applied Research Foundation's annual report, including its audited financials. This organization, its leadership, board of directors, science advisory board, and staff are all dedicated to maintaining the highest level of accountability and transparency, a trait we believe sets us apart from the rest.

Our effort in this regard continues to be acknowledged through third-party charity evaluators who this year, as in years past, gave us the highest grades and accolades. You can read more about it on page 4 of this publication.

Some of the highlights of working toward our mission in 2014 include reaching \$9 million in total awards granted through our research program. Our education and patient support program has been more popular than ever. In fact, by the end of 2014, we saw a jump in demand of services of 44%.

In 2014, we held three conferences – our usual annual Symposium was once again a main destination for members of the mesothelioma community with 250 members attending. This year's Symposium was also unique because, for the first time, it provided a unique session organized for clinicians and researchers to facilitate collaboration and information-sharing, which within the field of mesothelioma has been traditionally difficult to accomplish. Our conferences also took us to Philadelphia and Chicago, where we focused on showcasing local experts and their specialty areas.

Funding for mesothelioma, as for other diseases and causes, has been more and more difficult to achieve. In 2014, we also saw certain donations decrease, however with over 65% of our funding coming from individuals, we are proud of our community's participation in our common mission to end mesothelioma.

Across the following page, you will find in more detail, information about our work – I invite you to read through these pages and know that these accomplishments would not be possible without your steady support.

With gratitude,



Melinda Kotzian, Chief Executive Officer  
Mesothelioma Applied Research Foundation

# LEADERSHIP 2014

**Melinda Kotzian**  
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**Mary Hesdorffer, Nurse Practitioner**  
Executive Director  
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## BOARD OF DIRECTORS

Volunteer members of the Meso Foundation's board of directors are responsible for the Meso Foundation'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 (SAB) 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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# FINANCIALS 2014

The following financial information is compiled from the Meso Foundation's 2014 audited financial statements.

Total Assets: \$2,883,896

Public Support and Other Income	2014		2013	
General Contributions	\$	1,689,278.00	\$	2,550,426
Investment Income	\$	29,419.00	\$	99,214
<b>Total</b>	<b>\$</b>	<b>1,718,697.00</b>	<b>\$</b>	<b>2,649,640</b>

Expenses	2014		2013	
Research	\$	660,544	\$	987,213
Education, Support, Awareness	\$	906,471	\$	540,912
Advocacy	\$	81,697	\$	195,035
Fundraising	\$	129,627	\$	202,244
Management	\$	301,159	\$	117,730
<b>Total</b>	<b>\$</b>	<b>2,079,498</b>	<b>\$</b>	<b>2,043,134</b>

## ABOUT THE MESO FOUNDATION

The Meso Foundation is the only 501(c)3 non-profit organization dedicated to eradicating mesothelioma and easing the suffering caused by this cancer. The Meso Foundation actively seeks philanthropic support to:

- Fund the highest quality and most promising mesothelioma research projects from around the world through our rigorous peer-reviewed process;
- Help mesothelioma patients connect with national mesothelioma experts and obtain the most up-to-date information on treatment options;
- Advocate in Washington D.C. for federal mesothelioma research funding to stop this national tragedy.



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](http://curemeso.org/accreditations).

The Foundation has been vetted by the **National Cancer Institute (NCI)** and is listed on their website as a resource.

In 2014, as a result of 65 positive reviews, **GreatNonprofits** rated the Meso Foundation as a Top-Rated Nonprofit.

