

2011

UNITING THE MESOTHELIOMA
COMMUNITY ACROSS THE
WORLD.

KNOWLEDGE IS HOPE!

ANNUAL REPORT 2011



Dear friends and supporters,

I am pleased to present to you this 2011 Mesothelioma Applied Research Foundation's Annual Report.

As you may already know, the Meso Foundation is a public, 501(c)3, non-profit organization. This IRS designation is awarded only to those organizations whose activities are performed strictly for charitable purposes. As a result of this designation, your gifts to the Foundation are tax-deductible to the fullest extent allowed by law and all funds raised by the Foundation are used to further its mission.

Ultimately, the Board of Directors of the Meso Foundation (please see the 2011 BOD members listed on the following page) determines how these funds are allocated and the Foundation's priorities.

At the end of every year, auditors provide the Meso Foundation with audited financial statements for the previous fiscal year. As a public charity, we immediately make these financials available to you and to the public. Page 4 of this annual report includes our audited financials for 2011 with a 2010 comparison.

For those of you who aren't quite sure what to make of the numbers, we are always available to answer any questions you might have. Also, you may find it useful to research the Foundation, or any other organization you plan to support, through third-party non-profit/charity evaluation websites available to you at no charge (such as the Better Business Bureau, Guidestar.org, and Charity Navigator).

If you are already a Meso Foundation donor we wish to take this opportunity to thank you for your loyal support. Your commitment to curing mesothelioma and to providing help to those affected by it is the heart and soul of this organization and we hope you will continue to support our common cause.

In an effort to keep you informed, this report provides a summary of the Foundation's activities throughout 2011. Our focus in 2011 was on knowledge. For example, two grants we awarded address the need to increase our knowledge-base of mesothelioma by examining gene profiling in this disease.

Our education and support programs saw an expansion in specific services provided (such as the introduction of our '*Meet the Experts*' series) and an increase in the number of people taking advantage of these services and gaining invaluable knowledge of mesothelioma, available clinical trials, and an opportunity to interact with the world's top experts in the field.

Meanwhile, our advocacy agenda was instrumental in obtaining additional government funding of mesothelioma research and an increased awareness among the ten states and 34 localities in the United States that chose to officially acknowledge *Mesothelioma Awareness Day*.

As we further our mission, we believe that more knowledge among those affected by mesothelioma, those looking to develop treatments and cures, and the public at large is fundamental to ending mesothelioma and we hope that you'll continue to join us in this work.

Knowledge is hope!

A handwritten signature in blue ink, appearing to read 'Mary Hesdorffer', with a long horizontal flourish extending to the right.

Mary Hesdorffer, NP, Executive Director
Mesothelioma Applied Research Foundation

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

The following board members served on our Board of Directors and our Science Advisory Board in 2011.

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Financials

The following financial information is compiled from the Meso Foundation's audited financial statements, which are finalized and released in November of each year, for the previous year.

Public Support and Other Income	2011		2010	
General Contributions	\$	1,953,611	\$	1,561,936
Investment Income	\$	34,696	\$	139,675
Total	\$	1,988,307	\$	1,701,611

Expenses	2011			2010	
Research	\$	950,664	48%	\$	201,859 15% *
Education, Support, Awareness	\$	458,009	23%	\$	541,141 40%
Advocacy	\$	210,352	10%	\$	235,255 17%
Fundraising	\$	197,300	10%	\$	185,786 14%
Management	\$	172,829	9%	\$	198,488 15%
Total	\$	1,989,154		\$	1,362,529

Total Assets **\$2,329,955**

* This figure does not include the \$700,000 invested in mesothelioma research in 2010. The 2010 grants were awarded in January 2011 and therefore were included in the 2011 financials.

Accreditations

The Meso Foundation, as a national 501(c)3 organization, must comply with federal non-profit standards. Several independent organizations exist to ensure such standards are followed. Below are some organizations that have vetted the Meso Foundation in 2011.



