

# BREATH OF HOPE

a publication by the Mesothelioma Applied Research Foundation

Summer 2020

MESOTHELIOMA AWARENESS DAY  
SEPTEMBER 26 **2020**

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SEPTEMBER 26, 2020

on page 17



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# NEW CHALLENGES, SAME RESILIENT COMMUNITY

By Mary Hesdorffer, NP  
Executive Director, Mesothelioma Applied Research Foundation

This year has without a doubt been a tough year — and now, over six months into the pandemic, after a very hectic period, we are all trying to adjust to a new normal. Here at the Mesothelioma Applied Research Foundation, we keep pressing on. Our goal has been to continue providing our community with the services they need and expect from us. To do so has meant re-thinking some programs, expanding others, and creating new ones where new needs have arisen.

As you know, in early March of this year, we were forced to cancel our annual Symposium. This was a devastating decision for several reasons. Our staff had spent countless hours meticulously planning this event, and we were all heartbroken to give up our annual chance to meet face-to-face with our community. But aside from this loss, we were left with two major challenges that had to be addressed quickly: how to deliver the content we intended to share in person at the conference, and how to make up the massive financial loss we were to incur by losing our Symposium sponsorships?

Our answer to both these questions became our newly developed program called MesoTV (page 9). I am humbled by the support we continue to receive from our sponsors and donors. We truly could not have made it through this time without them. Please take a moment to see who they are on the back cover and take a look at their acknowledgments distributed throughout this publication.

We know that this year will be a challenge fundraising-wise for us as it is for most nonprofit organizations around the country, but being able to quickly cover the gap left by the Symposium has nevertheless enabled us to commit another \$300,000 toward mesothelioma research, a crucial step to keep labs operational and research moving forward.

I personally continue to speak to patients daily, and I know that our community is experiencing new and unexpected challenges. An already very complicated treatment landscape can now seem insurmountable. Before giving up, or settling for the least complicated option, I urge you to call the Foundation to see if we can help. Usually we can.

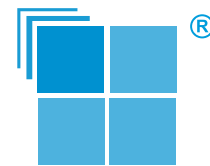
Yes, these are challenging times, but this community is strong and resilient. Every day I am inspired by each and every one of you.

Stay safe my friends,

Mary

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# THREE MESOTHELIOMA RESEARCH PROJECTS TO BE FUNDED, DESPITE COVID-19 UNCERTAINTY

The Mesothelioma Applied Research Foundation announced funding of three research projects for an investment of \$300,000 into mesothelioma research. This brings the total research funded by the Meso Foundation to \$10.5 million.

This funding comes at an uncertain time, during the Covid-19 pandemic, which has greatly disrupted the work of companies and nonprofit organizations alike. During this time, the Meso Foundation has continued providing services to the mesothelioma community uninterrupted and has expanded some of its service offerings to address new needs.

“We are keenly aware that mesothelioma patients still need effective treatments, first and foremost. We are deeply grateful to all of our donors and supporters who made this funding possible with their financial contributions,” said Mary Hesdorffer, nurse practitioner and the executive director of the Meso Foundation.

The Meso Foundation began funding mesothelioma research in 2000, when it created an unbiased, peer-review process to ensure the advancement of most promising research in this under-funded cancer. Over the years, 111 projects have been funded. The Foundation’s Science Advisory Board – comprised of a rotating group of renowned experts in the field of mesothelioma research and chaired by Dr. Tobias Peikert of the Mayo Clinic – is tasked with reviewing all grants applications and selecting and ranking the ones recommended for funding. The Board of Directors at that point determines how many of the recommended projects the Foundation is capable of funding, depending on the year’s finances.

“I am very glad to see that the Mesothelioma Applied Research Foundation’s peer-reviewed research program continues to thrive and attract the worldwide interest of excellent junior and senior scientists, who want to contribute to change the trajectory of this aggressive disease,” said Dr. Tobias Peikert of the Mayo Clinic, chair of the Science Advisory Board.

“Once again, we evaluated almost 50 letters of intent and invited eight very strong finalists to submit their full applications. From these finalists, we selected the most promising applications for funding, and I am glad to see that these outstanding and clinically relevant proposals will be able to go forward with the support of the Foundation during these most challenging times,” he added.

For the 2019 grant cycle, the projects funded will be looking at immunotherapy, each from a very different perspective. Immunotherapy in mesothelioma has shown much promise with impressive responses – however, those

responses occur in approximately 20% of patients only. These research studies seek to understand why immunotherapy works for some but not others, and which patients will benefit from it.

Listed below are brief summaries of the funded projects. More detailed information can be found on the Meso Foundation’s website.

## NEOADJUVANT IMMUNE CHECKPOINT BLOCKADE IN RESECTABLE PLEURAL MESOTHELIOMA

This project led by Dr. Joshua Reuss of the Johns Hopkins University School of Medicine seeks to learn about the impact of immunotherapy on patients with resectable mesothelioma. Within the context of a clinical trial, the safety and feasibility of giving immunotherapy to patients with stage 1-3 mesothelioma prior to surgery will be studied. The research project will examine samples of the cancer obtained before starting immunotherapy and samples from the cancer removed at the time of surgery following initiation of immunotherapy. It will also examine blood obtained before, during and following immunotherapy.

