



BREATH OF HOPE

Summer 2017

a publication by the Mesothelioma Applied Research Foundation



**“WE COMPLETE
EACH OTHER”**

Two friends — one left lung and one right lung between the two of them — discuss family, friendship, life after diagnosis.

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editorial

Published by the Mesothelioma Applied Research Foundation

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Research Foundation

MESSAGE FROM THE CHAIR OF THE BOARD OF DIRECTORS

As I reflect on the Mesothelioma Applied Research Foundation, all its accomplishments, and this past year, three themes resonate: transition, opportunity, and new hope. As the Foundation continues its critical missions of patient support and education, advocacy, and research, I would be remiss if I did not immediately acknowledge the exceptional work of our CEO Melinda Kotzian and her wonderful staff in tirelessly fulfilling our mission!

The Foundation has had a very successful year on all metrics. This year marks a major transition as Mary Hesdorffer has announced her plans to retire and spend some very well deserved time with her husband Charles, their children, and grandchildren. I know that the Foundation has been a major part of her life for many years and that she will continue to support our work even in retirement. As this transition evolves, we welcome the very capable Gleneara Bates, MSW, PhD(c) to the organization. As we welcome new faces to the organization, we are also moving our administrative headquarters a few miles away into Washington, DC proper, from Alexandria, VA. The new location offers a very professional and welcoming environment for our visitors and friends.

Overall, the Foundation had a very busy two-year cycle of public and scientific events starting with a series of smaller regional meetings held in Houston, Chicago, and San Francisco followed by a very well attended international scientific and community symposium on the campus of the National Institutes of Health. The regional symposia provided an opportunity for patients and families to engage the organization nearer to their homes and were received with enthusiasm. The combined scientific and community symposium was also a major success; having a meeting

where the scientific and general communities mingle and interact serves to bring energy and passion to everything we do. This year's scientific session highlighted advances being made in understanding the genetic basis of the disease as well as advances in novel therapeutics such as immunotherapy and molecular target agents. I believe we are emerging into the next era of mesothelioma management with new and more effective treatment options on the horizon. It is notable that many of the promising advances described at the symposium were research areas that were funded by the Foundation's research grants program over the past 10 years.

I want to thank the board of directors for their stewardship of the Meso Foundation as well as the Science Advisory Board (SAB) headed by Tobias Piekert. The SAB has the critically important charge of reviewing, scoring, and identifying the top ranked research proposals each year. This requires considerable time and effort as almost all the proposals are well-written and present very high quality science.

Although we have lots of work to do, I feel energized by the activities of the Meso Foundation. If we stop for a minute and imagine a world without this Foundation, we quickly appreciate all that it has done to shine a light on this cancer.

H. Richard Alexander, MD, Chair
Mesothelioma Applied Research
Foundation



Melinda Kotzian
Mesothelioma Applied
Research Foundation

Chief Executive Officer

MESSAGE FROM THE CEO

*“Alone we can do so little,
together we can do so
much.” --Helen Keller*

This is a statement that the Mesothelioma Applied Research Foundation stands behind. We know that it is not one person that enacts change; it is a team all working together who will work to “eradicate the suffering caused by mesothelioma.”

The Meso Foundation is blessed with a great team dedicated to our mission. We never want a patient, caregiver, or bereaved member to feel like they are alone. They are not. We are here to listen and to help. Many of you do not know about all the members of the Foundation’s team, so I am taking the time to introduce them to you.

Maja Belamaric, Director of Communications

Job: Maja is our communications lead who has been with the Foundation over ten years. If you are not hearing from her via e-mail, you need to be. She will keep you informed on everything that is happening within the mesothelioma world. Looking for updates on research, advocacy or support services? Keep an eye on your inbox for updates from Maja. Fun Fact: Maja has completed 10 marathons. Thank you for your dedication, Maja!

Gleneara Bates, Director of Research and Medical Outreach

Job: Gleneara is the team member you call to get help with medical related questions and support. She is a licensed social worker who has years of experience working with mesothelioma patients and doing research in mesothelioma. She is very zealous about her job and loves to speak with people from all

walks of life. Gleneara also works with our Science Advisory Board on our grants program. Fun Fact: Gleneara can read in 3 different languages. She reads one book a week and owns over 1,000 books.

Maureen Devine-Ahl, Director of Development

Job: The Meso Foundation is a non-profit that relies solely on donors who support our programs of patient support and funding research grants. Maureen works to ensure that we get the funding needed to keep the Foundation going. We are so thankful to our donors who believe in the work we provide. Thank you! Fun Fact: She has appeared on the show Days of Our Lives. Ask her about this the next time you chat.

Erica Ruble, Development Assistant

Job: Erica is knowledgeable in all things related to fundraising events. She can help you plan a 5K run or do a Music for Meso event. Whatever you love, you can turn into a fundraiser, and she will be there to help you through the process. Erica loves what she does and is passionate about finding a cure for mesothelioma, as she lost her father, Lance, to the disease. Fun Fact: Erica used to be a dancer for the Orlando Magic NBA Basketball Team.

Beth Posocco, Communications Associate

Job: Beth is an expert in all things social media. This means that when you are on Facebook and see posts about the Meso Foundation, they were probably created by Beth. She also writes stories and does graphic design work. To share your story, contact Beth. Fun Fact: Beth is expecting a baby soon. Guesses are being made about the sex, date of arrival and weight. Look to Facebook for the big announcement.

Jadmin Mostel, Patient Support and Research Assistant

Job: Jadmin is our newest member of the team. Jadmin can help you apply for a patient travel grant or assist you with getting into our support groups. She is also the keeper of our database. If you are moving, let Jadmin know so that you continue to stay informed. Fun Fact: Jadmin plays three instruments: the piano, the trombone, and the euphonium (looks like a mini tuba). I think we have a new member of the Meso Fighters Band!

These are the staff members that work tirelessly to implement the programs and services we provide. Backing this team is our esteemed Board of Directors, led by Dr. Rich Alexander from the University of Maryland and our Science Advisory Board, led by Dr. Tobias Peikert from Mayo Clinic. Both boards are comprised of passionate people who believe in serving this community. You can read more about our board and SAB at curemeso.org

Last but not least is YOU. Each of you is a part of our team. Together, we all work to support each other and find a cure for mesothelioma. Thank you for being a member of the mesothelioma team. As was stated in the beginning by Helen Keller, “together we can do so much.”

Melinda Kotzian, CEO
Mesothelioma Applied Research
Foundation

NEW DISCOVERY: BAP1 MUTATION INCREASES SUSCEPTIBILITY TO ENVIRONMENTAL CARCINOGENS



Michele Carbone, MD, PhD, Director of Thoracic Oncology at the University of Hawaii (UH) Cancer Center, along with his team, have discovered why people carrying mutations of the BAP1 gene are more susceptible to environmental carcinogens, including asbestos, radiation, and ultraviolet light.

BAP1 mutations are seen in approximately 20 percent of all cancers, and Dr. Carbone and his team found that in such cases, cancer cells are resistant to chemotherapy.

Very simply put, they discovered that the BAP1 gene regulates a channel (called IP3R3) inside the cell that moves calcium. When a BAP1 mutation is present, calcium levels inside the cells decrease, making it more likely that the cells will become malignant when exposed to environmental carcinogens. (Or as Dr. Carbone himself says it: "The lack of the IP3R3 channels caused by BAP1 alterations, keeps the calcium confined within a cell organelle known as the endoplasmic reticulum (ER), so it cannot be released to the mitochondria, another cell organelle that controls cell respiration and cell death. The result is an inability of the cell to execute apoptosis (suicide) when its DNA is damaged by asbestos, UV, etc. Therefore cells with damaged DNA replicate and expand. These cells are prone to malignant transformation. When these cells become transformed they are primed for tumor growth.")

BAP1 mutations make up tumor cells of 70 percent of mesotheliomas. There are two types of BAP1 mutations: germline and somatic. A germline BAP1 mutation is inherited, meaning a person is born with it, and thought

Pictured from left to right, Drs. Yang, Carbone, and Bononi.

to be extremely rare. A somatic BAP1 mutation can occur spontaneously, such as when BAP1 is damaged as the cell becomes cancerous. Somatic BAP1 mutations are the type that are resistant to chemotherapy, and it is this type of mutation to which these new findings apply.

The team found that fixing and stabilizing the calcium channels and restoring BAP1 levels will make the cancer cells more responsive to chemotherapy. "The fixed channel should be able to prevent cancer in people who have inherited BAP1 mutations and to help treat cancers whose tumor cells have developed BAP1 mutations," said Dr. Carbone.

The findings by Dr. Carbone and his team at UH Cancer Center have been published in *Nature*, a premier scientific journal.

"I came to Hawaii all the way from Italy and I achieved my dreams. I very much hope that our discovery will help save many lives," said Angela Bononi, co-author and post-doctoral fellow in Dr. Carbone's lab.

On the significance of the findings, Dr. Carbone stated, "We want to prevent and treat cancer in as many people as possible. We hope to start a clinical trial, within five years or less, to test the susceptibility to chemotherapy in patients with BAP1 mutated tumors."

Dr. Michele Carbone is a past recipient of the Meso Foundation's Pioneer Award for his achievements in mesothelioma research, including his role in the discovery of the BAP1 gene mutation in mesothelioma.



Advocacy Update: Patient Registry Bill

In 2015, following an Advocacy Day meeting with Meso Foundation constituents, Rep. John Katko introduced the very first bill of its kind for mesothelioma called the "Mary Jo Lawyer Spano Mesothelioma Patient Registry Act of 2015." After a busy election season, the bill was ultimately never brought up for a vote.

At the beginning of this year, after the 2017 Congress was seated, Rep. Katko re-introduced the same bill now titled "Mary Jo Lawyer Spano Mesothelioma Patient Registry Act of 2017."

We need as many representatives as possible to sign on to this legislation before it can be brought to the floor of Congress for a vote. Please visit our website at

curemeso.org/advocate to find out if your elected official has signed on. On that same web page you will find information on how to contact them and talking points.

Currently, there is no formal registry to keep track of mesothelioma patients, their demographics, and other important information that researchers need to develop more effective treatments. The profound impact of patient registries has been demonstrated in other diseases such as gastrointestinal stromal tumors, Gaucher's disease, newborn screening for inborn errors of metabolism, interstitial pulmonary fibrosis, muscular dystrophy and many others; which, following their implementation, have seen an acceleration in treatment development and acceleration toward cures.

Since the introduction, we have seen a huge outpouring of support from the scientific community, as well as a number of health organizations. We have also seen at least 500 of our own supporters email and call their elected officials asking them to support the bill.