In addition, in 2011 the Meso Foundation was reviewed by both, Charity Navigator and Guidestar.org. At the same time, the Foundation also submitted all necessary documentation to the Better Business Bureau to become an accredited non-profit in 2012.



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 2011, five grants were awarded, bringing the Foundation's total research funded to \$7.6 million.**

Tao Dao, MD, PhD

Memorial Sloan Kettering Cancer Center

TCR-like mAb specific for WT1 peptide/MHC complexes on mesothelioma

Assunta DeRienzo, PhD

Brigham and Women's Hospital

Identification of Novel Mutations in Malignant Pleural Mesothelioma using Deep Whole-Genome Sequencing

Marc Ladanyi, MD - Ron Simkins Memorial Grant

Memorial Sloan-Kettering Cancer Center

Frequent inactivation of BAP1 in mesothelioma: biology and new therapeutic opportunities

Liang-Chuan S Wang, PhD

Perelman School of Medicine at the University of Pennsylvania

The Role of the IFN response in Chemosensitivity of Mesothelioma to Pemetrexed

Nadia Zaffaroni, PhD

Fondazione IRCCS Istituto Nazionale Tumori, Milan, Italy

Identification and validation of miRNAs as novel biomarkers and therapeutic targets in diffuse malignant peritoneal mesothelioma

Named Research Grants Program

The Meso Foundation's rigorously competitive grant awards (\$100,000 each) support the research critically needed to find a cure for mesothelioma. This research, when published in medical journals or presented at medical meetings, becomes part of the permanent scientific knowledge base, deepens the scientific community's understanding of the disease and its potential targets of treatment, and provides essential links in the chain leading ultimately to a cure.

In 2011, the **Ron Simkins Memorial Grant** was awarded to Marc Ladanyi, MD for his research into "*Frequent inactivation of BAP1 in mesothelioma: biology and new therapeutic opportunities*".



Education and Support

The Meso Foundation understands that patients need effective treatments. Through the last decade of work we have demonstrated our commitment to mesothelioma patients and their families by funding the highest quality, peer-reviewed, mesothelioma research which has shown steady advancements in the field.

While life-saving research is a crucial investment for all mesothelioma patients and their families, patient support and education play an indispensable role immediately following a patient's diagnosis and throughout their mesothelioma journey. During the last several years, patients and their families have told us that during those difficult times they seek guidance in better understanding their options, including available treatments, and clinical trials. They want to know that the life-altering and often frightening decisions they are forced to make are based on comprehensive and accurate information.

We listened to our community, and in 2011 have begun the expansion of services provided to even better accommodate these needs. In 2011, the Meso Foundation continued to offer the following, free of charge:

- *One-on-one medical consultations with Mary Hesdorffer, Nurse Practitioner*
- *Educational materials for patients and their families*
- *Educational videos from world's most respected mesothelioma experts*
- *Clinical trial referrals*
- *Annual Symposium*
- *Telephone support groups*
- *Peer support*

In 2011, we also expanded services to include:

- *Private and moderated Facebook support groups*
- *"Meet the Experts" teleconferences and podcasts*

All education and support services are provided under the supervision and guidance of Mary Hesdorffer, Nurse Practitioner.

Mary Hesdorffer, Nurse Practitioner

Mary Hesdorffer received her undergraduate degree at the College of New Rochelle in NY and went on to receive her Masters of Science at the same institution.

She is fully credentialed as a Nurse Practitioner and has spent 15 years actively treating patients with mesothelioma. Mary has extensive expertise in the development and implementation of clinical trials.

She has published in peer-reviewed journals and has lectured nationally on topics pertaining to mesothelioma with particular emphasis on clinical trials as well as symptom and disease management.

Mary is passionate in her commitment to the treatment and management of this disease and hopes to increase awareness of the need to advance the science that will lead to a cure. She is available via phone or email to assist patients and caregivers as they move from chaos to control of this new situation they find themselves thrust into.