## NK CELL IMMUNOTHERAPY FOR MESOTHELIOMA (THE ANDERSON FAMILY GRANT)

Dr. Manish Patel of the University of Minnesota leads this study into Natural Killer (NK) cells, an important part of the immune response known to be suppressed by malignant mesothelioma. Dr. Patel and his team hypothesize that this suppression is a reason for limited success with immunotherapy. Therefore, they will test the hypothesis that activation of suppressed NK cells in the tumor microenvironment will lead to enhanced killing of malignant mesothelioma in combination with immune checkpoint inhibitors (such as PD-1, PD-L1, CTLA-4). They will do so by testing two agents known to stimulate NK cells in vitro in donor cells and in mice.

## ENHANCING ONCOLYTIC VIRAL IMMUNOTHERAPY WITH ADAR1 SILENCING

Dr. Robert Kratzke of the University of Minnesota will test the hypothesis that a protein called ADAR1 causes resistance to immunotherapy. In other studies the presence of this protein has shown to promote mesothelioma growth. Dr. Kratzke and his team will first evaluate the process of inactivating ADAR1 in vitro in human and mice cells. They will then combine this inactivation process with immunotherapy to test whether it makes immunotherapy treatment more effective against mesothelioma.

# INTRODUCING THE COMMUNITY ADVISORY BOARD

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**The Mesothelioma Applied Research Foundation exists for the benefit of those directly impacted by mesothelioma. As such, it is important that this community's input be considered in the organization's decision-making process.**

We are thrilled to announce the launch of our Community Advisory Board. Comprised of mesothelioma patients, caregivers, and community members who have lost a loved one to mesothelioma, this volunteer-led group brings together individuals from across the country with a personal connection to mesothelioma. The board centers its service on building and maintaining an inclusive, connected, and informed mesothelioma community.

Katie Jamieson and Heather Von St James are the founding co-chairs of the board and have spent the last several months building its membership.

"I've always said the meso community is unlike any I've ever been a part of. The realization of the community board is something Mary Hesdorffer and I have discussed for a while. By bringing together members with different experience, but all having been touched by meso, we can help support every part of the journey. Whether it be a caregiver, a child

of a patient, or a patient themselves, we bring together so much passion and experience. Being co-chair with Katie is a fantastic opportunity and utilizes both our talents. I'm so excited to see where this goes," said Heather Von St James.

Heather and Katie are joined by 18 other board members.

Originally scheduled to get underway at the spring 2020 Symposium, the group shifted to commence virtually after the Symposium's cancelation due to Covid-19.

The board's initial discussions focused on direct ways the Foundation could serve the meso community's needs during the pandemic, including providing input on interview topics for the new MesoTV program. To complement the medical and treatment-focused interviews the board led topics such as a demonstration of acupuncture/tapping and a "life after treatment" virtual panel discussion.

Look for more to come from this group soon via updates at [curemeso.org](http://curemeso.org) or the Foundation's social media channels.

## **Interested in becoming involved?**

*The Community Advisory Board invites your service on a committee. Committees will focus on core areas such as community connections, patient, caregiver and grief support, advocacy, and education. Contact Katie Jamieson at [katie@curemeso.org](mailto:katie@curemeso.org) to learn more.*





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# CONGRESSIONAL PROGRAM THAT FUNDS MESOTHELIOMA RESEARCH RECEIVES A \$20 MILLION INCREASE

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**The Department of Defense (DOD) Peer Reviewed Cancer Research Program (PRCRP) has received \$110 million in Fiscal Year 2020 (FY20) from Congress – a \$20 million increase from FY19 – thanks to the efforts of advocates and organizations like the Mesothelioma Applied Research Foundation.**

This increased funding also means an anticipated increase in the number of research proposals for the FY20 PRCRP topic areas, which include mesothelioma; bladder cancer; blood cancers; brain cancer; colorectal cancer; esophageal cancer (new); head and neck cancer (new); immunotherapy; liver cancer; metastatic cancers (new); neuroblastoma; pediatric brain tumors; pediatric, adolescent and young adult cancers; and stomach cancer.

As part of its advocacy in 2008, the Foundation succeeded in adding mesothelioma to the list of eligible conditions and diseases within the Congressionally Directed Medical Research Program's (CDMRP) on the basis of military relevance. These efforts have resulted in nearly \$22.5 million dollars in mesothelioma research funding through the CDMRP to date, a large part of which funded projects that initially received seed funding from the Meso Foundation — demonstrating both that the Foundation's peer review is effective in identifying the most promising research, and that the Foundation played an important role in jump-starting such promising research.

Advocacy for increased mesothelioma research funding is central to the Meso Foundation's mission of eradicating mesothelioma and the suffering caused by it. Every year, the Foundation brings together the mesothelioma community – patients, their families, caregivers, medical professionals, researchers and those who have lost a loved one to meso — to educate leaders and lawmakers on the devastation caused by the disease and to advocate for federal programs that help alleviate the effects of mesothelioma on our communities.