UPDATES FROM THE AMERICAN SOCIETY OF CLINICAL ONCOLOGY (ASCO)



Pictured from left to right: Melinda Kotzian and Gleneara Bates.

The American Society of Clinical Oncology (ASCO) held its Annual Meeting on June 2-6, 2017 in Chicago. The Meso Foundation's CEO, Melinda Kotzian, and Director of Research and Medical Outreach, Gleneara Bates, MS, MSW, PhD (c), had the opportunity to attend the conference and hear the latest news reported in mesothelioma research.

Breaking news in mesothelioma came from Arnaud Scherpereel, MD, PhD, head of the Pulmonary and Thoracic Oncology Department at the University Hospital of Lille in France, who presented the results of the IFCT-1501 MAPS-2 clinical trial. The study reported a disease control rate (DCR) at twelve weeks of 44.4% with nivolumab alone and 50% with nivolumab plus ipilimumab. Nivolumab and ipilimumab are immunotherapy drugs known as immune checkpoint inhibitors, targeting PD-1 and CTLA-4, respectively. In simple terms, these drugs work to allow the immune system to attack cancer cells. Both drugs have shown promise in the treatment of other types of cancer, most notably melanoma.

The study included 125 patients with proven unresectable malignant pleural mesothelioma. All participating patients had

previous treatment by 1 or 2 systemic chemotherapy lines, including at least first-line treatment with pemetrexed and cisplatin or carboplatin.

In other ASCO news, Hedy Lee Kindler, MD, of the University of Chicago, presented a poster on the results from a phase II clinical trial, funded by a grant from the Meso Foundation, studying the anti-PD-1 antibody pembrolizumab in patients with malignant mesothelioma. The study included 35 previously treated mesothelioma patients, and achieved a 21% response rate and a disease control rate of 80%. Biomarkers established in other cancers did not correlate statistically with response. Part B of the study is ongoing and currently enrolling at the University of Chicago.

Luana Calabro, MD, PhD, of the University Hospital of Siena in Italy, presented a poster on the safety analysis from the phase II NIBIT-MESO-1 study investigating the efficacy and safety of anti-CTLA-4 immunotherapy drug tremelimumab in combination with anti-PD-L1 immunotherapy drug durvalumab in malignant mesothelioma patients. The study included 40 patients, and the safety analysis shows the drug combination is safe and manageable. This clinical trial is currently recruiting participants at the University Hospital of Siena.

Marjorie G. Zauderer, MD, of Memorial Sloan Kettering Cancer Center, presented a poster on the patterns of comorbidity, treatment, resource utilization, and referral in malignant pleural mesothelioma patients in the US. The data from 1,869 patients showed that only 4.1% of patients received radical surgery, 15.6% had first-line chemotherapy, 33.2% had first-line chemotherapy plus radiotherapy, 11.7% had radiotherapy, and 39.5% had no chemotherapy or radiotherapy. The number of patients who did not receive any treat-

ment indicates a large unmet need for effective treatments. Additionally, the median time from the first lung-related visit up to diagnosis was 77 days, and showed that the pathway to a malignant pleural mesothelioma diagnosis is challenging and often involves multiple healthcare contacts.

Raphael Bueno, MD, of Brigham and Women's Hospital and Harvard Medical School, presented a poster on the effects of defactinib, an oral focal adhesion kinase inhibitor, for malignant pleural mesothelioma patients prior to surgery. The study included 30 patients, and three cohorts of 10 patients each received defactinib for 12, 35 and 21 days. The data show that brief preoperative use of defactinib was well tolerated, did not alter resectability or mortality, and showed evidence of therapeutic and immunomodulatory effects.

Peter Szlosarek, MD, PhD, of St. Bartholomew's Hospital in London, presented a poster on the new ATOMIC-Meso study, a randomized, placebo-controlled, double-blind, phase 2/3 global clinical trial to assess the efficacy of ADI-PEG20 with the standard chemotherapy of pemetrexed and cisplatin in up to 386 patients with non-epithelioid malignant pleural mesothelioma. The TRAP Phase 1 trial of ADI-PEG 20 with pemetrexed/cisplatin revealed a 94% disease control rate. The primary endpoint for the phase 2 stage will be overall response rate with a secondary endpoint of overall survival, safety, and toxicity. The primary endpoint of the phase 3 stage will be overall survival. This clinical trial is currently recruiting patients in the United States and Asia, and enrollment will open in Europe and Australia soon.



IMPORTANT: THE MESO FOUNDATION HAS MOVED

Please note that the Meso Foundation's offices have moved from Alexandria, VA to Washington, DC. Our new address is:

Mesothelioma Applied Research Foundation
641 S Street NW
Washington, DC 20001

Our phone numbers remain the same.

OVERVIEW AND GUIDE TO CLINICAL TRIALS IN MESOTHELIOMA IN THE U.S.

Recently, we have been witnessing a renaissance of sorts in mesothelioma research. While still no new treatment has been approved, arguably mesothelioma's own personal cancer moonshot is underway with more drug trials than ever before and with unexpected responses being observed in a subset of the mesothelioma population.

With only one, non-curative FDA-approved treatment for mesothelioma in the medical kit bag, mesothelioma clinical trials are often the most effective and, sometimes, the only way a patient can access innovative treatment options. When deciding whether a clinical trial is the right choice for you, it is wise to ask questions and to fully understand the risks and expected benefits before signing the informed consent form. **If you have any questions about clinical trials, and would like help navigating all available options, please contact Gleneara Bates, the Meso Foundation's director of research and medical outreach.**

Chemotherapy

Last year, a randomized controlled trial of 448 newly diagnosed pleural mesothelioma patients demonstrated a statistically significant increase in overall survival when bevacizumab was added to pemetrexed and cisplatin. Bevacizumab is a vascular endothelial growth inhibitor (VEGF inhibitor) that prevents angiogenesis, which is the formation of new blood vessels used to feed tumors the nutrients they need for continued growth, thus, starving tumors of these nutrients. Studies are currently underway to confirm those results.

Nintedanib, another drug in the same class as bevacizumab currently tested in a clinical trial setting, inhibits VEGF, platelet derived growth factor (PDGFR), and fibroblast growth factor (FGFR). These three factors are thought to be responsible for sustaining tumors, tumor growth, and the cancer's ability to metastasize. A randomized placebo controlled global trial is currently underway to determine if adding nintedanib to the current first line approved combination of pemetrexed and cisplatin is superior to pemetrexed and cisplatin plus a placebo.

Checkpoint Inhibitors

Other current trials are testing the use of checkpoint inhibitors as a form of immunotherapy. Such cancer immunotherapy strategies tested in the clinic have typically been aimed at stimulating a T-cell response against spe-

cific tumor antigens. There are two types of T-cells. Killer T-cells are able to see inside our bodies' own cells simply by scanning their surface. This mechanism allows killer T-cells to hunt down and destroy cells that are infected with germs or that have become cancerous. The other main type of T-cells is called helper T-cells. Helper T-cells orchestrate an immune response and play important roles in all arms of immunity.

One reason prior approaches, including therapeutic cancer vaccines, have not generally been successful is that T-cells have "checkpoints," such as PD-1 and CTLA-4, to guard against autoimmunity and to protect tissues from damage by an overly enthusiastic immune response. We are now testing PD1/PDL1 and CTLA-4 inhibitors to stop the immune system from protecting cancer cells, essentially taking the brakes off the immune system.

Some such agents, including pembrolizumab, avelumab, atezolizumab, tremelimumab and ipilimumab, are currently in testing or have recently been tested in malignant mesothelioma. Though some studies have not reported favorable results, these immunotherapies will continue to be tested in clinic as we continue to gain further understanding of how best to use them. We may see them used in the newly diagnosed, after surgery to prevent the return of cancer, in the metastatic setting, and/or combined with others in this class of agents.

Mesothelin Directed Therapy

Mesothelin is a protein found on the outside of epithelial mesothelioma cells, which was discovered at the National Cancer Institute. This has been an exciting breakthrough in mesothelioma, resulting in a number of clinical trials being developed to exploit mesothelin as a target.

Amatuximab, a monoclonal drug antibody that targets mesothelin, is now being tested in a trial to determine if adding amatuximab to our current FDA approved regimen is better than the standard treatment.

Anetumab ravtansine, an antibody drug conjugate that targets mesothelin, is being tested in a randomized trial of vinorelbine vs. anetumab. The results of this trial, if positive,

could bring about an approval for anetumab in the second line setting for mesothelioma. BMS-986148 is another antibody drug conjugate that targets mesothelin, and it is currently in a Phase I/II trial for solid tumors (there are a number of additional cancers which express mesothelin).

Vaccines are also being developed to target mesothelin. For example, CRS 207 is a vaccine that utilizes a modified version of the listeria virus to kill mesothelioma tumors.

There are also a number of trials that modify the patients' own immune cells (T-cells) to recognize and attack mesothelioma tumors by targeting mesothelin.

Below you will find a list of currently available clinical trials in the US. Please keep in mind that some trials may have closed or opened while we were in print. Please contact us for the most updated information.



A Phase 2 Study of Durvalumab in Combination With Tremelimumab in Malignant Pleural Mesothelioma

Condition: Mesothelioma
Interventions: Drug: Tremelimumab|Drug: Durvalumab
Phases: Phase 2
Location/s: Massachusetts

A Pilot Window-Of-Opportunity Study of the Anti-PD-1 Antibody Pembrolizumab in Patients With Resectable Malignant Pleural Mesothelioma

Condition: Pleural Mesothelioma
Interventions: Drug: Pembrolizumab|Drug: Cisplatin and Pemetrexed
Phases: Phase 1
Location/s: Illinois

Intrapleural Cryotherapy for Malignant Pleural Mesothelioma

Condition: Mesothelioma
Interventions: Device: Cryotherapy|Other: Control
Phases: Phase 1
Location/s: Minnesota

MEDI4736 Or MEDI4736 + Tremelimumab In Surgically Resectable Malignant Pleural Mesothelioma

Condition: Mesothelioma
Interventions: Drug: MEDI4736|Drug: Tremelimumab|Other: Untreated arm (control)
Phases: Phase 2
Location/s: Texas

Adjuvant Pembrolizumab After Radiation Therapy for Lung-Intact Malignant Pleural Mesothelioma

Condition: Malignant Pleural Mesothelioma
Interventions: Radiation: Hemithoracic Radiation Therapy|Radiation: Palliative Radiation Therapy|Drug: Pembrolizumab
Phases: Phase 1
Location/s: Texas

Transarterial Chemoperfusion: Cisplatin, Methotrexate, Gemcitabine for Unresectable Pleural Mesothelioma

