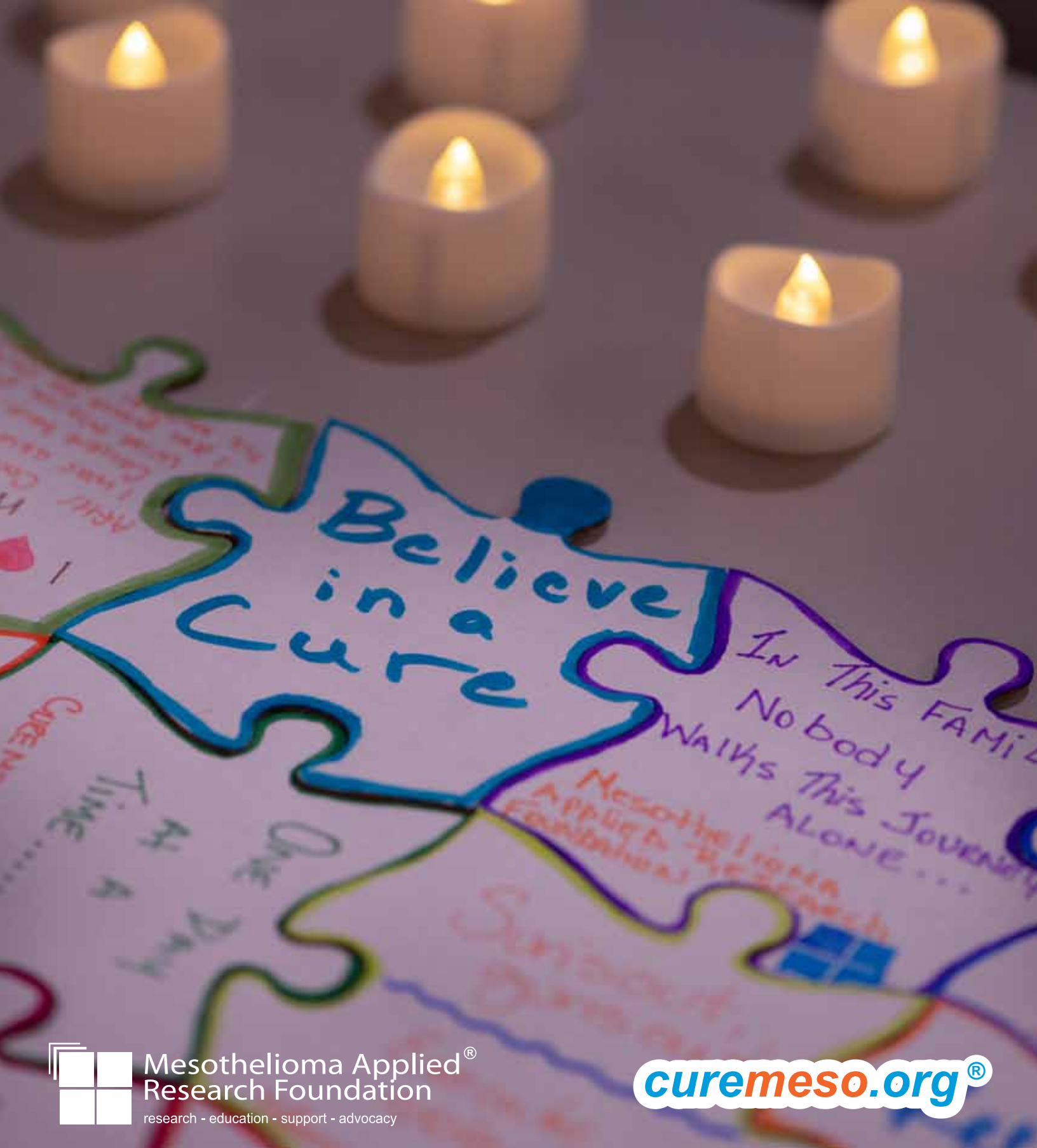


BREATH OF HOPE

a publication by the Mesothelioma Applied Research Foundation

Summer 2022



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BACK TOGETHER IN NEW AND OLD WAYS

By Julie Powers
Executive Director, Mesothelioma Applied Research Foundation

Dear Friends,

It is my pleasure to share the Summer 2022 edition of "Breath of Hope" with you and to invite you to learn about what we are doing to connect our community to end mesothelioma.

I am just wrapping up my first year with the Foundation and I want to begin with giving thanks to my predecessor, Mary Hesdorffer, NP. Mary was integral to establishing the Foundation as the patient advocacy and research organization that it is today, and she continues to provide wise counsel to our new Patient Services Director, Shannon Sinclair, RN, BSN, OCN.