## When the world changes, we're here to help

We are a proud sponsor of the Mesothelioma Applied Research Foundation.

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# THE MESO FOUNDATION AND ITS TEAM

The mission of the Mesothelioma Applied Research Foundation spans across four distinct areas: through research, education, support, and advocacy the Foundation seeks to eradicate the vicious effects of mesothelioma.

Led by the Board of Directors (list on back cover of this newsletter and full bios are available on our website), our team works collaboratively to develop and administer our programs, and to fundraise to pay for those programs (the Foundation is funded by private individual and corporate contributions only -- it does not receive any government funding).

Despite being small in number, the Foundation's staff works directly on projects large and small. Delivery of programs, creation of materials, fundraising, and even the planning of our annual Symposium, are all done by us.

This approach does require that each team member wear several different hats, so to speak, but it also provides for very distinct benefits. For instance, not hiring vendors who are often unfamiliar with the unique challenges of mesothelioma helps us maintain consistency and accuracy in everything we do. It also simultaneously allows us to keep our overhead costs as low as possible, thereby giving us the ability to invest the bulk of our funding toward our programs.

Please take a moment to learn more about each of our team members, and feel free to reach out to them should you have any questions or comments. Visit [curemeso.org/team](http://curemeso.org/team) for detailed bios and contact information.



**Mary Hesdorffer, Nurse Practitioner**  
Executive Director

In addition to the responsibility of leading the organization in all of its areas of operation, Mary is also the head of our patient support department. She is an expert in mesothelioma treatment with over 25 years of experience specific to mesothelioma. She provides one-on-one consultations with patients and supervises all other service areas. She is our main liaison with the medical and scientific communities.



**Maja Belamaric, MBA**  
Director of Communications and Operations

Maja's dual role touches on most aspects of the organization's work from development and supervision of internal operational processes to the public facing informational materials, and implementations of tech solutions.



**Jordan Fingerhut**  
Patient and Grants Program Senior Associate

Jordan works closely with Mary supporting our community of patients, caregivers, and bereaved. She coordinates research and travel grant programs, and support groups. Jordan is typically the first point of contact with the Foundation.



**Trey Meehan**  
Communications and Operations Manager

Trey works with Maja on all things communications and operations. In addition, he supports the work of the Foundation through content development, social media marketing, and other forms of digital communications.



**Katie Jamieson, CAE**  
Special Projects Manager

Katie supports the Foundation part-time with a focus on community engagement. She works to bridge the work of the Foundation with the community it serves, as well as other projects as assigned.





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for a cure, we join you in dreaming  
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# INTRODUCING MESOTV



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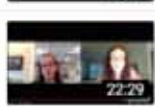



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Make sure to subscribe to our channel in order to be notified as we post new videos.

MesoTV is the Mesothelioma Applied Research Foundation's newest initiative specifically developed to deliver pertinent, timely, and detailed information to the mesothelioma community. Topics covered through this series vary, but over the course of the next weeks and months, we will continue releasing coverage of what mesothelioma treatment means during the time of Covid-19. As mesothelioma treatment programs around the country find their new normal, we will also provide our usual updates on treatment advances, clinical trials updates, and other topics of interest to our patients and their families. Think of this new project as a variation of a socially-distanced, year-long Symposium. Until we're able to see you again safely in person, we will use technology to help you stay informed and connected.

This special series has been made possible by the generous support of our sponsors and donors whose commitment to the mission and work of this Foundation on behalf of the mesothelioma community has remained steadfast during this globally difficult time. Please take a moment to see who they are on the back cover of this publication.

## SAMPLE VIDEOS

- |  |   |  |  |
|--|---|--|--|
| <br>18:08 | <b>MesoTV   Mesothelioma Program at the University of Chicago During C...</b><br>Interview with Bursley Rose, MSN, RN, nurse navigator at the Mesothelioma Program at the University of Chicago discussing how the program has...         | <br>29:09   | <b>MesoTV   Conversation with the FDA regarding Expanded Access, Com...</b><br>Interview with Dr. Adrian Jaeger, MD, FACS of the FDA discussing expanded access, compassionate use, right to try laws as they related to mesotheliom...      |
| <br>27:17 | <b>MesoTV   Dr. Taylor Ripley Talks about Mesothelioma at Baylor</b><br>R. Taylor Ripley, Baylor College of Medicine, discusses the mesothelioma program at his institution at time of COVID-19. Interviewed by Mary...                   | <br>45:37   | <b>MesoTV   Life After Treatment Community Panel</b><br>Heather Von St James, Jill Watts, Rich Mosca, Liam Bradley, John Panza, and Sara Babin discuss their own experiences with mesothelioma and how their...                              |
| <br>22:29 | <b>MesoTV   Mesothelioma at Memorial Sloan Kettering Cancer Center wit...</b><br>Interview with Marjorie G. Zauderer, MD, Memorial Sloan Kettering Cancer Center, about the mesothelioma program at the center during COVID-19. Le...     | <br>1:37:03 | <b>MesoTV   Charles Hedorffer, MD Explains the Immune System as it rel...</b><br>Dr. Charles Hedorffer discusses the function of the immune system and how it is affected by viral infections such as COVID-19. He also talks about...       |
| <br>22:33 | <b>MesoTV   Mesothelioma Program at Cleveland Clinic with Dr. James St...</b><br>Interview with Dr. James Stevenson of the Cleveland Clinic about their mesothelioma program at the time of COVID-19, led by Mary Hedorffer,...           | <br>23:14   | <b>MesoTV   Michael Becich, MD, PhD, University of Pittsburgh, Talks Meso...</b><br>Dr. Michael Becich, chairman of the Department of Biomedical Informatics at the University of Pittsburgh School of Medicine, explained the background... |
| <br>18:40 | <b>MesoTV   University of Pittsburgh Medical Center's (UPMC) Dr. Wozniak...</b><br>University of Pittsburgh Medical Center's Dr. Antonette Wozniak discusses mesothelioma treatment during the time of COVID-19. Tune in to learn abou... | <br>24:01   | <b>MesoTV   Tapping with Licensed Acupuncturist Susan Gillette</b><br>Katie Jamieson and Heather Von St James, co-chairs of the Community Advisory Board of the Mesothelioma Applied Research Foundation, do a...                            |