Condition: Malignant Pleural Mesothelioma|Mesothelioma
Interventions: Drug: Cisplatin|Drug: Methotrexate|Drug: Gemcitabine|Other: Lung Cancer Symptom Scale for Mesothelioma Questionnaire
Phases: Phase 2
Location/s: Florida

Mesothelin-Targeted Immunotoxin LMB-100 in People With Malignant Mesothelioma

Condition: Mesothelioma
Interventions: Drug: LMB-100|Drug: nab-paclitaxel
Phases: Phase 1
Location/s: Maryland

Study of Cytoreductive Surgery and Hyperthermic Intraoperative Chemotherapy With Pemetrexed and Cisplatin for Malignant Pleural Mesotheliomas

Condition: Mesothelioma
Interventions: Drug: Pemetrexed|Drug: Cisplatin
Phases: Phase 1
Location/s: Texas

Accelerated Hypofractionated Radiation Therapy Immediately Before Surgery in Treating Patients With Malignant Pleural Mesothelioma

Condition: Pleural Epithelioid Mesothelioma|Pleural Malignant Mesothelioma
Interventions: Radiation: Hypofractionated Radiation Therapy|Radiation: Intensity-Modulated Radiation Therapy|Other: Laboratory Biomarker Analysis|Procedure: Therapeutic

Conventional Surgery
Phases: Early Phase 1
Location/s: California

Trial of Adcetris in CD30+ Malignant Mesothelioma

Condition: Lung Diseases Due to External Agents|Mesothelioma
Interventions: Drug: Brentuximab Vedotin
Phases: Phase 2
Location/s: Texas

Intrapleural Measles Virus Therapy in Patients With Malignant Pleural Mesothelioma

Condition: Recurrent Malignant Mesothelioma|Stage IA Malignant Mesothelioma|Stage IB Malignant Mesothelioma|Stage II Malignant Mesothelioma|Stage III Malignant Mesothelioma|Stage IV Malignant Mesothelioma
Interventions: Biological: oncolytic measles virus encoding thyroidal sodium iodide symporter|Other: laboratory biomarker analysis|Procedure: single photon emission computed tomography|Procedure: computed tomography
Phases: Phase 1
Location/s: Minnesota

Pembrolizumab in Treating Patients With Malignant Mesothelioma

Condition: Biphasic Mesothelioma|Epithelioid Mesothelioma|Peritoneal Malignant Mesothelioma|Pleural Biphasic Mesothelioma|Pleural Epithelioid Mesothelioma|Pleural Malignant Mesothelioma|Pleural Sarcomatoid Mesothelioma|Recurrent Peritoneal Malignant Mesothelioma|Rec
Interventions: Biological: Pembrolizumab|Other: Laboratory Biomarker Analysis|Other: Pharmacogenomic Study
Phases: Phase 2
Location/s: Illinois

MPM PDT Phase II Trial

Condition: Epithelioid Malignant Pleural Mesothelioma
Interventions: Radiation: Photodynamic Therapy|Procedure: Radical Pleurectomy|Radiation: Chemotherapy|Drug: Photofrin 2.0 mg/kg
Phases: Phase 2
Location/s: New York, Pennsylvania

Genetically Modified T Cells in Treating Patients With Stage III-IV Non-small Cell Lung Cancer or Mesothelioma

Condition: Advanced Pleural Malignant Mesothelioma|HLA-A*0201 Positive Cells Present|Recurrent Non-Small Cell Lung Carcinoma|Recurrent Pleural Malignant Mesothelioma|Stage III Non-Small Cell Lung Cancer|Stage III Pleural Mesothelioma|Stage IIIA Non-Small Cell Lung C
Interventions: Biological: Aldesleukin|Biological: Autologous WT1-TCRc4 Gene-transduced

CD8-positive Tcm/Tn Lymphocytes|Drug: Cyclophosphamide|Other: Laboratory Biomarker Analysis|Procedure: Therapeutic Conventional Surgery
Phases: Phase 1|Phase 2
Location/s: Washington

Ph 2/3 Study in Subjects With MPM w/Low ASS 1 Expression to Assess ADI-PEG 20 With Pemetrexed and Cisplatin

Condition: Mesothelioma
Interventions: Drug: ADI-PEG 20 plus Pem Cis|Other: Placebo plus Pem Cis
Phases: Phase 2|Phase 3
Location/s: Florida, New York

Nintedanib in Treating Patients With Malignant Pleural Mesothelioma That Is Recurrent

Condition: Recurrent Pleural Malignant Mesothelioma|Stage IV Pleural Mesothelioma
Interventions: Drug: Nintedanib
Phases: Phase 2
Location/s: Michigan

±DC1 Vaccine + Chemokine Modulatory Regimen (CKM) as Adjuvant Treatment of Peritoneal Surface Malignancies

Condition: Malignant Neoplasm of Pancreas Metastatic to Peritoneal Surface|Malignant Peritoneal Mesothelioma|Peritoneal Carcinomatosis
Interventions: Biological: DC vaccine|Drug: Celecoxib|Drug: Interferon Alfa-2b|Biological: rintatolimod
Phases: Phase 1|Phase 2
Location/s: Pennsylvania

Malignant Pleural Disease Treated With Autologous T Cells Genetically Engineered to Target the Cancer-Cell Surface Antigen Mesothelin

Condition: Malignant Pleural Disease|Mesothelioma|Metastases|Lung Cancer|Breast Cancer
Interventions: Genetic: iCasp9M28z T cell infusions|Drug: cyclophosphamide
Phases: Phase 1
Location/s: New York

CAR T Cell Receptor Immunotherapy Targeting Mesothelin for Patients With Metastatic Cancer

Condition: Cervical Cancer|Pancreatic Cancer|Ovarian Cancer|Mesothelioma|Lung Cancer
Interventions: Drug: Fludarabine|Biological: Anti-mesothelin CAR|Drug: Cyclophosphamide|Drug: Aldesleukin
Phases: Phase 1|Phase 2
Location/s: Maryland

CAR T Cells in Mesothelin Expressing Cancers

Condition: Lung Adenocarcinoma|Ovarian Cancer|Peritoneal Carcinoma|Fallopian Tube Cancer|Mesotheliomas Pleural|Mesothelioma Peritoneum
Interventions: Biological: Hu-CART meso cells
Phases: Phase 1
Location/s: Pennsylvania

Mithramycin for Lung, Esophagus, and Other Chest Cancers

Condition: Lung Cancer|Esophageal Cancer|Meso-
thelioma|Gastrointestinal Neoplasms|Breast
Cancer
Interventions: Drug: Mithramycin
Phases: Phase 2
Location/s: Maryland

Evaluation of CRS-207 With Pembrolizumab in Previously Treated MPM

Condition: Malignant Pleural Mesothelioma
Interventions: Biological: CRS-207|Biological:
Pembrolizumab
Phases: Phase 2
Location/s: Florida, Illinois

Phase II MEDI4736 in Combination With Chemotherapy for First-Line Treatment of Unresectable Mesothelioma

Condition: Mesothelioma|Pleural Mesothelioma
Interventions: Drug: Concurrent
Durvalumab|Drug: Maintenance Durvalumab
Phases: Phase 2
Location/s: California, Colorado, Illinois,
Maryland, New Jersey, New York, Pennsylvania

Nintedanib (BIBF 1120) in Mesothelioma

Condition: Mesothelioma
Interventions: Drug: Nintedanib|Drug:
Pemetrexed|Drug: Cisplatin|Drug:
Cisplatin|Drug: Pemetrexed|Drug: Placebo
Phases: Phase 3
Location/s: Alabama, California, Colorado,
Nevada, Pennsylvania, South Carolina, Texas,
Washington

Study of Nivolumab Combined With Ipilimumab Versus Pemetrexed and Cisplatin or Carboplatin as First Line Therapy in Unresectable Pleural Mesothelioma Patients

Condition: Mesothelioma
Interventions: Biological: Nivolumab|Biological:
Ipilimumab|Drug: Pemetrexed|Drug:
Cisplatin|Drug: Carboplatin
Phases: Phase 3
Location/s: Connecticut, Florida, Illinois,
Michigan, New York, Ohio, Pennsylvania, West
Virginia

Pleurectomy/Decortication (Neo) Adjuvant Chemotherapy and Intensity Modulated Radiation Therapy to the Pleura in Patients With Locally Advanced Malignant Pleural Mesothelioma

Condition: Mesothelioma
Interventions: Procedure: Pleurectomy/
Decortication|Drug: pemetrexed and cisplatin
or carboplatin|Radiation: Intensity Modulated
Radiation Therapy
Phases: Phase 2
Location/s: New Jersey, New York

Continuous 24h Intravenous Infusion of Mithramycin, an Inhibitor of Cancer Stem Cell Signaling, in People With Primary Thoracic Malignancies or Carcinomas, Sarcomas or Germ Cell Neoplasms With Pleuropulmonary Metastases

Condition: Esophageal Neoplasms|Lung
Neoplasms|Mesothelioma|Thymus
Neoplasms|Neoplasms, Germ Cell and
Embryonal
Interventions: Drug: Mithramycin
Phases: Phase 1|Phase 2
Location/s: Maryland

Methoxyamine, Cisplatin, and Pemetrexed Disodium in Treating Patients With Advanced Solid Tumors or Mesothelioma That Cannot Be Removed by Surgery or Mesothelioma That Is Refractory to Pemetrexed Disodium and Cisplatin or Carboplatin

Condition: Advanced Malignant Solid
Neoplasm|Advanced Peritoneal Malignant
Mesothelioma|Advanced Pleural Malignant
Mesothelioma|Recurrent Malignant Solid
Neoplasm|Recurrent Peritoneal Malignant
Mesothelioma|Recurrent Pleural Malignant
Mesothelioma|Stage III Non-Smal
Interventions: Drug: Cisplatin|Other: Laboratory
Biomarker Analysis|Drug: Methoxyamine|Drug:
Pemetrexed Disodium|Other: Pharmacological
Study
Phases: Phase 1|Phase 2
Location/s: California, Colorado, Maryland,
Minnesota, Ohio, Pennsylvania, Tennessee,
Wisconsin

Bosutinib in Combination With Pemetrexed in Patients With Selected Metastatic Solid Tumors

Condition: Carcinoma, Non-Small-Cell
Lung|Mesothelioma|Bladder Cancer|Ovarian
Cancer|Peritoneal Cancer|Thymoma|Thymus
Cancer|Uterine Cervical Cancer
Interventions: Drug: Bosutinib|Drug: Pemetrexed
Phases: Phase 1
Location/s: Ohio