The ongoing pandemic has pushed us to deliver more programs and services online and to shift from telephone support groups to video chats via Zoom. This shift has dramatically increased our participation and we're now serving hundreds of patients, caregivers and bereaved each month. We even launched Virtual Community Socials which we host regularly to bring everyone together for some lighthearted fun. Please join us in September for our Mesothelioma Awareness Day Social – details forthcoming!

Our mesothelioma community has generously supported important initiatives including three new research grants this year (see page 3 for details), expanding the travel grants program (more info on page 4), adding new episodes of MesoTV to keep you updated about new research, treatment options, and common questions, revamping the Peer Support Program, and updating educational content. All these efforts were identified by you, funded by you, and will make a difference because of you – together.

Together, we will fund important and relevant research, support our patients and their loved ones throughout their journeys, and advocate for federal funding and policies that will protect people and find better treatments. We are in this fight together and we are stronger together.

Onward,



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BREAKING NEWS: MESO FOUNDATION AWARDS THREE NEW RESEARCH GRANTS BRINGING TOTAL FUNDED TO \$11.1 MILLION

The Mesothelioma Applied Research Foundation is proud to announce the recipients of its most recent round of research funding. Through a rigorous review process that spanned over six months and involved a scientific peer review by the members of the Science Advisory Board of the organization, as well as a community review by members of the Community Advisory Board, three promising research projects were chosen for funding.

The projects will be awarded \$300,000, bringing the organization's total research funded to date to \$11.1 million and total projects funded to 117.

"The resources for our research program, just like the rest of the funding for the Foundation, come from patients, family members, friends, those who have lost a loved one to mesothelioma, and our community fundraisers," said Julie Powers, Executive Director, Mesothelioma Applied Research Foundation.

The following three projects rose to the top out of 36 proposals and were approved for funding by the Foundation's Board of Directors.

Identifying novel Treg targets to sensitize mesothelioma to immune checkpoint blockade

Joachim Aerts, MD, PhD, Erasmus University Medical Center

Dr. Aerts is a veteran mesothelioma researcher from the Netherlands with dozens of peer-reviewed publications under his belt. This project seeks to answer questions surrounding one very particular aspect of immunotherapy: the regulatory T cells (also known as Tregs). Immunotherapy has been a very hopeful area of progress for mesothelioma. However, while some patients show remarkable responses to this therapy, most don't. In order to understand who responds and why, and to then be able to apply that knowledge to make the non-responders also respond, researchers have looked at various parts of the immune system for answers. One of the reasons for this lack of response in some patients is thought to be tied to the regulatory T cells. As it turns out, immunotherapy activates both the immune system AND the regulatory T cells. The activation of regulatory T cells, in turn, inactivates the immune system thus canceling out its actual intended therapeutic effect. In this project, investigators will try to better understand the role of immunotherapy on the regulatory T cells with the goal of developing a treatment that, when combined with immunotherapy, would activate the immune system without activating the immune-suppressing regulatory T cells.

Radiation-induced vascular remodeling to boost immunotherapy outcomes

Alistair Cook, PhD, University of Western Australia (UWA)

This study, like the previous one, seeks to answer questions related to the disparate efficacy of immunotherapy. In this project, investigators will use knowledge derived from preclinical experiments that low dose radiation used prior to immunotherapy can boost the effect of the latter. Along these lines they will seek to better understand three specific areas.

1. They will analyze the alterations caused by radiation at the tumor microenvironment level.
2. They will define the window of time following irradiation when immunotherapy is most effective.
3. They will identify biomarkers that will help clinicians identify which tumors are more sensitive to immunotherapy based on the changes caused by radiation.