# UPDATES FROM ASCO 2020

At the end of May, in a brand new virtual format, the annual meeting for the American Society of Clinical Oncology (ASCO) was one of the first such meetings to take place since Covid-19 caused disruptions and cancellations across the board. Scientific meetings such as this one are an important venue where scientists and researchers report their newest finding among an audience of their peers. As you read through these studies, please use caution in interpreting statistical figures.

“We are on the cusp of several promising advances being mature enough to get integrated into patient care. I am so thankful to the patients and families who participate in these trials as it is the only way to move this field forward,” said Dr. Marjorie G. Zauderer, a thoracic medical oncologist at Memorial Sloan Kettering Cancer Center and the chair of the Board of Directors of the Mesothelioma Applied Research Foundation.

Dr. Zauderer was a discussant in the session titled “Adding to Chemotherapy in Mesothelioma” discussing two studies, both of which examined the addition of agents beyond cytotoxic chemotherapy in the treatment of mesothelioma. The first study looked at the addition of an immunotherapeutic agent to standard chemotherapy in previously untreated patients. The second study looked at the addition of a VEGF inhibitor, ramucirumab, in previously treated patients.

## COMBINATION CHEMO / IMMUNOTHERAPY

A phase 2 immunotherapy clinical trial combining durvalumab, an immunotherapy drug, with standard treatment of Alimta (pemetrexed)/cisplatin has shown promising overall survival results.

In May 2020, the full results of the “PrE0505: Phase II multicenter study of anti-PD-L1, durvalumab, in combination with cisplatin and pemetrexed for the first-line treatment of unresectable malignant pleural mesothelioma (MPM)—A PrECOG LLC study” were reported on at the annual American Society of Clinical Oncology’s (ASCO) virtual meeting.

The study enrolled 55 patients and showed a median survival of 20.1 months. Of those 55 patients, 31 demonstrated a partial response, and 22 had stable disease. Most frequently observed adverse events included fatigue, nausea, anemia, and constipation – all which are typically seen with platinum-based chemotherapy. Among adverse events that investigators thought were possibly related to immunotherapy are hypothyroidism and rashes.

Previously, a similar study out of Australia led by Anna Nowak, MD, PhD, a medical oncologist and researcher from the University of Western Australia, also reported similarly positive results.

A phase 3 trial combining the U.S. and Australian groups (PrE0506/DREAM3R) will commence later this year. That trial was delayed due to the Covid-19 pandemic.

“I am delighted to present the results of PrE0505 at ASCO and I would like to thank the patients and families who participated across the United States. The PrE0505 trial examined the role of durvalumab immunotherapy combined with standard chemotherapy for newly diagnosed mesothelioma patients. The results show a promising overall survival for the combination treatment, and PrECOG is planning to evaluate the results further in a phase 3 trial with colleagues from Australia,” said Dr. Patrick Forde of Johns Hopkins, the principal investigator of this study and also a member of the board of the Mesothelioma Applied Research Foundation.

His Australian counterpart, Dr. Nowak, is a previous recipient of a Meso Foundation research grant. That project seeks to identify biomarkers that will help differentiate responders from non-responders prior to the administration of treatment. The study is an extension of the previously mentioned DREAM trial.

## COMBINATION CHEMO / ANTI-ANGIOGENESIS

This Italian study (Randomized phase II study on gemcitabine with or without ramucirumab as second-line treatment for advanced malignant pleural mesothelioma (MPM): Results of Italian Rames Study) randomized 161 previously treated patients into two arms. Researchers added ramucirumab (an anti-angiogenesis drug that blocks growth of new blood vessels therefore limiting the supply of oxygen to the tumor similar to bevacizumab) to gemcitabine in one of the arms. They then compared outcomes between the arm receiving both drugs vs. the arm receiving only gemcitabine. Researchers found that overall median survival was significantly improved in the group receiving both ramucirumab and gemcitabine (13.8 months vs. 7.5 months).