Clinical Trial of Intraperitoneal Hyperthermic Chemotherapy

Condition: Ovarian Cancer|Peritoneal
Cancer|Fallopian Tube Cancer|Uterine
Cancer|Mesotheliomas|Gastrointestinal
Cancers|Cervical Cancer
Interventions: Device: HIPEC: MMC 30mg @
T0, 10mg @ T45min|Device: HIPEC: MMC +
CDDP 30mg @ T0, 10mg @ T45min 50 mg/
m2 @T0|Device: HIPEC: CDDP 75 mg/m2 @
T0|Device: HIPEC: CDDP+ Doxorubicin 50 mg/
m2 @T0 15 mg/m2 @T0
Phases: Phase 2
Location/s: California

Safety Study of MGD009 in B7-H3-expressing Tumors

Condition: Mesothelioma|Bladder
Cancer|Melanoma|Squamous Cell
Carcinoma of the Head and Neck|Non
Small Cell Lung Cancer|Clear Cell Renal
Cell Carcinoma|Ovarian Cancer|Thyroid
Cancer|Breast Cancer|Pancreatic
Cancer|Prostate Cancer|Colon Cancer|Soft
Tissue Sarcoma
Interventions: Biological: MGD009
Phases: Phase 1
Location/s: North Carolina, Pennsylvania, Texas

Phase Ib Study of Anetumab Ravtansine in Combination With Pemetrexed and Cisplatin in Mesothelin-expressing Solid Tumors

Condition: Medical Oncology
Interventions: Drug: BAY 94-9343|Drug:
Pemetrexed|Drug: Cisplatin
Phases: Phase 1
Location/s: Illinois, Maryland, Michigan, South
Carolina

A Study of LY3023414 in Participants With Advanced Cancer

Condition: Advanced Cancer|Metastatic
Cancer|Non-Hodgkin's Lymphoma|Metastatic
Breast Cancer|Malignant Mesothelioma|Non-
small Cell Lung Cancer
Interventions: Drug: LY3023414|Drug:
Midazolam|Drug: Fulvestrant|Drug:
Pemetrexed|Drug: Cisplatin
Phases: Phase 1
Location/s: California, New York, Oklahoma,
Pennsylvania, Tennessee

Study of the Glutaminase Inhibitor CB-839 in Solid Tumors

Condition: Solid Tumors|Triple-Negative Breast
Cancer|Non Small Cell Lung Cancer|Renal
Cell Carcinoma|Mesothelioma|Fumarate
Hydratase (FH)-Deficient Tumors|Succinate
Dehydrogenase (SDH)-Deficient Gastrointestinal
Stromal Tumors (GIST)|Succinate
Dehydrogenase (SDH)-D
Interventions: Drug: CB-839|Drug: Pac-CB|Drug:
CBE|Drug: CB-Er|Drug: CBD|Drug: CB-Cabo
Phases: Phase 1
Location/s: California, Florida, Georgia,
Massachusetts, New York, Pennsylvania,
Tennessee, Texas

A Study of the Safety, Tolerability and Pharmacokinetics of ABBV-368 as a Single Agent and Combination in Subjects With Locally Advanced or Metastatic Solid Tumors

Condition: Advanced or Metastatic Solid Tumors
Interventions: Drug: ABBV-368|Drug: Nivolumab
Phases: Phase 1
Location/s: North Carolina, Texas, Virginia

Phase 1/2 Study Exploring the Safety, Tolerability, and Efficacy of INCAGN01876 Combined With Immune Therapies in Advanced or Metastatic Malignancies

Condition: Advanced Malignancies|Metastatic
Malignancies
Interventions: Drug: INCAGN01876|Drug:
Nivolumab|Drug: Ipilimumab
Phases: Phase 1|Phase 2
Location/s: California, New Jersey

A Study of ABBV-181 in Participants With Advanced Solid Tumors

Condition: Advanced Solid Tumors
Interventions: Drug: ABBV-181
Phases: Phase 1
Location/s: Illinois, North Carolina, Texas,
Virginia

LUME-Meso

Are you or a loved one
recently diagnosed
with malignant pleural
mesothelioma?

Considering your options?

Learn about LUME-Meso, a clinical research study testing the safety and effectiveness of Nintedanib, an investigational medication for adults with malignant pleural mesothelioma.

Nintedanib is an oral product that can be taken at home.

To Learn More: Contact us at: 800-243-0127
or clintriage.rdg@boehringer-ingelheim.com

LUME-Meso



MESOTHELIOMA AWARENESS DAY 2017

In recognition of Mesothelioma Awareness Day (September 26), the Meso Foundation is back with a multitude of initiatives to help shine a spotlight on the nearly 3,000 Americans impacted by this aggressive, rare cancer each year.

Since launching in 2004 by our very own volunteers, it's hard to believe that Mesothelioma Awareness Day is now in its 13th year. The Meso Foundation is proud to be the driving force behind the movement to bring more attention and funding to this cancer.

We hope you will join us in showing your support for those impacted by mesothelioma in your community. Here's how!

For starters, we'll be kicking off the month by embarking on a national Satellite Media Tour to help raise awareness of mesothelioma risks and symptoms, the importance of medical research, and the crucial work we are doing to help usher in new treatments that can potentially improve the lives of those affected by this burdensome condition. Stay tuned for a chance to catch our spokespeople spreading our message on television stations across the country.

We'll also be hosting a multitude of awareness activities across the nation!



You can show your support by:

- Donning matching blue t-shirts and bracelets
- Sharing meso-related posts on social networks
- Educating yourself and talking with others about mesothelioma

Also, be sure to check out the family activities taking place in your area. See page 21 for a full list.

Catch more details on our social channels and foundation website at curemeso.org to stay up to date on the events taking place on and around this exciting day.

We hope you'll join us in spreading the word as we build momentum leading up to Mesothelioma Awareness Day!

opinion

WHAT CONCERNS DOES IMMUNOTHERAPY PRESENT?

BY LUCIANO MUTTI, MD

Immunotherapy has presented cancer patients with brand new hope for the future of therapies. However, with only a small subset of mesothelioma patients benefiting from this type of treatment and with the potential of serious side-effects, it is important for patients to be as informed as possible. For this reason, we publish below a critique of immunotherapy, penned by Dr. Luciano Mutti of the University of Salford.

For help understanding the points made below, or to become better informed of risks of immunotherapy, please contact Gleneara Bates, Meso Foundation's director of research and medical outreach.

Background

- The chronic inflammation that drives malignant pleural mesothelioma (MPM) leads to an altered immune response, which may partially explain the general lack of efficacy of immunotherapy.
- Just a small subpopulation of patients with MPM are eligible.
- Similarly, the low mutational load of MPM compared to other cancer types presents an additional explanation for potential reasons for immunotherapy therapy failure. Moreover, T-cell exclusion looks to be likely to confer resistance of MPM to this type of therapy (Feig et al., 2013, Schuberth et al., 2013).

Biological concerns

- Low mutation load eliciting weaker immune response.
- Inflammation leading to immunosuppression.
- High expression of FAP1 in tumor associated fibroblasts that causes lymphocytes exclusion.
- Switch to M2 (Guazzelli et al., 2017)

Clinical Concerns

End point

It has recently been demonstrated that surrogate end points for clinical trials (i.e. progression-free survival) do not reflect overall survival for immunotherapy trials and may often be significantly different. Caution has, therefore, been advised when analysing results containing only progression-free survival and not overall survival data. Future trials should aim to include information on overall survival wherever possible so as to provide the most comprehensive information available (Tan et al., 2017, Gyawali and Prasad, 2017a).

Clinical results so far

At the moment there are no clinical trials that show any significant improvement of overall survival of patients with MPM (Bakker et al., 2017).

In terms of the IFCT-1501 MAPS2 trial presented at ASCO 2017 we note:

- Selection bias: only patients with very good performance status (PS 0-1) were selected. Staging and other prognostic factors are not assessed. Other biases in patient selection cannot be ruled out.
- Just a small subpopulation of patients with MPM are eligible
- Overall survival was the same obtained with second line chemotherapy (Toyokawa et al., 2014, Stebbing et al., 2009).
- Intracavitary IL-2 achieved very similar results in terms of disease control rate and overall response rate (Castagneto et al., 2001).

irRC (immune-related response criteria):

If one also considers the difficulty to apply the immune-related response criteria to MPM and the rate and degree of side effects, it is obvious that particular caution is needed before drawing conclusions on tumour size reduction of MPM after ICIs.

Adverse effects

- Other than general concerns of combo treatment (Gyawali and Prasad, 2017b) in MAPS2 study the combo treatment caused 5% of treatment-related death.
- Moreover PDL1 toxicity is increasing debating and raising safety concerns (Kalluvila, 2017)

SYMPOSIUM: THE LAST THING I WANTED, THE BEST THING I NEEDED

BY LIZ MCNEECE



After a hard fought eleven-month battle of fighting this horrific disease called mesothelioma, my husband John died on August 29, 2016. After over 42 years of marriage, we had been through many, many roller coaster rides but hearing this news back in September 2015 was by far the worst news we have ever had. He is now resting peacefully and out of the pain, anguish and all the other emotional and physical experiences he had no choice but to face.

The question after his funeral was: Now what, and where do I go from here? Well, now it was time for me to do the suffering. Those of you who have had no choice but to join “the club” know of the physical and emotional pain you go through; again, this is no choice, it is a requirement. I have depended and will continue to rely on God, my family and friends to get me through each and every day. However, ultimately, the task is in my court. It is up to me to continue my life; clearly it was not me who died and my work on earth is not yet done.

During John’s illness, I was privileged to meet and have many conversations with Mary Hesdorffer. Initially, I was introduced to Mary at the advice of Dr. Joseph Friedberg at The University of Maryland Medical Center. She met with John and me after an appointment to discuss where he was at that particular stage and to answer any questions we may have had.

She was always a strong support for our family; her wisdom, knowledge, genuine concern and sensitivity to the situation was always a comfort. I began my introduction to the Mesothelioma Applied Research Foundation through Mary. She suggested I join an online support group for caregivers on Facebook. I then introduced my family to the foundation. We began to do some research to learn more

about its mission to combat mesothelioma. My family rallied together this past year to make a family donation to the cause. My relationship with the foundation has grown from there. I have since joined the spousal bereavement group through Facebook as well.

As I began receiving emails about the International Symposium on Malignant Mesothelioma, I started wondering if this might be something I would want to attend. I decided to call the foundation and spoke to Maja Belamaric, Director of Communications for the Mesothelioma Applied Research Foundation. I, at that point, had mixed emotions about attending. I was hesitant because I wasn’t sure if I would “fit in.” Maja was most gracious about answering my questions. I gave it much thought after that conversation, registered, and decided to go.