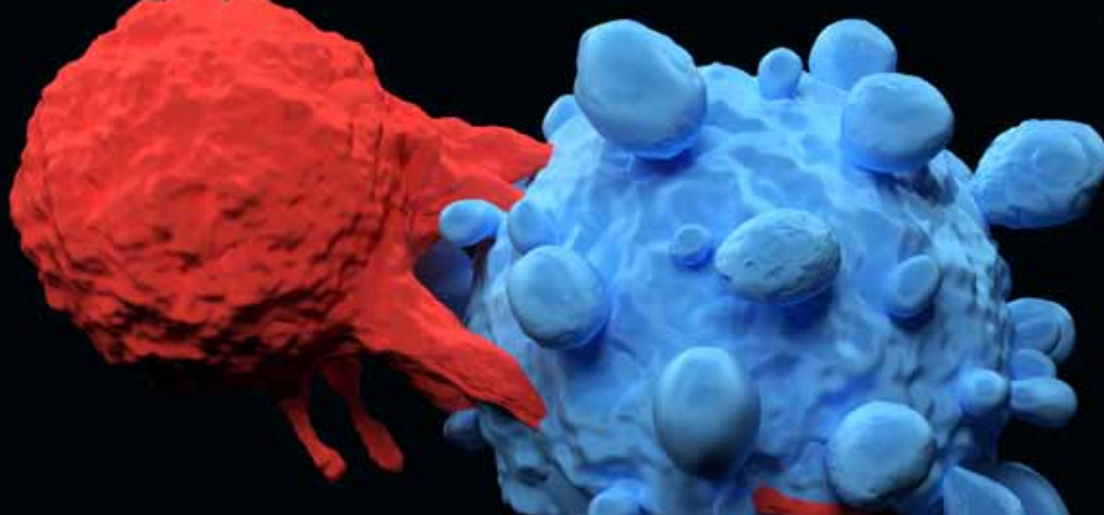
This information will be useful in clinic and will help investigators as they develop a future clinical trial testing low dose radiotherapy plus immunotherapy.

Reactivation of mesothelial progenitor genes in mesothelioma

Christian Mosimann, PhD, University of Colorado Anschutz Medical Campus

Dr. Mosimann and his research group at the University of Colorado have been researching various basic processes of disease development by observing zebrafish. Through their work they identified that a protein called Hand2, which is typically implicated in telling cells to grow and divide, and which typically becomes inactivated in adulthood, becomes reactivated in mesothelioma tumors. Through this study, investigators seek to accomplish two main aims.

1. They want to understand what instruction the Hand2 protein is actually giving mesothelioma cells.
2. They want to test the effect of switching off the Hand2 protein on mesothelioma tumors.



Three-year survival data for nivolumab/ipilimumab immunotherapy for mesothelioma

Three-year overall survival data from the CheckMate -743 study into nivolumab/ipilimumab combination immunotherapy for mesothelioma showed promising results on the heels of the FDA approval of the treatment protocol. According to Bristol Myers Squibb, the pharmaceutical maker of both agents, 23% of patients treated with the recently FDA-approved treatment combination were alive at 35.5 months (roughly three years) compared to 15% of patients treated with chemotherapy only. No new side effects were identified during this additional study period.

The complete set of data was presented at the 2021 European Society for Medical Oncology (ESMO) meeting.

CheckMate-743 is a phase 3 randomized clinical trial evaluating Opdivo (nivolumab) in combination with Yervoy (ipilimumab) in

previously untreated patients with malignant pleural mesothelioma. The trial's positive results led to the FDA approval of the combination immunotherapy for mesothelioma in October 2020.

Nivolumab is an immunotherapy agent that blocks the PD-1 protein from binding to the PD-L1 protein (also known as immune checkpoint blockade), thus "giving permission" to the immune system to attack the tumor cell. Ipilimumab is a monoclonal antibody and operates similarly but through a slightly different pathway.

The primary endpoint of the trial was overall survival. Secondary endpoints included objective response rate (ORR), disease control rate (DCR), progression-free survival (PFS), and efficacy measures according to PD-L1 expression level.

NEW! EXPANDED TRAVEL GRANTS PROGRAM

OFFERING FINANCIAL ASSISTANCE FOR TRAVEL EXPENSES INCURRED WHILE SEEKING TREATMENT

This program provides a one-time grant of up to \$1,000 to cover expenses incurred by a patient to consult with a mesothelioma expert (or multiple grants up to \$6,000 for clinical trial visits). This grants can be applied toward the costs of travel, lodging and meals. To receive a grant, patients are required to complete an application and document financial need.



Results of chemotherapy plus immunotherapy study published

Combination chemotherapy plus immunotherapy is currently being studied in large international clinical trials. While those Phase 3 studies are underway, data from their Phase 2 counterpart, called PrE0505, along with genomic and immunologic analyses, was recently published in *Nature Medicine*. The trial, which took place between 2017 and 2018, sought to investigate safety and efficacy signals of combination standard chemotherapy plus immunotherapy in previously untreated patients who are not surgical candidates.

(Patients and their families must be careful when comparing data between clinical studies. For help interpreting studies and determining the right treatment option for you, please contact the Mesothelioma Applied Research Foundation at (703) 879-3821 or speak with your physician).