Important to note is that in 2015 a relatively large French study showed a significant survival benefit when bevacizumab (a similar agent blocking the formation of new blood vessels) was added to the standard chemotherapy of pemetrexed (Alimta)/cisplatin in a first-line therapy setting. Also of note is that another large phase 3 randomized study using a similar agent called nintedanib did not meet its progression-free survival endpoint.

## PERITONEAL MESOTHELIOMA AT THE FOCUS OF AN IMMUNOTHERAPY + ANTI-ANGIOGENESIS STUDY

A new approach of anti-PD1 immunotherapy (atezolizumab) combined with bevacizumab (an agent that blocks the growth of new blood vessels therefore limiting the supply of oxygen to the tumor), was tested in a phase 2 clinical trial for patients with malignant peritoneal mesothelioma and data from the study were reported at this year’s ASCO’s virtual meeting.



continued from page 10

“This data represents an important step forward in the investigation of potential treatment strategies for patients with peritoneal mesothelioma after progressing on initial treatments. While this trial is admittedly small in absolute numbers, thus limiting our ability to make a definitive assertion, it is comparatively large for this rare disease,” said Dr. Michael Offin, a medical oncologist at Memorial Sloan Kettering Cancer Center and a discussant on this paper.

The study — A phase II trial of atezolizumab and bevacizumab in patients with relapsed/refractory and unresectable malignant peritoneal mesothelioma — enrolled 20 patients who previously received treatment of a platinum-based chemotherapy such as cisplatin and pemetrexed (Alimta). The 1-year overall survival was 79% with a 54% progression-free survival at the same 1-year interval. Hypertension and anemia were two most common adverse events.

“The initial efficacy signals showed promise and the safety of the combination was similar to that one would expect with these types of medications. Future study of the role of immunotherapy with or without VEGF inhibitors is warranted in patients with peritoneal mesothelioma,” added Dr. Offin.

Unlike pleural mesothelioma, which affects the lining of the lung, peritoneal mesothelioma affects the lining of the abdomen (peritoneum). There are approximately 250 cases of peritoneal mesothelioma annually in the United States, and they make up approximately 10-15% of all mesothelioma cases. For this reason, research into peritoneal mesothelioma is just as rare as the disease itself.

# WHITE PAPER FROM FOUNDATION-ORGANIZED PATIENT REGISTRY WORKSHOP, PUBLISHED

A white paper documenting presentations and discussions from the Mesothelioma Patient Registry workshop, which was convened by the Mesothelioma Applied Research Foundation in March of 2019 in Bethesda, MD, was recently published in the American Journal of Industrial Medicine.

The paper, “Workshop summary: Potential usefulness and feasibility of a US National Mesothelioma Registry,” addresses the current state of mesothelioma research from epidemiological and clinical perspectives, and discusses ways to bridge research gaps through the development of a national mesothelioma patient registry. Furthermore, the paper outlines examples of currently existing registries in other diseases and their impact on research for those diseases, as well as currently existing tools in mesothelioma, such as the mesothelioma tissue bank.

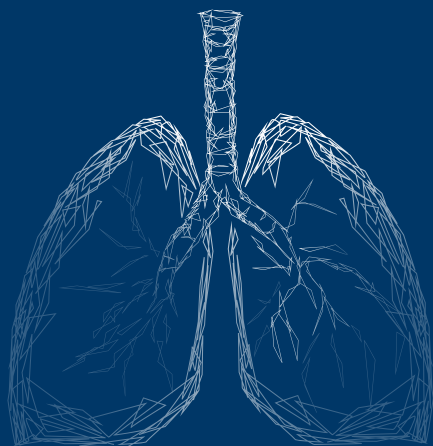
In authors’ own words, “The workshop began with formal presentations by subject matter experts, which were followed by a moderated group discussion. Workshop participants reviewed the epidemiology of mesothelioma and clinical and research needs; the strengths and limitations of existing databases, including cancer surveillance programs and the National Mesothelioma Virtual Bank (NMVB); and the lessons learned from a national registry for amyotrophic lateral sclerosis (ALS) and from mesothelioma registries in other countries.”

One of the primary benefits discussed in terms of a Mesothelioma Patient Registry would be the ability to connect patients with available clinical trials. This would present patients with access to novel therapies, while simultaneously helping researchers obtain critically important data to move the field forward.

Another distinct benefit of a patient registry is the support it would provide for research into detection, prevention and treatment of this cancer, all crucial to the task of alleviating the deadly effects of mesothelioma.

A Mesothelioma Patient Registry would be a reliable step toward gaining this understanding.

**VOGELZANG LAW**  
ADVOCATES FOR MESOTHELIOMA VICTIMS



**DURING THIS PANDEMIC,  
VOGELZANG LAW IS PROUD TO  
OFFER CONTINUED SUPPORT  
TO THE MESO FOUNDATION.**

# MANAGING MESOTHELIOMA AMIDST A PANDEMIC

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**During the best of times, a mesothelioma diagnosis is difficult and complicated to manage. What exactly is a mesothelioma patient to do during a pandemic when fear of contracting the virus along with disruptions to the healthcare system make management of mesothelioma even more complicated?**

**W**e realize that mesothelioma patients are faced with decisions about how and when to access care amidst continuous changes within the healthcare system, and are here to help. Should patients have any questions about obtaining treatment, particularly during this time, we encourage them to contact the Foundation directly at (877) 363-6376 or [info@curemeso.org](mailto:info@curemeso.org). We are in continuous communication with treatment centers across the country and can provide up-to-date options, guidance, and information about currently available treatment and clinical trials. We have also expanded our telephonic and online support groups — find more information about joining and a full schedule at [curemeso.org/supportgroups](https://curemeso.org/supportgroups).