It was a huge step for me. I am fortunate to live only 31 miles from NIH, but packing up for three days and walking into a hotel by myself, not knowing how I was going to be greeted, was stressful. The first positive thing that happened was being able to meet one of the women in my support group and another spouse of a meso warrior at the hotel for dinner. That helped my anxiety level and gave me the courage to get up the next morning, get on the bus, and experience the Symposium and what it had to offer.

I attended seminars, support groups and met many people. I was fortunate to be embraced by two of John’s doctors along with two of his nurses. They were pleasantly surprised to see me.

As I listened to encouraging words from them, I continued my first experience with the symposium.

What was incredible was the warm embrace I received from everyone. You see, the one thing we all have in common —hundreds of people gathered in one location all affected by mesothelioma whether as a health care provider, scientist, warrior, or loved one — we all truly know what the other was feeling. Even though I continue to receive support through my friends, church, etc., they have not walked in my shoes; however, all the attendees at the symposium could offer the empathy we all need.

I attended some medical seminars which helped me understand the disease a bit better. The support groups were very helpful as

well. I listened carefully as other people spoke about their experiences. It was humbling. I knew I was not taking this journey alone any longer. My son was able to attend two afternoon seminars and met some adult children who had lost their parents to mesothelioma. It was a healing day for him, and both my son

...the one thing we all have in common —hundreds of people gathered in one location all affected by mesothelioma whether as a health care provider, scientist, warrior, or loved one...

and daughter are looking forward to attending future symposiums.

As I look back at my hesitation to participate in the symposium, I am very happy to have experienced what I did during the conference. I had good moments, bad moments, rewarding moments, sad moments, satisfying moments, and devastating moments. My life continues to be an emotional roller coaster; however, I am comforted to know the Mesothelioma Applied Research Foundation is providing the support I need. Whether it be the support groups, conferences, or just a phone call to add that special touch - I thank you immensely for introducing me to the symposium. Since I have no choice but to create a “new normal” for my life, I am safe in knowing you all are with me.



Celebration of Life

For those who have lost loved ones to mesothelioma.

Sardelli Italian Steakhouse
331 Van Buren Street
Hollywood, FL 33019

Friday, September 22
11am to 3pm

Contact Erica Ruble at (703) 879-3826 for more information.

THE PEOPLE BEHIND THE SCIENCE

Meet a few of the medical professionals and scientists who work, often behind the scenes, to find new treatments and improve existing ones.

Since the Meso Foundation's inception in 1999, we have worked with hundreds of doctors and nurses all devoted to finding better treatments and a cure for mesothelioma. Each medical professional brings with them a unique set of skills, interests, knowledge, and a background that have contributed to advancements in treating mesothelioma. Within the last five years, we have seen more clinical trials than ever before, and this has led to a longer life for patients with mesothelioma.

One of the ways that the medical community works with the Mesothelioma Applied Research Foundation is by serving as members of the Board of Directors. The Foundation's Board of Directors is responsible for laying the groundwork in all that we do to serve the mesothelioma community. Our fifteen

members of the Board are the fiduciary and ethical backbone of the organization.

The Meso Foundation's Science Advisory Board (SAB) is comprised of 15-20 mesothelioma researchers and physicians from around the world. They provide scientific and clinical direction for where the Foundation directs research funds. This is done through our esteemed peer-reviewed grant making process. The SAB also provides direction and insight into the mesothelioma field, which ensures that patients and caregivers hear about the latest cutting-edge treatments in mesothelioma.

In the following pages, you will get to read about some of our Board and SAB members who are making it their mission to advance mesothelioma research. We have members

who are looking at mesothelioma from unique angles, like SAB member Dr. Yang who is targeting a protein called HMGB1. This protein encourages cancer growth when activated, and Dr. Yang is looking for ways to halt that growth. There is also Board member Dr. Bechich. He knows that research cannot exist without access to tissue samples, so he has created the National Mesothelioma Virtual Bank, which provides samples to research professionals.

Those stories are just the beginning of the incredible work being done by the Board and SAB members. The Meso Foundation is proud to highlight these individuals. We will continue to work with thought leaders in this field as we move forward into the future with patient-centered treatment options.



Our CEO, Melinda Kotzian, recently had a brief conversation with Dr. Lee Krug, the former chair of the Meso Foundation's board of directors. Pictured above is Dr. Krug (middle) with two of our community members at the 2017 Symposium.

Melinda: First of all, congratulations on the Service Award.

Lee: Thanks so much! It was a really special honor for me. I am so proud of the work that

Lee Krug, MD

the Meso Foundation has done over the last several years, and it especially shows in the reputation that the organization has earned from both the patient and scientific communities. This was clearly evident at the Symposium this year which was a tremendous success.

Melinda: About two years ago, you left your position at Memorial Sloan Kettering Cancer Center to take a job in the pharmaceutical industry. How has that transition been for you?

Lee: The transition has been great, actually. Of course the biggest change is that I don't take care of patients anymore, and seeing the patients and families at the Symposium reminded me of what I left behind, which was hard. But this is such an unprecedented time in drug development, and it is exciting to be so directly involved in that. I have been able to leverage the skills and the connections that I had established at MSKCC, and just use them in a different way. It is especially encouraging to see how many promising clinical trials are currently ongoing in mesothelioma, and I am hopeful that at least some of these will lead to improved treatment options for patients. It's important to understand that any real progress

requires cooperation between the pharma companies, the researchers, and most importantly, the warriors and their caregivers.

Melinda: Can you describe your new role?

Lee: I lead a team within the group called "US Medical," and we have several broad functions. For example, our group works with the research team to help design clinical trials, and communicate the results once the data are available. We establish collaborations with researchers across the country to support their proposals. We also work closely with various partners within our company including Health Economics and Outcomes Research, Medical Information, Medical Education, and Commercial.

Melinda: Do you plan to stay involved with the Meso Foundation?

Lee: Absolutely! I hope to always remain a part of the Foundation's community. Furthermore, my company, and others, partner closely with many advocacy groups, and we are currently exploring ways to make that happen to an even greater degree with the Meso Foundation.

Dr. Becich, a member of the Mesothelioma Applied Research Foundation's board of directors, is a board certified Pathologist and is currently Distinguished University Professor and Chairman of the Department of Biomedical Informatics at the University of Pittsburgh School of Medicine. He is jointly appointed in Pathology, Bioengineering, Information Sciences/Telecommunications, and Clinical/Translational Research. He is Associate Director for Cancer Informatics of the University of Pittsburgh Cancer Institute (see http://www.upci.upmc.edu/about/research_leadership.cfm) as well as Associate Director of the Clinical and Translational Science Institute at the University of Pittsburgh School of Medicine (see <http://www.ctsi.pitt.edu/informatics.shtml>). Dr. Becich's research interests are focused on the interface between clinical informatics and bioinformatics, particularly in the use of biobanking as a key tool to enable translational research. His research is funded by the NCI, NCATS, NHLBI, NLM and PCORI, and includes clinical phenotyping of patients for genome wide association studies/next generation sequencing, tissue banking informatics, clinical informatics and bioinformatics with a special emphasis on data sharing. Dr. Becich has over 150 publications, and the majority relate to tissue banking informatics as a critical research enabler. The National Mesothelioma Virtual Bank (see <http://www.mesotissue.org>) funded by the National Institute of Occupational Safety and Health (NIOSH) of the Centers for Disease Control (CDC) since 2006 is the most recent example of the "open" data sharing information platforms coupled with innovative tissue and blood/DNA sharing work flows that Dr. Becich has developed over the years. Dr. Becich and his team have been national leaders in tissue banking, honest broker practices, HIPAA compliant de-identification of clinical data, and the accompanying biomedical informatics to enable translational research utilizing biospecimens. For a full research profile, see <http://www.dbmi.pitt.edu/person/michael-j-becich-md-phd>. Examples of his highest impact publications in tissue banking informatics are included below:

84. Becich, M.J. The role of the Pathologist as tissue refiner and data miner: The impact of functional genomics on the modern pathology laboratory and the critical roles of Pathology Informatics and Bioinformatics. *Molec Diag.* 2000;5(4):287-299.

126. Becich M.J. Lessons Learned from the Shared Pathology Informatics Network (SPIN): A Scalable Network for Translational Research and Public Health. *J Am Med Inform Assoc.* 2007 Jul-Aug;14: 534-535.

128. Mohanty S.K.; Mistry A.T.; Amin W.; Parwani A.V.; Pople A.K.; Schmandt L.; Winters S.B.; Milliken E.; Kim P.; Whelan N.B.; Farhat G.; Melamed J.; Taioli E.; Dhir R.; Pass H.I.; Becich M.J. The development and deployment of Common Data Elements for tissue banks for translational research in cancer - an emerging standard based approach for the Mesothelioma Virtual Tissue Bank. *BMC Cancer.* 2008 Apr 8;8:91.

130. Amin W.; Parwani A.V. ; Schmandt L.; Mohanty S.K.; Farhat G.; Pople A.K.; Winters S.B.; Whelan N.B.; Schneider A.M.; Milnes J.T.; Valdivieso F.A.; Feldman M.; Pass H.I.; Dhir R.; Melamed J. and Becich M.J. National Mesothelioma Virtual Bank: a standard based biospecimen and clinical data resource to enhance translational research. *BMC Cancer* 2008, Aug. 13;8(1):236. PMC 2533341

134. Dhir R.; Patel A.A.; Winters S.; Bisceglia M.; Swanson D.; Aamodt R.; Becich M.J. A multidisciplinary approach to honest broker services for tissue banks and clinical data: a pragmatic and practical model. *Cancer.* 2008 Oct 1;113(7):1705-15. PMID: 18683217, PMC 2745185

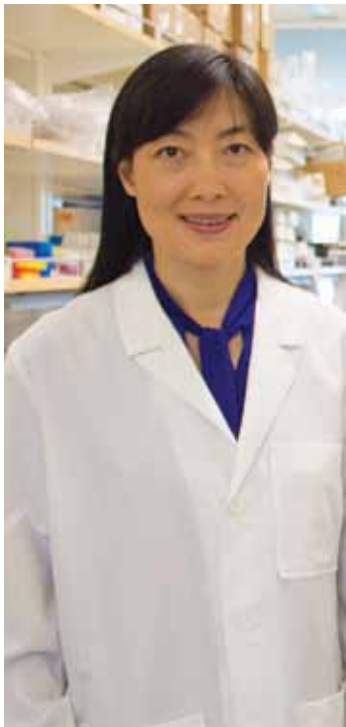
141. Amin W, Singh H, Pople AK, Winters S, Dhir R, Parwani AV, Becich MJ. A decade of experience in the development and implementation of tissue banking informatics tools for intra and inter-institutional translational research. *J. Pathology Informatics.* 2010 August 10, 2010:1:12. PMC 2941965