# 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 2014, three grants were awarded, bringing the Meso Foundation's total research funded to \$9 million.**

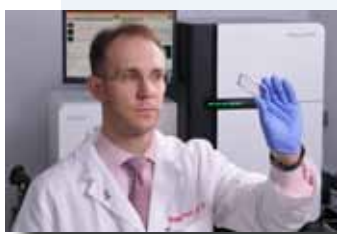


## **Ravi Salgia, The University of Chicago**

### *EPHA2 as A Novel Therapeutic Target in Malignant Pleural Mesothelioma*

In the U.S., approximately one in 100,000 people are diagnosed every year with malignant pleural mesothelioma (MPM). Median survival from the time of diagnosis is 9.2 months. Only one chemotherapeutic agent (pemetrexed) has been approved by the FDA for treatment of MPM. Thus, to make a significant impact on the therapy and overall survival for patients with MPM, newer biological mechanisms must be identified. Over-expression (a process that may cause cells to grow faster) of EPHA2 protein, a receptor of ephrin-A1 ligand, has been reported in many cancers. EPHA2 is associated with the growth and metastatic potential of tumors but the impact of abnormal EPHA2 on MPM patients/cell lines and the biological function/mechanism of EPHA2 in MPM is still uncertain.

Our initial study investigated these unknowns. Preliminary data showed that EPHA2 was found 66.7% (4/6) over-expressed in MPM cell lines and also in patient samples. 28% (11/39) of MPM patient samples had EPHA2 mutations (gene alteration). 10.3% (4/39) of MPM patient samples and 33% (2/6) of MPM cell lines had EPHA2 amplification (an increase in the frequency of replication of a DNA segment). Looking to the biological function/ mechanism of EPHA2 in MPM, we found that cells with EPHA2 mutations grew faster and spread further than cells without EPHA2 mutations. Furthermore, cells with EPHA2 mutations had more resistance to cisplatin (a traditional chemotherapeutic agent). All of these initial findings suggest firstly, that EPHA2 is irregular in MPM and secondly, that EPHA2 is a potential biomarker (a traceable substance whose detection indicates a particular disease state) of MPM and could be used for better therapeutic strategy. We first propose to determine EPHA2 expression, amplification, and presence of mutation in MPM; correlate these variables with clinical parameters; and arrive at useful information regarding patients' likely medical outcomes in MPM. Then, we will determine biological and biochemical functions with respect to EPHA2 and mutated EPHA2 in MPM. Finally, we will investigate the inhibition of EPHA2 in MPM cell lines and its effectiveness in combination with chemotherapies. We hope to use our improved understanding of EPHA2 mutations toward two ends: 1) to design effective therapies that target EPHA2 and 2) to identify the patient populations that will most benefit from this treatment.



## **Tanguy Seiwert, The University of Chicago**

### *The T-cell inflamed immune microenvironment in Malignant Mesothelioma*

Malignant Mesothelioma (MM) is a universally fatal cancer that arises from the mesothelial surfaces of the body, primarily the pleura, and the peritoneum. Current treatment consists of palliative cytotoxic chemotherapeutic agents namely cisplatin and pemetrexed. Benefit is limited and better treatment options, including modalities with lasting benefit and fewer side effects are urgently needed. It is well established that mesotheliomas are frequently infiltrated with immune cells of largely unknown function. The immune-microenvironment – specifically the potential presence of a tumor specific immune response, and presence of mechanisms of immune escape have not been

adequately characterized to date. We have discovered that the inflamed phenotype in a subgroup of approximately one third of mesotheliomas closely resembles that observed in other tumor types (i.e. melanoma) where marked and lasting benefit from immune therapies such as PD-1 and PD-L1 checkpoint inhibitors is now established. Hence we will characterize in detail the inflamed phenotype present in this subgroup of mesotheliomas. We will use patient samples including from a clinical trial with the PD-1 checkpoint inhibitor pembrolizumab that is being initiated at the Univ. of Chicago in order to understand, which patients are most likely to benefit from immune therapies, and how to optimize such treatments.



## **Travis Young, California Institute for Biomedical Research**

### *Controllable CAR-T Therapy for Mesothelioma*

Cell-based therapies engineer a patient's immune cells to seek and destroy tumor cells in the body. The therapies are incredibly potent and have cured many patients of blood cancers in clinical trials. However, with the potency of this therapy also comes dangerous side-effects including long-term immunosuppression and even death. Here, we propose a platform which adds safety to the potency of cell-based therapies. Already we have demonstrated this platform in the laboratory against many different diseases. In this proposal we will further develop this platform to target mesothelioma cells. Ultimately this therapy may provide a realistic hope for a cure for patients with mesothelioma.