Meanwhile, we have consulted with medical experts on our Board of Directors to provide us with general recommendations specific to mesothelioma patients and their families during Covid-19.

## MESOTHELIOMA MANAGEMENT RECOMMENDATIONS DURING COVID-19

- Continue active treatment with safety precautions as recommended by your treatment team.
- If your local area is not experiencing a surge, we recommend proceeding with your routine scans and visits.
- If your local area is experiencing a surge, consider delaying routine follow up scans and visits, especially if you are not on active treatment and are clinically stable without any new symptoms; ask your doctor if televisits are an option.
- Avoid air travel and airports. Car trips should be OK, but follow CDC precautions regarding handwashing and close contact.
- Avoid large crowds and gatherings. Consider remote activities as much as possible.
- Avoid contact with sick people.
- Hand washing and use of hand sanitizers are key. Also remember to clean your smartphones and other devices that are frequently touched.
- If you develop new symptoms (cough, fever, shortness of breath), please consult with your local physician and consider testing; home pulse oximetry may be a good way to measure oxygen saturation.
- Many hospitals, including those represented by us (Mayo and MSK), are taking precautions to separate acutely ill patients from those receiving ongoing treatment.
- Try to receive treatments locally, if possible, with least amount of travel.
- If you are in a study, please talk to the study team. Non-treatment study visits may not be needed or can be done by phone or video visit.
- Please remember there are also other viruses circulating, including influenza. Co-infection with multiple viruses is common. During influenza season, consider getting the influenza vaccine.

For more information about Coronavirus Disease 2019 (Covid-19), please consult the website for the Centers for Disease Control and Prevention (CDC) directly.



# AWARD RECIPIENTS 2020



The Mesothelioma Applied Research Foundation is honored to announce the 2020 recipients of the organization's Pioneer Award, Hope-Builder Award and the Above and Beyond Award. The awards acknowledge individuals and/or companies who through their work have helped advance the mission of the organization to eradicate mesothelioma as a life-ending disease. In lieu of the Symposium, they will be presented virtually via video. Please check our website for further information.

## THE PIONEER AWARD

**Michael J. Becich, MD, PhD**

Chair and Distinguished University Professor, Department of Biomedical Informatics, University of Pittsburgh School of Medicine

This award recognizes individuals who are pioneering scientific advances in mesothelioma research and treatment.

Over the past couple of decades, Dr. Michael Becich has been steadfast in his commitment to mesothelioma research. He established the National Mesothelioma Virtual Tissue Bank (NMVB) — representing the only national tissue and data repository exclusively dedicated to mesothelioma. He has also selflessly volunteered his time in support of the Mesothelioma Applied Research Foundation's Board of Directors and Science Advisory Board. Dr. Becich is Associate Vice Chancellor for Informatics in the health sciences at the University of Pittsburgh School of Medicine.

## BRUCE VENTO HOPE-BUILDER AWARD

**Heather Von St James**

This award recognizes an individual or individuals who create hope for mesothelioma patients and their loved ones through advocacy.

Heather Von St James is a 14-year mesothelioma warrior and ardent advocate for the mesothelioma community and the Meso Foundation. Her advocacy includes writing on her experiences as a mesothelioma warrior in prominent publications such as Thrive Global, Greenpeace and Baylor College of Medicine, traveling around the country speaking and raising mesothelioma awareness (including at the Foundation's annual Symposium and on the talk show Matter of Fact with Soledad O'Brien), and meeting and supporting fellow warriors. Heather turned the first anniversary of her extra pleural pneumonectomy (lung removal) into an annual Fundraise for Meso event, Lung Leavin' Day, that includes writing one's fears on a plate and smashing it into a firepit in her Minnesota backyard. She has raised over \$40,000 for the Meso Foundation as well as for the Von St James Travel Fund, which helps patients cover travel costs related to treatment or consults with mesothelioma specialists. Heather also guides and advises the Foundation's services and direction in her role as Community Advisory Board co-chair.

## KLAUS BRAUCH ABOVE AND BEYOND AWARD

**Jack and Ellen Brown**

This award recognizes an engaged and exemplary individual or individuals who has worked to advance the Foundation's mission through fundraising, advocacy, awareness and/or education.