143. Wilson RA, Chapman WW, DeFries SJ, Becich MJ, Chapman BE. Automated ancillary cancer history classification for mesothelioma patients from free-text clinical reports. *J Pathol Inform* 2010;1:24. PMC 2956176

Michael J. Becich, MD, PhD

Member, Board of Directors
Mesothelioma Applied
Research Foundation

Haining Yang, MD, PHD Member, Science Advisory Board
Mesothelioma Applied Research Foundation



Dr. Haining Yang's research work focuses on the pathogenesis of mesothelioma, a malignancy often related to exposure to asbestos or other carcinogenic mineral fibers. Her research goal is to find novel strategies for mesothelioma early detection, prevention, and therapy. During years of study, Dr. Yang has discovered some key mechanisms of asbestos-induced carcinogenesis. She found that asbestos induces cell necrosis, causing the release of a critical factor called High Mobility Group Box 1 protein (HMGB1). HMGB1 functions as the "master switch" that when turned on, kick starts a series of inflammatory responses that over time lead to malignant transformation of mesothelial cells and mesothelioma development. Moreover, she found that mesothelioma cells that grow out of an HMGB1-rich environment are "addicted" to HMGB1 and require it for tumor growth and progression. Therefore, Dr. Yang is exploring targeting HMGB1 as a novel therapeutic strategy for mesothelioma. Dr. Yang and her research team found that both mesothelioma patients and asbestos-exposed individuals have significantly higher serum HMGB1 levels compared

to heavy smokers or healthy people. They also discovered that HMGB1 and its specific isoforms are sensitive and specific biomarkers to detect asbestos exposure and to identify mesothelioma patients.

Besides the studies on HMGB1, Dr. Yang, in collaboration with Dr. Michele Carbone, discovered that heterozygous germline BAP1 mutations predispose to malignant mesothelioma. These findings opened a new research field studying the mechanisms of gene-environment interaction in causing mesothelioma, and led to the discovery of a new cancer syndrome that was named the "BAP1 cancer syndrome".

Dr. Yang's research is funded by the National Cancer Institute, the V-Foundation, and the Department of Defense. Dr. Yang received EU Marie Curie Scholarship from the European Commission Marie Curie Actions Program in 2005, and she was one of the recipients of the American Association for Cancer Research (AACR) Innovative Landon Award for International Collaboration in Cancer Research in 2008.

**Marjorie G. Zauderer,
MD, MS, FACP**

Member, Science Advisory Board
Mesothelioma Applied Research Foundation



As a medical oncologist and Co-Director of the Memorial Sloan Kettering (MSK) Mesothelioma Program, my research interests revolve around improving treatment options for this disease. My work is translational, meaning that I facilitate laboratory discoveries finding their appropriate applications in clinical care. Similarly, I help bring noteworthy clinical observations and outcomes back to the laboratory so that we can learn more about the biology and underpinnings of what is happening in people with mesothelioma. In addition to standard care, the MSK Mesothelioma Program has at least one clinical trial option available at most points in care.

In particular, our program focuses on thorough tumor specimen profiling to help align patients with the therapies from which they

are most likely to benefit. To that end, I have worked extensively on trying to target and exploit BAP1 loss, the most common molecular aberration in mesothelioma. We recently completed accrual to a multicenter phase II trial of tazemetostat in BAP1 deficient mesothelioma (NCT02860286) and eagerly await the results. Additionally, we have a new clinical trial opening this summer to target alterations in NF2 by using a NEDD8 inhibitor, pevonedistat.

We are also exploring a variety of immunotherapeutic treatments that exploit our tumor profiling efforts. For example, for tumors with high mesothelin expression, we have a clinical trial in which T-cell chimeric antigen receptors (CARs) are generated to target mesothelin (NCT02414269). After a blood donation, T-cells are extracted from the blood and

modified to target mesothelin. Patients subsequently receive back their own modified T-cell CARs to attack their mesothelioma. We are also investigating the optimal use of a WT1 cancer vaccine, Galinpepimut-S, to trigger people's own immune systems to selectively target and destroy cancer cells with WT1, which is usually highly expressed in mesothelioma. Importantly, the early stages of research and development of this vaccine were partially supported by the Mesothelioma Applied Research Foundation. While subsequent federal grants and industry funding supported the recently completed randomized phase II study of this vaccine in mesothelioma (NCT01265433), it would not have been possible to bring this novel therapeutic into the clinic without the crucial early support of the Meso Foundation.

Melissa Culligan, RN, MS Member, Board of Directors
Mesothelioma Applied Research Foundation



Mesothelioma research has been an important focus and passion in my 30-year career as a thoracic surgery nurse. My current roles as a Clinical Instructor in Surgery at the University of Maryland School of Medicine, Director of Clinical Research for the Division of Thoracic Surgery at the University of Maryland Medical Center and Program Administrator for the Division of Thoracic Surgery afford me the ability to actively participate in both patient care and clinical research. I have served as a member of the Board of Directors for the Mesothelioma Applied Research Foundation for nearly three years and I am the current Chair of the International Thoracic Oncology Nurse Forum. Both of these roles further broaden my exposure and ability to make a positive impact on the care and outcomes of mesothelioma patients beyond my home institution. I received my undergraduate degree from Wilkes University and went on to receive a Masters of Science degree from

Drexel University's College of Medicine in area of Clinical Research Organization and Management.

I first started caring for mesothelioma patients at the Hospital of the University of Pennsylvania in 1987. It was at that time when I first realized the limited treatment options available for mesothelioma patients and how important it was to find not only more effective treatments but to also improve the post-operative care patients received after undergoing diagnostic, palliative or cytoreductive surgery. Since that time, I have had the great fortune of participating in multiple mesothelioma clinical trials including lung-sparing surgery combined with intraoperative photodynamic therapy and intra-pleural gene therapy. My work as a clinical research nurse in thoracic surgery has allowed me to meet with countless mesothelioma patients and their families and help them to better understand the role and importance of clinical research and support them through their journey. I have witnessed and shared in the experience of tremendous advances in the field of mesothelioma over the past 30 years, among them including Alimta coming on the scene as the first effective systemic therapy, lung sparing surgery evolving as the preferred cytoreductive procedure for pleural mesothelioma, the advent of indwelling pleural catheters for the management of recurrent pleural effusions, advances in immunotherapy and combined treatments for mesothelioma, and the establishment of international collaborative mesothelioma research networks. In my current role, I am working with our multidisciplinary team to grow and expand the Comprehensive Mesothelioma Center at the University of Maryland where we are focused on providing state-of-the-art treatment and care to mesothelioma patients including not only standard of care treatments but innovative clinical trials. Over the next 20 years, I will continue my work with basic science, translational and clinical researchers in our shared mission of working to improve the lives of those affected by mesothelioma.

Brooke Mossman, MS, PhD Member, Science Advisory Board
Mesothelioma Applied Research Foundation



Brooke Taylor Mossman, MS, PhD, has over 30 years of research and training experience in the field of environmental and occupational lung diseases. After elucidating the important roles of oxidative stress and related cell signaling pathways in the development of mesotheliomas by amphibole asbestos fibers, she and her laboratory have focused on blocking these pathways in prevention and therapy of human mesotheliomas. The discovery that pathogenic asbestos fibers stimulated a number of growth and survival-related pathways linked to protein receptors, e.g. the Epidermal Growth Factor Receptor (EGFR), mitogen-activated protein kinases (MAPK), and receptor tyrosine kinases (RTKs), many of which are

activated in mesotheliomas, has led to multi-functional therapeutic approaches in human mesothelioma patients. Her research has been supported by funding from several institutes of the NIH, the EPA, the American Cancer Society, and the Meso Foundation. She received a Career Achievement Recognition Award for her scientific accomplishments from the American Thoracic Society and the Wagner Award from the International Mesothelioma Interest Group for historic contributions to mesothelioma research. She currently is a member of the Science Advisory Boards of the Meso Foundation and the National Virtual Mesothelioma Bank and has published more than 300 scientific articles and book chapters.



“WE COMPLETE EACH OTHER”

Two friends — one left lung and one right lung between the two of them — discuss family, friendship, life after diagnosis.

Heather and John, two mesothelioma warriors, found one another in 2013 on Facebook. Shortly after connecting, they realized their experiences were similar, and hit it off from there. The friendship developed easily. “We’re both punks at heart. It was a natural fit,” John told us. Through their mesothelioma experience, they’ve now been friends for five years. Recently, we caught up with them to ask them some questions about their lives, families, and life after diagnosis.

Can you tell us a bit about your diagnosis? What led you to seek medical help to begin with?

John: In spring of 2012, I began experiencing flu-like symptoms. I went in for an x-ray and a pleural effusion was found around my right lung. This began a three-month process of exploration and elimination as I got two thoracentesis procedures and eventually a VAT surgery that determined I had malignant pleural mesothelioma.

Heather: I was diagnosed with malignant pleural mesothelioma on November 21st, 2005, just 3 ½ months after the birth of my only baby. I had never heard of mesothelioma that I could recall, and my doctor had never

treated it. He, along with his colleagues, found surgical options for me and presented them to my husband and me. They said my best option for beating this was to opt for the surgery, called an extra pleural pneumonectomy, and proceeded to give me a brief description. They said my best chance for success was with Dr. David Sugarbaker, who at the time was in Boston 1400 miles away from my home in Minnesota. He has since moved his practice to Houston. Without missing a beat, my husband said, “Get us to Boston.” Twelve days later I was there, and got the news that I was a perfect candidate for the surgery. Wanting to be alive to raise my daughter was all the motivation I needed to see a specialist and beat this cancer. I knew I was up against some pretty steep odds but I had a couple of things on my side, my age, and the fact my cancer had not spread. It was worth the risk for us to try and do everything we could.

What procedures/treatments did you undergo following diagnosis?

John: After the VAT determined it was mesothelioma, I underwent three rounds of chemotherapy (Alimta and Cisplatin), an EPP surgery (removal of the lung, diaphragm, and the pericardium), and then radiation. All of my treatment was handled at the Cleveland Clinic, mercifully five minutes from my house. My treatment ran from June until December of 2012.

Heather: On February 2, 2006, I had an extrapleural pneumonectomy with heated chemotherapy, with Dr. Sugarbaker. I was in the hospital 18 days due to kidney failure, but the issues got better and I was finally released. I spent a month in Boston recovering, then finally got the green light to go home. I followed surgery with adjunct chemotherapy, (carboplatin and Alimta) 4 sessions, and then 6 weeks or 30 sessions of IMRT Radiation. IMRT means Intensity-moderated radiation therapy. The radiation was by far the worst part.