Services for Those Coping with Loss

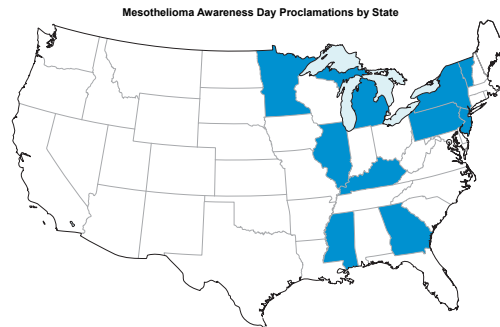
Besides the very critical one-on-one services provided to patients, we also support their caregivers and in the event a loss should occur, we are here for the patient's family and friends for as long as they need us.

- *Telephonic and online support groups*
- *Specific "loss" sessions offered in-person at the Symposium*
- *Peer Support*

Advocacy and Awareness

In 2011, the Mesothelioma Applied Research Foundation took the directive from the community to raise awareness about the devastating disease to another level. As a result, Mesothelioma Awareness Day was more prominent than ever. The community continued to seek proclamations across the country, reaching a grand total of 10 states and 34 localities that proclaimed September 26 as Mesothelioma Awareness Day. By the end of 2011, those states included:

Kentucky
Vermont
Georgia
Illinois
Michigan
Minnesota
Missouri
New Jersey
New York
Pennsylvania



On September 26th, meso community members, including patients, family members, advocates, health care providers, and staff gathered on Rockefeller Plaza to participate in the audience of the *Today Show*. Al Roker approached the group and told the program’s nationwide audience to visit curemeso.org for information about mesothelioma.

Further, volunteers held events around the country to raise awareness and funds to support the mission of the Foundation. Our volunteers and supporters organized eight official events, counting over 1,000 attendees and approximately \$65,000 raised for mesothelioma research. Many more gathered informally, and raised awareness by wearing their shirts and bracelets, by posting meso-related posts on their social media networks, by sharing literature and talking about it, by establishing workplace fund-drives, and by creating personalized license plates in their states.

Advocating in Congress

Once again, in 2011, Meso Foundation advocates stormed Capitol Hill in conjunction with the Meso Foundation’s annual Symposium. 55 advocates met with 65 congressional offices.



The congressional briefing.

We also hosted a public congressional briefing, sponsored by Senator Patty Murray’s office on Capitol Hill. The briefing featured meso warrior and Navy veteran Mike Clements, who fearlessly shared the story of his service to his country, exposure to asbestos and ongoing battle with mesothelioma.

Meso Foundation’s executive director Mary Hesdorffer, Nurse Practitioner, testified before the Senate Appropriations Subcommittee on Defense on the need for sustained and increased funding of mesothelioma research through the Congressionally Directed Medical Research Program’s (CDMRP) Peer Reviewed Cancer Research Program (PRCRP) for Fiscal Year 2012. The Meso Foundation proudly reports that

mesothelioma was included as a disease eligible for funding through the PRCRP in Fiscal Year 2012. The CDMRP has awarded \$8.8 million to meso research since 2008, and the FY 2012 grants are due to be awarded by the end of December 2012. We hope to see additional mesothelioma research funded.

In 2011 again, the Meso Foundation nominated meso warriors as CDMRP grant reviewers. Three meso warriors – Julie Gundlach, David Lerman and Rich Mosca – graciously represented the meso community on the peer review panel.

The Mesothelioma Ambassador Program was also launched in 2011. This was the Foundation’s first coordinated effort to regularly engage mesothelioma advocates to raise awareness and to advocate for increased federal funding for mesothelioma research. Each month, Ambassadors are asked to work with the Meso Foundation staff on special assignments to advance the Foundation’s advocacy efforts by sharing their story and requesting support and funding.

Thank You!

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- Join a telephonic or online support group
- Organize a fundraising event
- Attend our Symposium and/or regional conferences
- Connect with other mesothelioma families on the Meso Foundation's Facebook page
- Participate in our "Meet the Experts" series and ask questions important to you
- Donate