Jack and Ellen Brown organize The Em' for Emily in their hometown of Greer, SC, to honor the life and legacy of their daughter, Emily Brown Kocis, a wife, mother and peritoneal mesothelioma warrior who passed away at 28 in January 2017. This fundraiser is a week-long event encompassing Mesothelioma Awareness Day (September 26), a dine and donate event, a Ride for the Em' cycling event and a golf tournament. Following a successful inaugural fundraiser in 2017, the Browns have made The Em' for Emily an annual Fundraise for Meso event and have since raised \$65,000 for the Meso Foundation toward mesothelioma research and the Patient Travel Grant Program. Save the date! They are eagerly planning this year's The Em' for Emily slated for Saturday, Oct. 3, 2020.

# SILENCING A GENE COULD YIELD THERAPEUTIC BENEFITS

In 2016, the Mesothelioma Applied Research Foundation funded a grant to Antonio Giordano, MD, PhD, director and founder of the Sbarro Health Research Organization at Temple University, to investigate how silencing a protein-coding gene called PRMT5 could have therapeutic effects in the treatment of mesothelioma.

In May 2020, the answer was published in the *Journal of Cellular and Molecular Medicine*. Researchers demonstrated that silencing PRMT5 in certain key enzymes does, in fact, slow the growth of malignant mesothelioma. This work was done in collaboration with the University of Siena in Italy, where researchers studied *in vitro* cancer cell lines. Though promising, these results are in their very early stages and have not yet been tested in patients. You can read the full published article [here](#).

“In this work we demonstrated that PRMT5 silencing slowed MM cell growth and abrogated their clonogenic

potential. For other oncologic diseases this strategy has been proven to be effective enough to start clinical trials with PRMT5 inhibitors. Considering the high toxicity of the standard chemotherapy with platinum and anti-folate drugs and the extremely poor prognosis for mesothelioma, this research opens the way to consider mesothelioma as another cancer that could benefit from treatment with this new class of molecules,” said Antonio Giordano, MD, PhD, the study’s principal investigator.

The Mesothelioma Applied Research Foundation’s grants program funds cutting-edge mesothelioma research through a rigorous peer-review with the main objective to accelerate the development of treatment advances for mesothelioma.

To date, the program has awarded over \$10.5 million in funding for 111 projects worldwide.

We honor the people  
who inspire us every day.

UPMC salutes the Mesothelioma Applied Research Foundation for its dedication to ending mesothelioma and providing support for mesothelioma patients and their families.

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# ONE MISSION. ONE COMMUNITY. YOUR FOUNDATION.

To say 2020 has had a rough first half is an understatement but I am thankful to report that through these challenging times the Mesothelioma Applied Research Foundation has remained fully operational. Where other organizations have had to pause their work amidst a financially uncertain future, the Foundation has ramped up its activities recognizing that mesothelioma hasn't stopped or slowed down. In addition to our regular services, we are now also helping our patients navigate treatment in light of disruptions and limitations endemic within healthcare.

Here is how we have stayed focused on our mission and the needs of the mesothelioma community:

## SUPPORT

Our [Mesothelioma Support Groups](#) continue uninterrupted, as do our [Patient Guidance & Support Services](#) and our [Patient Travel Grant Program](#) – all provided free of charge, and supported by the generosity of our donors and sponsors.

For patients needing treatment, Covid-19 has added a layer of complexity to an already difficult-to-navigate treatment landscape. We have been working with patients to identify best ways to manage their disease as treatment centers paused surgeries and clinical trials and made treatment more difficult to obtain. As the country continues to move toward re-opening, we will continue to provide patients with the most up-to-date information they need to make informed decisions and to make them quickly.

## RESEARCH

Our peer-reviewed [Research Grant Program](#) likewise remains fully operational in 2020 despite the pandemic. Guided by our Board of Directors and Science Advisory Board, the Mesothelioma Applied Research Foundation has approved \$300,000 to be awarded to three new mesothelioma research projects, bringing our total research funding to \$10.5 million.

## EDUCATION

As you know, earlier this year we had to make the difficult but necessary decision to forgo our [International Symposium on](#)

[Malignant Mesothelioma](#). We fully intend to resume our Symposium as soon as conditions permit and the health and well-being of our community is assured.

Therefore, we have created a virtually-delivered education and outreach program called [MesoTV](#) to keep our community well-informed and empowered.

Our [Meet the Meso Experts](#) broadcast series, with which many of you are already familiar, remains an important part of our support and education programs.

## ADVOCACY

Our work to fund a [national mesothelioma patient registry](#) continues. This fiscal year and last fiscal year Congress appropriated a total of \$200,000 for a feasibility study through the Centers for Disease Control (CDC). We are working on a request for this fiscal year for an additional \$300,000 to complete the project. Learn here how patient registries help advance scientific research into difficult-to-treat diseases.

With all of this in mind, I humbly ask that you consider a making a gift today at a level that is right for you. As a 501(c)(3) nonprofit organization, we rely on charitable contributions to fund our work.

We never forget that we exist *because* of and *for* you.

From the bottom of my heart, I thank you for your support and encouragement.

In solidarity,



Mary Hesdorffer, NP  
Executive Director  
Mesothelioma Applied Research Foundation

## TAX DEDUCTIBILITY

For the majority of people who no longer itemize their charitable giving, the CARES Act — legislation Congress passed in response to the Covid-19 crisis — will allow these individual taxpayers to deduct donations to charity of up to \$300 on their 2020 federal tax return, even though they take the standard deduction. Married-filing-jointly taxpayers will get an above-the-line deduction of up to \$600.