How long was your recovery?

John: Each stage of the treatment process had its own recovery time and issues, so that is a complex question. I weathered chemotherapy rather well, only experiencing tiredness and the development of a blood clot in my good lung. The infusions were spaced three weeks apart. My last infusion was two weeks before my surgery, which was the first week of September. So I had a summer’s worth of chemotherapy. After my EPP surgery, I spent six weeks recovering before the radiation treatments began. I had twenty-seven sessions of radiation. One side effect of the radiation was the slowing of the healing from the surgery, but I healed anyway. My radiation treatments ended in early November. Both during and afterward, I had complications due to dehydration; these complications hospitalized me twice, once in November

and again in December. I was home and done with it all by mid December. It was at least five months into 2013 before I felt well again. The major issue was weight loss — I lost around 30 pounds — which I countered with a milk shake before bed each evening. By summer of 2013 I was feeling fully myself again. Five years later, I don't remember what it feels to have two lungs. My pre-EPP life feels like antiquity.

Heather: Sometimes I STILL feel like I'm recovering. I don't know if one ever does recover 100% from all that my body has been through. I would say that by 18 months post surgery I felt like I was actually going to be ok, but now, over 11 years later, I still struggle with breathing issues, pain and stamina.

You each have one lung – how is your life/life-style different because of it?

John: On the whole, I function pretty well. I sometimes struggle on stairs and inclines. Extreme humidity and cold both affect me. Swimming is tough both from a pressure and buoyancy standpoint. Nothing serious though. I carry on like a regular dude, working, playing, coaching, having fun. I am a musician, so getting back behind the drums was a priority for me. The removal of a rib in my back as part of my surgery has made my drumming a tad more complicated, but I've adapted and found that limiting my right arm movement a bit has helped. I've worked hard to maintain normalcy when it comes to my health and my lifestyle. I think I've succeeded.

Heather: I had to quit my job as a salon professional and sell my portion of the business I owned. I was never able to return to the salon industry because of breathing issues and complications with my left hand going numb after treatment. I started blogging and doing patient advocacy to be able to give back to the community. I know I don't have the energy I used to have, but I try to do my best. I live very much in the moment and know how quickly life can change. I look at things far differently than I did before cancer and would say that I'm a better person for it. I've tried to take something terrible and find the good. The people I've met ARE the good! Also, getting out of my head and helping others. That is what gave me purpose again. Cancer takes away so much; finding your footing again is hard for so many. I'm lucky, I guess, I was able to use my cancer diagnosis and experience and have been able

to help others along the way.

How long after meeting one another did it occur to you that you each have retained the opposite lung?

John: That was a sudden and exciting revelation. I thought for sure that I was the only late 30s patient with a missing lung. Turns out Heather and others are in similar boats. This gave me hope that others out there can relate to the treatment I received but also to the emotional stuff about this rather intense diagnosis, especially since Heather and I are both parents.

Heather: I'm pretty sure we figured that out in our first conversation. **Me:** "What lung did you have taken out?" **John:** "My right, you?" **Me:** "My left. HEY!! Together we make a whole person!" **John:** "You complete me!" (Ok, so maybe it wasn't EXACTLY like that, but close!)

Another similarity between the two of you that comes to mind is that you both have daughters. What is the best thing about parenthood to you? What's the worst?

John: My Eva was four when I was diagnosed. Now she is nine. I cannot think of her without thinking about my cancer. I lost time with her when I was in treatment and recovering. I cannot be the complete father I want to be each day. People need to understand that a mesothelioma diagnosis is paradoxical. The average survival for a patient is eighteen months. The five-year survival rate is 5%. Therefore every day, week, month, year a patient lives, the more likely the cancer returns. The cancer is incurable. It's a troubling thing to live with each day. I just passed five years post-diagnosis, quite a feat. But the reality of this cancer and its inevitable return lives with me each day. So how does that impact my parenting? I can summarize it this way: Whereas some folks might lament their child growing or long for those times when their children were babies or toddlers, I embrace and cherish each and every step Eva takes growing up. I'm living on borrowed time. It's a privilege to experience her growth. That's my reality.

Heather: Simply being here to be a parent is the best. PERIOD. I was told I would possibly

live only 15 months. It was a very real possibility I would not live to see my baby turn two. So yeah, just simply being here to watch her grow and turn into a pretty amazing person is awesome. The worst? Knowing that every day she lives with the knowledge that the cancer could come back at any time. As a parent, sometimes you want to shield your young kids from hurtful things. This is such a part of our lives, that every day I talk to someone newly diagnosed, she knows how fast things can change — we don't hide it from her. She handles it really well by talking openly and honestly about her feelings on the matter. It helps, I think, to do that, and not make it a big off limits subject.

Is there anything I didn't ask here that you absolutely feel like sharing with our readers?

John: Any cancer diagnosis can make a person feel lonely and desperate. There were multiple times early on when I thought about just walking into Lake Erie and walking until I either reached Canada or drowned. That kind of thinking is unavoidable. Being told you have an incurable cancer is quite a blow. Therapy has helped immensely. As has music, my real therapy. But finding Heather, hearing her story, seeing the normalcy of her life, meeting others like Heather...

like me — it all helped me understand I am not alone and that although I can't always be rosy and graceful, I can live a normal, happy, peaceful, and productive life with my family and friends. With or without cancer, these things are universal.

Heather: We all have our path with this disease, and no two journeys are the same. Even though John and I have similar experiences, we each have had our own personal struggles, setbacks, and triumphs, but we don't concentrate on those. I live in the moment, I concentrate on the good and try to find the light. This community is unlike any other — we support each other when we need, cry with each other, and celebrate when we have good news. These friendships are special — hold them, nurture them, they are life-changing. John and I hit it off for more than just the reasons here, but it is what brought us together. We call ourselves the Punk Rockers of the meso world. The people... it's the people that are the silver lining in every storm.

The people - it's the people that are the silver lining in every storm.

Whereas some folks might lament their child growing or long for those times when their children were babies or toddlers, I embrace and cherish each and every step Eva takes growing up. It's a privilege to experience her growth.

THE MESO FOUNDATION: WHO WE ARE

Each day, we work with patients, caregivers, family members, doctors, scientists, pharmaceutical companies, advocates, to name a few. Regardless of where you fit on this spectrum, we like to think of ourselves as **your partner in navigating mesothelioma.**

how **WE** help patients, caregivers, family members

One-On-One Support

Patient Travel Grant Program

Online Support Groups

Telephone Support Groups

Conferences

Meet the Mesothelioma Experts Series

how **WE** help scientists, physicians, medical professionals

Peer-Reviewed Research Funding

Scientific Conferences

Scientific Workgroups

Development of Materials to Help Your Patients

how **WE** help those who have lost a loved one

One-On-One Support

Support Groups

Private Gatherings

Informational Materials

how **YOU** can help us

In my many years working with this organization, there is a common thread throughout all our work, and that is our unique sense of community: doctors and scientists who socialize with patients and families at our Symposium; support groups helping patients and families through tough times; and the many Fundraise for Meso events organized by friends, families and companies to support researching a cure. I believe our unique community is a powerful asset in fighting the challenges of meso and ultimately improving patient outcomes, funding more research, and ensuring patients have access to the resources they need.

[If you are reading this letter, you are a member of our powerful community.](#)

Each year, more than 80% of our funding comes from individuals like you. And each year, demand for research grants, patient services, travel grants, educational events and community outreach continues to grow, along with the number of diagnosed cases of meso. [It is the meso community that comes together to help us meet this growing demand, and I write today to ask for your continued support. Whether you are new to the meso community, or a long-standing member, I hope you'll show your commitment to the fight against meso by using the enclosed envelope to make a gift today.](#) As the only nonprofit, charity organization dedicated to ending mesothelioma and the suffering caused by it, I can promise your gift is an investment in conquering this disease.

On behalf of everyone who will be impacted by meso this year, I thank you, and our community, for your generosity and commitment to finding a cure for meso.

Sincerely,

Melinda



Melinda Kotzian, Chief Executive Officer
Mesothelioma Applied Research Foundation

THE IMPORTANCE OF YOUR SUPPORT

As you can see, we rely on the generosity of individuals like you to support the research and patient services programs that have made a dramatic difference in the lives of those battling mesothelioma!

Visit curemeso.org/donate today, where you can make a gift in memory of a loved one, in support of one of our Fundraise for Meso fundraising events, in support of research, or for the general good of the organization.



BY THE NUMBERS

\$9.8 million
in mesothelioma research grants funded

103 studies
funded through the research grant program

\$12.4 million
in government funding directed to mesothelioma research

\$0.86 cents
of every dollar donated goes to programs

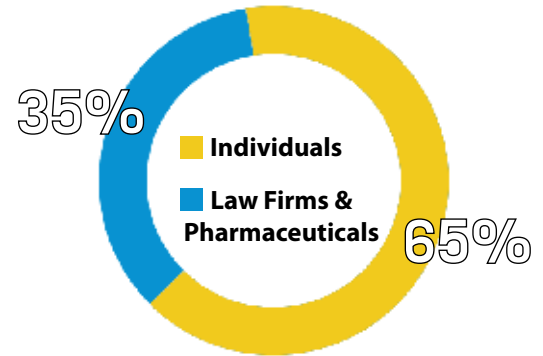
600 people
helped every month, including patients, caregivers, and bereaved

527 proposals
submitted to the research grant program

240 articles
resulted from Meso Foundation funding

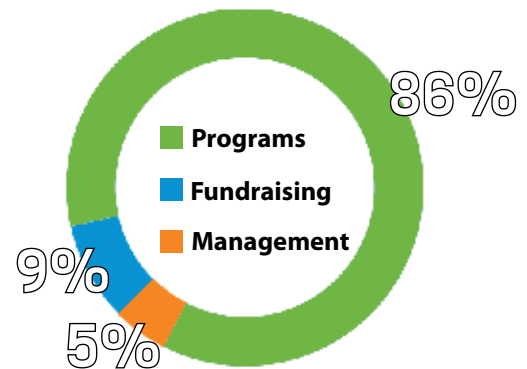
83 journals
published research funded by the Meso Foundation

WHERE THE MONEY COMES FROM



The Meso Foundation receives 65% of its donations from individual donors and 35% from law firms and pharmaceutical companies.

HOW THE MONEY IS USED



The Meso Foundation uses 86% of donations received to support its programs, 9% on fundraising, and 5% on management.