The PrE0505 study showed a significantly higher overall median survival of 20.4 months as compared to historical data from the Alimta/cisplatin study which reported a median overall survival rate of 12.1 months. The objective response rate was 56.4%, meaning that over half of enrolled patients responded to this type of treatment. The study reported that 4 patients out of 55 discontinued treatment due adverse events. Overall, the addition of durvalumab immunotherapy led to few immune-related side effects grade 2 or lower. Overall, side-effects were consistent with those observed in patients undergoing chemotherapy treatment (such as anemia and fatigue).

The study emphasized that histology plays a significant role in both survival and response rate (epithelioid mesothelioma patients responded better than those with biphasic or sarcomatoid types, with overall survival in the epithelioid group beyond 2 years).

Within the context of the study, investigators also analyzed genomic and immunologic factors within the tumor to help them better understand underlying drivers of response.

"We are at a point in mesothelioma treatment research where we know that what works very well for some patients may not work at all for others," said Shannon Sinclair, RN, BSN, OCN, the patient services director at the Mesothelioma Applied Research Foundation.

"Understanding which patients benefit from which treatment and why will be a crucial next step in mesothelioma research," she added.

The Phase 3 randomized controlled trial of the same agents is currently open to previously untreated, unresectable (not surgical candidates) patients in the United States and Australia. Just like its preceding Phase 2 trial, this one combines standard chemotherapy of pemetrexed (Alimta) and cisplatin (or another platinum-based chemo) with durvalumab. Durvalumab, also known by the brand name Imfinzi, is a PD-L1 checkpoint inhibitor.

The new paradigm of combining chemotherapy with immunotherapy could be misunderstood as an effort to "throw the kitchen sink" at the cancer, but it is based on science that shows chemotherapy to have an immunogenic effect. What this means in simple terms is that when tumor cells are treated with chemotherapy, they release certain immune targets that can then be seen and attacked by the immune system, particularly when that immune system is incentivized by immunotherapy. This is why the combination of the two therapies has shown better results than the combined results of the two therapies administered separately.

Foundation's community members review research proposals for DoD

Jessica Blackford-Cleeton and Rich Mosca, both mesothelioma patients, recently participated in the evaluation of 2021 research proposals for funding through the Congressionally Directed Medical Research Program (CDMRP). The program, housed within the Department of Defense (DoD), distributes cancer research funding toward research into cancers and diseases disproportionately affecting current and former military personnel.

Specifically, mesothelioma is part of the Peer Reviewed Cancer Research Program (PRCRP) within the CDMRP. The 2021 PRCRP received a congressional appropriation of \$115 million to allocate among 20 cancers. As consumer reviewers, Jessica and Rich were full voting members alongside prominent scientists who participate as scientific peer-reviewers.

Mesothelioma was added to the CDMRP first in 2008 following extensive advocacy efforts by the Mesothelioma Applied Research Foundation.



Over the years, mesothelioma researchers have obtained nearly \$30 million in mesothelioma-specific research funding from this government source. Quite frequently, researchers who received initial seed funding from the Mesothelioma Applied Research Foundation were able to use data obtained from those projects to apply and receive larger funding from the DoD.

For the fiscal year 2022, three new members of the mesothelioma community were nominated by the organization to become consumer reviewers and their applications are currently under consideration. Together with Jessica and Rich, they will have a say in the allocation of \$130 million in funding through the Peer Reviewed Cancer Research Program and \$15.5 million in available funding through the Rare Cancers Research Program.



Medical and surgical care for mesothelioma patients with BAP1 mutations

Earlier this year, the paper “Medical and surgical care of mesothelioma patients and their relatives carrying germline BAP1 mutations,” by Drs. Michele Carbone, Harvey Pass, and colleagues, was published in the *Journal of Thoracic Oncology*. This paper is the first of its kind addressing surveillance and treatment guidance and considerations for this specific group of patients.

The relatively recent discovery of the inherited BAP1 mutation in patients with mesothelioma has led scientists to study its implications on various aspects of disease progression and management, including a close look at how it impacts survival. For some time, literature has shown a significant improvement in survival of these individuals, which is remarkable because until recently, mesothelioma was considered inevitably fatal.

“Now we know that there is a fraction of patients, those who carry germline BAP1 and some other mutations, who actually live 10-20 years and probably will not die of mesothelioma,” said Dr. Michele Carbone, the lead author of this study.