## HOW TO DONATE

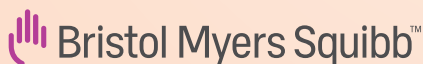
- Online by visiting our website at [curemeso.org/donate](https://curemeso.org/donate)
- By phone
- By mailing your contribution to: Mesothelioma Applied Research Foundation, 1615 L Street NW, Suite 430, Washington, DC 20036



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# MESOTHELIOMA AWARENESS DAY SEPTEMBER 26 2020

Mesothelioma Awareness Day is a grassroots effort developed in 2004 by Meso Foundation volunteers to raise awareness of mesothelioma in our communities, among media, and with our elected officials. By increasing the visibility of mesothelioma and the challenges that are commonly faced by mesothelioma patients and their families, we seek to build a wide network of allies to help us achieve our mission to once and for all eradicate mesothelioma as a life-ending cancer.

Throughout September and culminating on September 26 we encourage you to become involved in the acknowledgment of the 17th annual Mesothelioma Awareness Day in the following ways:

VISIT [curemeso.org/awareness](https://curemeso.org/awareness) FOR UP-TO-DATE INFORMATION AND LINKS.

## PAINT THE WORLD IN MESOTHELIOMA BLUE

- Take photos of yourself and your family, friends and colleagues wearing blue.
- Share those photos on social media to raise awareness, tag the Meso Foundation and use #curemeso.
- Email us your photos so we can cross post them on the Foundation's Facebook, Twitter and Instagram.
- Any blue will do, but if you'd like, you can purchase blue shirts from our store.

## SHARE THE MESO FOUNDATION'S SOCIAL MEDIA POSTS

- Share infographics, facts, important information and other posts that we will publish on the Foundation's social media channels.

## UPDATE YOUR FACEBOOK PROFILE PICTURE

- Download our Mesothelioma Awareness Day graphic and use as your Facebook profile picture.

## OBTAIN A MESOTHELIOMA AWARENESS DAY PROCLAMATION FROM YOUR STATE OR LOCALITY

- Download the how-to guide at [curemeso.org/awareness](https://curemeso.org/awareness)

## "ATTEND" A THIRD-PARTY VIRTUAL FUNDRAISER BENEFITING THE MESO FOUNDATION

- A full listing of events is available on our website calendar.

## CONTACT YOUR LOCAL MEDIA AND REQUEST A STORY ABOUT MESOTHELIOMA

- Visit our website to download our sample text, tips on how to customize it, and instructions on how to find editors at your local media outlets.



As part of the Meet the Mesothelioma Experts (MTME) series, the Meso Foundation invites specialists in the field of mesothelioma to discuss their current research interests as well as promising developments in the treatment of mesothelioma. You can view our full library of interviews at [curemeso.org/MeetExperts](http://curemeso.org/MeetExperts).

Are you a mesothelioma expert interested in participating in our MTME as a guest speaker? Contact us at [info@curemeso.org](mailto:info@curemeso.org) or 703-879-3797.



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# FUNDRAISE FOR MESO



This fall, many *Fundraise for Meso* events have gone virtual for the safety of all attendees. These events benefit the Foundation while raising mesothelioma awareness in communities around the United States. Virtual fundraisers provide a unique opportunity for our community members to support any event, no matter where they live.

Below is a list of upcoming fundraisers, their organizers and a little bit about the event. Interested in hosting your own? Contact Trey Meehan at [tmeehan@curemeso.org](mailto:tmeehan@curemeso.org) or 703-879-3817.

## UPCOMING EVENTS

### 10th Annual Kayaking 4 Meso

July 1 - September 12

Virtual

### Music for Meso

Saturday, August 22

Virtual

### Third Annual Mesothelioma Race for Justice

September 1 – September 26

Virtual

### Bruce A. Waite 5k Run/Walk

Sunday, September 20

Ontario, Ohio

### John Slagle Memorial Golf Tournament

Saturday, September 26

River Falls, Wisconsin

### Second Annual Steve Torrey Memorial Golf Outing

Saturday, September 26

Vassar, Michigan

### Mesothelioma Awareness Day

Saturday, September 26

Global

### The 2nd Annual David E. Watterson

#### Walk to End Meso

Sunday, September 27

Putnam, Connecticut

### Fourth Annual The Em' for Emily

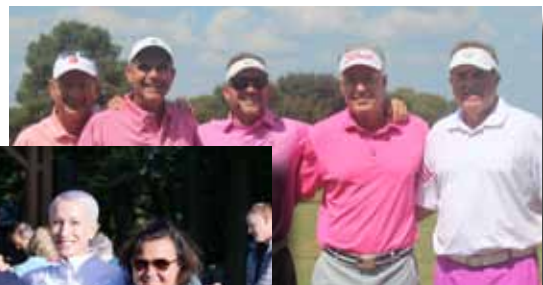
Saturday, October 3

Greer, South Carolina

### Kick Out Mesothelioma 5-Miler & 2.5 Mile Walk

Sunday, November 8

Portland, Maine







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