Ways to Give

Stock Transfer

Give the gift of stock by initiating a transfer of stock to the Meso Foundation. Tax advantages may apply.

Estate Planning

Include the Meso Foundation in your estate planning. Tax advantages may apply.

Cash, Credit Card, Checks

Process your credit card safely and securely on our website, or send cash or check by mail.

Employer Matching Gift

Many companies will match employee contributions up to 100%. Visit your HR office to learn about options.

IS PALLIATIVE CARE RIGHT FOR YOU?

Palliative Care is an excellent option, available to anyone facing a life threatening diagnosis. A Palliative care team is a specialized team of medical professionals who focus on working along with the person's doctor, in providing relief from the symptoms and stress of such a diagnosis. The main goal of palliative care is to improve one's quality of life. They will help you gain control over your care, by closely communicating with you the patient, along with your medical care team, and to help you carry out your daily life, by helping you match your goals to your treatment choices. Palliative care can be employed while the patient is continuing active treatment through different phases of their life limiting condition. Recent guidelines have suggested that individuals, who are newly diagnosed with advanced cancer, should receive a palliative care consult within 8 weeks of their diagnosis

Hospice is a special kind of palliative care, used for patients who are either not being helped by active treatment, or for whom the burden of their treatment outweighs any benefits. Hospice care begins after treatment of the disease is stopped and when it is clear that the person is not going to survive the

illness. It is usually offered when the person is expected to live 6 months or less.

The palliative care/hospice team works closely with the patient and their family in caring for the patient in their home, for as long as possible. Teams also work with patients in hospitals, in hospice care centers, nursing homes and other long term facilities. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs and other managed care organizations.

Members of the hospice team make regular visits to assess the patient, and with the help of his/her family, determine the patient's needs. A family member will serve as the primary caregiver, to help make decisions for their loved one. The hospice team will develop a care plan to meet each patient's individual needs for pain management, symptom control and emotional support. This support is available on call 24 hours a day, seven days a week.

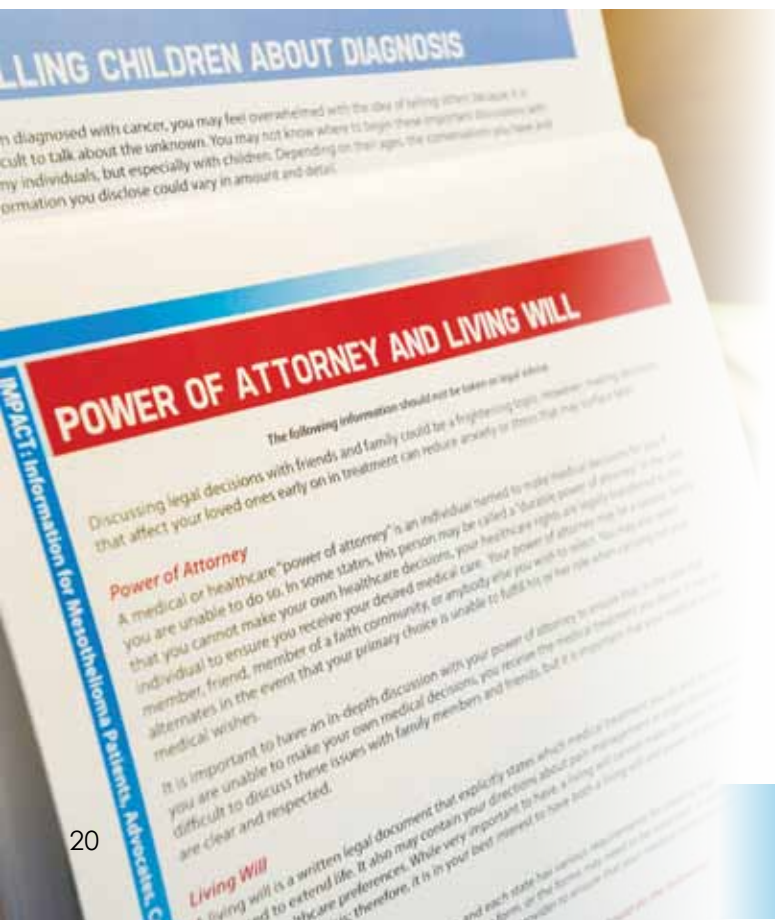
So what makes up a hospice team? First of all, of course, is the patient's personal physician. But the hospice team also has a physician (medical director) that the team can contact. Each person in hospice will have a nurse visiting him/her regularly. Also available

is a social worker, clergy, home health aides, trained volunteers, and therapists (such as physical, occupational and speech.)

The services provided by the hospice care team include:

- Managing pain control and symptoms.
- Assisting the patient with the emotional, psychosocial, and spiritual aspects of dying.
- Providing needed drugs, medical supplies, and equipment.
- Teaching the family caregiver in how to care for the patient.
- Making short-term, inpatient care available, when pain or symptoms become too difficult to manage at home, or if the caregiver needs respite time.
- Providing bereavement care and counseling to the patient's surviving family and friends.

For more information contact:
Gleneara Bates, MSW, PhD(c)
(703) 879-3821
gbates@curemeso.org



IMPACT PAGES

IMPACT stands for "Information for Mesothelioma Patients And Caregivers going through Treatment." We have developed these IMPACT pages for all members for our community to use as a guide in navigating challenges presented by a mesothelioma diagnosis.

Topics Currently Covered by the IMPACT Pages

- Talking with Friends and Family
- Power of Attorney and Living Will
- Reconnecting after Cancer: Body Image and Intimacy
- Telling Children about Diagnosis
- Traveling with Cancer
- Palliative Care vs. Hospice
- Managing Treatment Side-Effects
- Pain Diary
- Emotional and Mental Health
- Essentials for Treatment and Clinical Trials
- Coping with the Loss of a Loved One
- Family Planning

To obtain information about any of these topics, call (877) 363-6376 or email gbates@curemeso.org



LOOKING BACK AT THE 2017 INTERNATIONAL SYMPOSIUM ON MALIGNANT MESOTHELIOMA

The 2017 Symposium took place on March 27-29 at the National Institutes of Health in Bethesda, Maryland. In addition to science and treatment sessions for general attendees, the 2017 Symposium included a two-day special session for scientists and medical professionals. Mesothelioma experts from around the world came together to share their work and find collaboration opportunities in an effort to speed up mesothelioma advances.

Symposium attendees took part in two full days of sessions on topics including mesothelioma treatments, screening, immunotherapy, surgery, clinical trials, pain management, support groups, getting involved, and more. The Meso Foundation's Awards Dinner offered attendees the opportunity to recognize and honor award recipients, and the Community Dinner was a night of socializing and dancing to the Meso Fighters Band. The third day of the Symposium was Advocacy Day, during which participants traveled to Capitol Hill to meet with representatives to advocate in person for a mesothelioma patient registry and federal funding for mesothelioma research. Videos of Symposium sessions are available online at curemeso.org/symposium.



AWARD RECIPIENTS

BRUCE VENTO HOPE BUILDER AWARD Fred Hirsch, MD, PhD, University of Colorado, International Association for the Study of Lung Cancer

PIONEER AWARD Anna Nowak, MD, PhD, University of Western Australia

LIFETIME ACHIEVEMENT AWARD Mary Hesdorffer, MS, APRN

KLAUS BRAUCH ABOVE AND BEYOND AWARD Diana Stewart, Patricia Dyhrman, and Pat Hatley

SPECIAL HONOREES Lee Krug, MD, Ted Lackner, and Terry Lynch





Plan a 'Fundraise For Meso' Event!

Throughout the year, dozens of events are hosted to benefit the Meso Foundation. We've seen walks, runs, kayaking, poker tournaments, corn hole tournaments, birthday gifts, happy hours and more. Join our growing community of fundraisers by planning your own Fundraise for Meso event. We can help coach you through every step of planning from concept to execution, and provide access to the tools and resources you'll need to plan a successful event. Get started at curemeso.org/fundraiseformeso.

Have Questions or need help getting started?

Contact the Meso Foundation's development assistant Erica Ruble at eruble@curemeso.org or by phone at (703) 879-3826.



UPCOMING COMMUNITY FUNDRAISING EVENTS

AUG 12

American Legion Post 610 Golf Outing

This event will be held on Saturday, August 12 at 9AM in Columbia Station, Ohio. Contact Wally Ciokajlo at wallyciok@aol.com for more information.

AUG 26

Seisholtzville Fire Department Memorial Picnic in memory of John Edwards

This event will take place on Saturday, August 26 in Barto, Pennsylvania, from 3-8PM. Contact Nancy Edwards at efonqueak@aol.com for more information.

AUG 29

Fundraiser in memory of John T. McNeece

This event will take place on Tuesday, August 29 in Ellicott City, Maryland. Contact Daniel McNeece at 443-829-0986 for more information.

SEPT 9

Kayaking 4 Meso

This event will be held on Saturday, September 9 at 9:30AM in Waterford, New York. For further information, contact Mark Wells at markwells@kayaking4meso.org or visit the website at kayaking4meso.org.

SEPT 9

“Jumpin” John Edwards Memorial Car Show

This event will be held on Saturday, September 9 from 9AM to 3PM in Macungie, Pennsylvania. Contact Nancy Edwards at efonqueak@aol.com for more information.

SEPT 16

Oktoberfest

This event will take place on Saturday, September 16 from 11AM to 8PM in Edwardsville, Illinois. Contact Caitlin Lagemann at caitlin@gorijulianlaw.com for more information.

SEPT 16

8th Annual RODs Benefit for Meso

This event will take place on Saturday, September 16 in Eleanor, West Virginia. Contact Missy Bowles at 304-395-0636 for more information.

SEPT 17

5K Walk to Cure Meso

This event will be held on Sunday, September 17 in East Meadow, New York. Contact Erica Iacono at 516-729-9986 or eiacono@gmail.com for more information.

SEPT 17

6th Annual Bruce A. Waite 5K

This event will be held on Sunday, September 17 at 2PM in Ontario, Ohio. Contact Jill Waite at info@brucewaite5k.com for more information.

SEPT 24

Muffins for Meso

This event will be held on Sunday, September 24 in Casa Grande, Arizona. Contact Dira Reeves at jreeves04@cox.net for more information.

SEPT 30

John Boy Memorial Golf Tournament

This event will be held on Saturday, September 30 at 9AM in River Falls, Wisconsin. Please contact Vicki Slagle at vickislagle@gmail.com for more information.

NOV 25

14th Annual Christmas Breakfast & Bazaar in memory of George Brazee

This event will be held on Saturday, November 25 from 9AM to 1PM in Tewksbury, Massachusetts. Contact Joyce Brazee at jbrazee@massbay.edu for more information.

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