Survival considerations

As already reported in literature, one-third of BAP1 germline mutation carriers develop 2-7 cancers during their lifetime, with mesotheliomas being one of those. Conversely, approximately 10-12% of patients with mesothelioma have this inherited mutation. It is important to outline that an inherited BAP1 mutation confers very different characteristics of disease development and progression when compared to a somatic, or acquired, BAP1 mutation. For instance, the significant improvement in survival does not apply to those patients with an acquired (rather than inherited) mutation.

Screening

Considering the high risk of developing cancers among BAP1 germline mutation carriers, screening can be life-saving.

However, a cost vs. benefit analysis of testing must be performed to avoid excess radiation or other invasive procedures. A clinical trial is now underway at the NCI (National Cancer Institute) to assess the effectiveness of surveillance via CT scans in individuals with the BAP1 inherited mutation (germline) who are 30 years

old or older. However, there is currently no surveillance standard for mesothelioma. Two other clinical trials now open also at the NCI are studying the natural history of patients and their families who carry this mutation with a secondary objective of defining mesothelioma risk.

“These two NCI trials will teach us the best approach to treat mesothelioma in carriers of BAP1 mutations,” commented Dr. Carbone.

He added that the understanding we will acquire through these studies will save lives, as these patients often die because they develop additional cancers, mostly eye and skin melanomas and renal cell carcinomas.

“These cancers can be cured by surgical resection when detected at an early stage, and the protocol at the NCI focuses on early detection,” he added.

Therapeutic applications in mesothelioma

The article outlines several ways in which the knowledge of a germline BAP1 mutation in a patient is therapeutically actionable.

BAP1 mutation status has been found to be a good prognosticator of efficacy of platinum-based chemotherapies such as cisplatin.

PARP inhibiting drugs such as Olaparib have been found ineffective in patients with germline BAP1 mutations.

In a study of durvalumab in combination with pemetrexed (Alimta) and a platinum (such as cisplatin or carboplatin), patients with germline BAP1 mutations achieved significantly longer progression-free survival and overall survival.

For Dr. Carbone, the most exciting side of this newly acquired knowledge is that carriers of BAP1 mutations are able to “fight” mesothelioma and survive for many years.

“We are studying how they do so: if we figure out how they fight mesothelioma — and we will if we get enough support — we shall be able to make therapies “to teach” all patients how to fight mesothelioma,” said Dr. Carbone.

“Once we achieve that, I will retire, happy,” he added.

Enrolling in a clinical trial far from home is a little easier with help



When John Lewis and his wife saw a post about the Foundation's Travel Grant Program (a program providing financial assistance for travel for mesothelioma treatment) on Facebook, their reaction was: "That's exactly what we need."

Lewis, 45, was diagnosed with pleural mesothelioma and was approved for a clinical trial in Seattle.

"We live in Portland, Oregon and we were traveling to Seattle, Washington for our treatment because they were running a clinical trial there," said Lewis. "It is 187 miles away, and our treatment sequence was significant, so it was chemotherapy session; it was a two-week stay surgery; it was radiation therapy. So, there was a lot of presence required in a city where we did not live, so the Travel Grant Program was just unbelievably helpful to us."

Financial assistance for travel for mesothelioma treatment

Lewis and his wife, Nikke, spent weeks looking for financial assistance for travel to mesothelioma treatment before they learned about the Foundation's program. The social workers in the Swedish Hospital in Seattle were unable to offer them any kind of financial assistance.

"This disease takes people away from doing their everyday jobs, and when you are removed from the work environment, a lot of financial benefits from working disappear, and you know, you find yourself financially in a difficult position," said Lewis.

The Foundation's travel grant covers two types of travel: travel for a consultation with a mesothelioma expert, and/or travel for enrolling in a mesothelioma clinical trial. The program provides up to \$1,000 in eligible expense reimbursement for expert consultation and up to \$6,000 in eligible expense reimbursement for participation in a mesothelioma clinical trial.

What did the travel grant cover?

The grant that Lewis received covered gas and accommodations, which included a combination of hotels and Airbnb expenses to meet their budget, and it covered some Uber and bus rides.

"We had a lot of hotel stays," said Lewis. "We had to be in Seattle for five weeks for radiation therapy. We had to be at the hospital every day for five weeks, so there were a lot of expenses, and travel back and forth, so it was about \$6000 altogether; it is a significant amount."

His treatment also included four rounds of chemotherapy, which meant being up in Seattle on four different occasions for injections. "We drive up, stay a night in a hotel, get the chemotherapy and then drive home the next day," said Lewis. His chemotherapy sessions were followed by a lung resection, which is a major surgery that helped him keep both of his lungs, but he had to stay for two weeks in the hospital. Nikke managed to stay at a nearby Airbnb during that time.