# EDUCATION AND SUPPORT

In 2014, the Mesothelioma Applied Research Foundation continued growing its education and support services, and began the process of evaluating them and improving them as needed. To keep up with demand for services, the Foundation added a new staff member to focus specifically on patients' (and their caregivers' and families') needs.

Mary Hesdorffer, APRN, Meso Foundation's executive director and expert nurse practitioner, provides one-on-one medical 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

The Meso Foundation also provides:

- support groups, including in-person, telephonic, and online
- national and regional conferences covering malignant mesothelioma
- 'Meet the Mesothelioma Experts' Live Interview Series
- online and printed materials providing both education and support
- support services for the bereaved community



# ADVOCACY AND AWARENESS

## ADVOCACY

2014 was an important year for the Meso Foundation's advocacy efforts as we set the wheels in motion for much of our future activities.

In 2014, we focused on strengthening our relationships within the Department of Defense's Congressionally-Directed Medical Research Program to ensure continued funding, which already awarded \$8.8 million in mesothelioma research. As a result, additional funding was allocated through this program.

Early in the year, the Foundation joined the Deadliest Cancers Coalition, which is a collaboration of national non-profit organizations focused on addressing policy issues related to our nation's most lethal, or recalcitrant, cancers, defined as those that have five-year relative survival rates below 50 percent. It was established in 2008 by the Pancreatic Cancer Action Network and other patient advocacy organizations and professional societies. Mesothelioma, with a survival rate of less than 10 percent at five years post diagnosis, fits this criterion.

Earlier in 2013, the Recalcitrant Cancer Act was passed by Congress directing the NCI to focus specifically on recalcitrant cancers defined as those with a five-year survival rate below 50 percent, and which have not seen substantial progress in the diagnosis or treatment. This is when the Meso Foundation saw an opportunity arise and attempted to add mesothelioma to the list of NCI's focus cancers. On our behalf, Congresswomen Pingree and McCollum circulated among their congressional colleagues a Dear Colleague letter requesting support for adding mesothelioma to the Recalcitrant Cancer Act. In 2014, the Meso Foundation continued the push of garnering support which ultimately saw more than 20 representatives from both parties sign on. Although no other cancers were added to the act, through this process we gained valuable allies in the political sphere.

In March 2014, during the annual International Symposium on Malignant Mesothelioma, our community advocates took the stage by visiting their congressional representatives on Capitol Hill. In their ask, they addressed two issues. One was to add supporters to the Dear Colleague letter (discussed above), and the other was to continue and increase the Department of Defense medical research funding.

Over the year, collaborations took front and center as the Foundation signed on to several initiatives sponsored by groups such as the Coalition for Health Funding, the Ad Hoc Group for Medical Research, and the Friends of the Centers for Disease Control.

## AWARENESS

In 2014, 45 community members organized 39 events raising funding and awareness of mesothelioma. Many of these events occurred concurrently with Mesothelioma Awareness Day, helping us gain critical momentum in visibility. In addition, Mary Hesdorffer, our executive director, participated in a media tour, whereby she gave radio and television interviews to over 20 programs, which promoted the Foundation as well as its programs and services.



# AWARDS 2014



*Rev. Eric Linthicum received the Compassion Award.*



*Dr. Michele Carbone received the Pioneer Award.*



*Bruce Vento Hope Builder Award honored Congresswomen Pingree and McCollum.*



*Olga Pavlick and Sarah Pavlick received the Klaus Brauch Volunteer of the Year Award.*



*Anne Alessandrini of the Brigham and Women's Hospital was the recipient of the June Breit and Jocelyn Farrar Outstanding Nurse Award.*



# COMMUNITY





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