The reimbursement process

Lewis and Nikke paid their expenses out of pocket, using a credit card, "then the Foundation reimbursed us directly by direct ACH payment to our bank account, I believe, and so by the time the credit card payment came, we had the money to pay off the bill. That's how it worked." The Foundation requires that the expenses for each trip to participate in a clinical trial not exceed \$1000 and the total expenses for all the trips not exceed \$6000.

Starting the application

To start the financial assistance for travel process, Lewis contacted the Foundation by email. Then he was directed to fill out an application and submit a medical authorization form signed by his doctor along with an expenses form.

Applying for the Foundation's Travel Grant Program was easy for Lewis who considers himself tech-savvy, and he credits his previous role as a sales manager for the smooth experience. Meso Foundation staff member, Meghan Butler, is available to help if anyone needs assistance filling out the application or has any questions.

Now, Lewis is in the monitoring stage: "I feel fortunate, and I am doing pretty good right now," he said.

The Gori Law Firm is a proud sponsor of the
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Advances in imaging technology for diagnosis and treatment

The field of radiology and imaging has relatively quickly advanced from simple x-rays that allow us to take a non-invasive, albeit limited, peek inside the human body, to incredibly complex technologies that nowadays are able to do so much more. Particularly in a malignancy like mesothelioma, imaging technology and the field of radiology play a role beyond what we could ever have imagined even a decade ago.

This article is based on the journal article titled “Imaging in pleural mesothelioma: A review of the 15th International Conference of the International Mesothelioma Interest Group (iMiG),” authored by Dr. Samuel Armato (of the University of Chicago) and colleagues. Dr. Armato and colleagues compiled and explained studies presented at the iMiG conference, which took place virtually last May. The Meso Foundation regularly covers scientific meetings to keep you updated on progress in mesothelioma treatment and science.

When it comes to radiology, our collective ability to see so accurately inside the human body without surgically opening it is nothing short of remarkable. While we may think that machines and technology are responsible for this progress, it is actually the discipline of radiology and the people who work tirelessly to move it forward that make it all possible.

Advances in imaging for monitoring treatment response

The reason behind imaging becoming such a reliable tool for monitoring disease progression and disease response to treatment is due to extensive multi-disciplinary research that regularly goes into it. In mesothelioma, much work in this area has taken place in the last few years through a massive project meant to standardize mesothelioma staging across all institutions and providers. The staging project is extremely complex and reaches across several disciplines. To put it simply, one part of this massive project involved comparisons of tumor volume readings from machines available at most centers against readings from more precise equipment (which is only available at certain institutions), and then against actual biopsied tumor tissue obtained surgically. The data from this study was then used to calibrate the widely-available systems to be as precise as possible in assessing tumor burden. Because of this project, today, a patient will receive a more precise scan interpretation consistently regardless of institution.

In the future, imaging could be used as a guide for selecting treatment

Much progress in the treatment of mesothelioma is being made in the area of targeted therapies. Targeted therapies usually operate on the basis of identifying a protein to target like mesothelin, for instance, which tends to be expressed on the surface of the tumor but not normal tissue. Some times that target can be a genetic mutation. A targeted therapy aims a drug at the determined target and delivers therapy much more precisely than a systemic therapy would, thus sparing healthy tissue while aggressively attacking tumor tissue. The complication with targeted treatments arises when, as is the case with mesothelioma, the potential targets are expressed on certain parts of the tumor, but not on others, or are present in different quantities across the tumor. Understanding which targets are most available on the tumor's surface, and where, helps identify those patients most likely to benefit from a certain treatment. Novel techniques in imaging will enable physicians to make that determination more accurately with fewer invasive procedures. Currently, early-stage lab studies are underway to test the feasibility of binding these molecular targets to a substance visible on a PET scan. In other cancers, early study results for this technique show promising activity and safety.

Adapting mesothelioma radiology to new and innovative treatment options

As mesothelioma treatments advance toward new and innovative strategies, radiologists have also had to adapt their readings. In the area of immunotherapy, for example, inflammation in parts of the body unrelated to the tumor is a frequent side effect. When inflammation occurs in the areas surrounding the tumor, it can, sometimes, appear on imaging as new tumor growth. This phenomenon is called a pseudo-progression because once the inflammation subsides, the apparent tumor growth disappears. While there aren't yet definitive solutions to this problem, the good news is that research is currently underway exploring and addressing these important issues for healthcare providers and patients alike.



ONE YEAR OF TREATMENT NEWS IN REVIEW

10

While sometimes it may seem that science moves at a glacial pace, in recent years much has changed in the mesothelioma treatment landscape. To understand where we are today, what has changed and what has remained the same, we summarized two recently published articles by mesothelioma experts. Please keep in mind that mesothelioma treatment is complex, and each case is different. If you have any questions, please consult your oncologist or contact the Mesothelioma Applied Research Foundation's experts.

The first publication we summarize is a commentary penned by Hedy Kindler, MD, University of Chicago Medicine. The article titled "Systemic Therapy for Mesothelioma: Turning the Corner" discusses the currently available systemic therapies for both pleural and peritoneal patients, with emphasis on how new data has affected treatment approaches and treatment protocols prescribed by medical oncologists.

The second article titled "New Era for Malignant Pleural Mesothelioma: Updates on Therapeutic Options," (written by Dr. Anne Tsao, MD, MBA, MD Anderson Cancer Center; Harvey Pass, NYU Langone; Andreas Rimner, MD, Memorial Sloan Kettering Cancer Center; Aaron Mansfield, MD, Mayo Clinic) is an overview of the full spectrum of treatment options for pleural mesothelioma, including surgery, radiation therapy, and certain novel therapies.

Both articles were published in the *Journal of Clinical Oncology*.

Systemic therapies (chemotherapies, immunotherapies, chemioimmunotherapies, VEGF-inhibitors)

For nearly two decades, the foundation of mesothelioma treatment has been the combination chemotherapy of Alimta (pemetrexed) with a platinum drug such as cisplatin or carboplatin. In 2004, this treatment became standard of care in the first line setting. Recently, bevacizumab, an anti-angiogenesis drug (inhibiting blood vessels around the tumor, also referred to as a VEGF inhibitor) demonstrated an additional survival benefit when combined with the original combination.

The big mesothelioma treatment news occurred in 2020, and into 2021, when for the first time since 2004, a new mesothelioma treatment became approved by the FDA. This new treatment consists of an immunotherapy drug combination, combining nivolumab (brand name Opdivo) with ipilimumab (known by brand name Yervoy). Both agents are checkpoint inhibitors and function by taking

the breaks off of the individual patient's immune system thus allowing it to attack the tumor. While immunotherapy demonstrated a promising improvement in overall survival across all histologies (cellular types of mesothelioma such as epithelioid (least aggressive), sarcomatoid (most aggressive) or biphasic (combination of least and most aggressive)), it benefited non-epithelioid types the most, doubling their median survival when compared with standard chemo.

Currently, several Phase 3 clinical trials are in progress to determine the potential benefits of combining chemotherapy with checkpoint inhibiting immunotherapy. The Phase 2 counterparts of these showed much promise. Most, if not all of these trials, will include genomic analyses that will provide clinicians with detailed information about who benefits most and least from these treatments.

As for novel systemic treatments for mesothelioma, several are currently under examination in early clinical trials. Therapies engineering the patient's own t cells have seen only limited efficacy, but new and innovative solutions to problems encountered continue to move this field of study forward. Similarly, early studies targeting certain genetic mutations are currently underway.

On the peritoneal mesothelioma side, systemic therapies often extrapolated from data from the more common pleural type. At the moment, a new study for peritoneal mesothelioma is looking into efficacy of chemotherapy with or without immunotherapy prior to surgery.

Surgery

In the United States, surgery is an accepted treatment option for mesothelioma. To qualify for surgery a patient must meet certain criteria in terms of disease stage, overall well-being, and histological type of mesothelioma. Pleurectomy decortication (PD), also known as lung-sparing surgery, is the most frequently performed procedure for pleural mesothelioma. EPP, or extrapleural pneumonectomy, which involved the removal of the entire affected lung is currently only used in conjunction with neoadjuvant radiation therapy (neoadjuvant means that the therapy is prescribed prior to surgery). When undergoing surgery, a patient will often also undergo certain systemic therapies before and/or after surgery to maximize the surgical benefit. Currently, studies are underway to understand if immunotherapy can be beneficial before and/or after surgery.

Surgical approaches for peritoneal mesothelioma are different and follow very different guidelines. This topic was recently covered in a session of our 2022 Symposium and is available for viewing at curemeso.org/symposium.

Radiation therapies

Treatment with radiation is often used to manage mesothelioma, and it's typically administered in conjunction with surgery. Sometimes, radiation therapy can be used in a palliative setting to ease disease symptoms for the patient.

Tumor treating fields (TTF) device

In 2019, a tumor treating field device received an FDA approval making mesothelioma treatment news, however its efficacy has not

yet been demonstrated in a randomized trial. The device was studied in a Phase 2 trial of 80 participants in which investigators compared their outcomes to those of patients in the 2004 Alimta/cisplatin study. Currently, the device is being tested in non-small-cell lung cancer in conjunction with immunotherapy. It is possible that the newly acquired data will have applicability in mesothelioma.

Overall, while mesothelioma is still a difficult to manage cancer, in 2022, patients have many more treatment options available to them. While researchers continue to seek answers into which aspects of a cancer's biology and genetics play a part in determining which treatment options will be effective, this muddy field is slowly providing more clarity.

MESOTHELIOMA NEWS DIRECTLY FROM THE SOURCE



**Tune in for
interviews with
medical, surgical,
and radiation
oncologists
who treat
and study
mesothelioma!**

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2022 SYMPOSIUM

On July 22 and 23rd, the mesothelioma community once again gathered at the Mesothelioma Applied Research Foundation's International Symposium on Malignant Mesothelioma (also known more simply as "the Symposium" among community members). The Symposium is a unique mesothelioma conference that provides patients and their families with direct access to experts in addition to bringing together everyone working toward the common cause. This was the first time this event was held in person since 2019.

Due to this three-year gap, the event was highly anticipated by all, and needed to fulfill several needs. To maximize on this time together, the event combined a community conference, a board meeting and a strategic planning session for the organization, a scientific conference, and a welcome reception. Most events were organized in a hybrid fashion between in-person and virtual to enable participation even for those attendees who were unable to travel.

If you had to miss the event, don't worry! Recordings of the event are already up on our website and can be viewed on demand. Make sure to visit our website at curemeso.org/symposium for all the latest information.

The day of the conference began with welcome remarks by Julie Powers, Executive Director together with Dr. Daniel Sterman who is a member of the board of the Foundation. After the welcome, medical professionals gathered in a meeting of their own just down the hallway where they discussed important, albeit sometimes controversial, topics in mesothelioma treatment and research. A summary of that session was provided by Dr. Marjorie G. Zauderer at the end of the event.

The subsequent sessions covered a lot of ground addressing basic terms and concepts, systemic therapies and clinical trials, treatment side effect management and palliation surgical options for pleural and peritoneal mesothelioma, radiation therapy, genetics and the tumor microenvironment. The conference also included a legal panel discussing legal issues as they pertain to mesothelioma patients.

For a detailed recap, visit our website at www.curemeso.org.



Get to know Shannon Sinclair, RN, BSN, OCN Patient Services Director



For nearly a year, Shannon Sinclair, RN, BSN, OCN, has been the Foundation's primary point of contact for patients, their families and caregivers. In her role, Shannon helps patients and their families navigate a diagnosis of mesothelioma by helping them understand their options, clarify any concerns and answer questions, guide them through clinical trials and treatment side effects, and can help patients access specialized care. As the Foundation's on-staff mesothelioma expert, Shannon has a direct line of communication to mesothelioma specialists across a variety of disciplines and across the country.

Shannon is an experienced nurse who prior to working at the Mesothelioma Applied Research Foundation has worked in a busy oncology center, served as an oncology clinical nurse educator for a major pharmaceutical company, and has worked with a specialty oncology pharmacy advising medical professionals and supporting patients. Shannon is an Oncology Certified Nurse (OCN) and has additional certifications in chemotherapy, biotherapy, and immunotherapy.

Shannon lives in Ohio on a small farm populated with rescued animals and loves to spend time outdoors with her family.

If you haven't yet had a chance to speak with her, we invite you to reach out and get to know her.

(703) 879-3821
shannon@curemeso.org

Get To Know The Entire Team!



Julie Powers, Executive Director
jpowers@curemeso.org

Julie Powers has spent the last 25 years in the nonprofit sector, most recently as the Senior Director, Patient Advocacy with the Aplastic Anemia and MDS International Foundation. Julie is an alumna of Alma College (Michigan) and is an active community volunteer. She serves as a PCORI Ambassador and is a member of numerous coalitions on behalf of the Foundation. She is passionate about supporting patients, families, and caregivers throughout their journey. In her spare time, Julie and her rescue dog Maggie, enjoy hiking, dragonboating, and needlework.



Shannon Sinclair, RN, BSN, OC, Patient Services Director
shannon@curemeso.org

Shannon is an oncology nurse with 14 years of experience working at a large cancer center in Ohio where she worked with a multidisciplinary team comprised of medical and radiation oncologists, surgeons, and other specialties involved in cancer care. Shannon also spent time working as an oncology clinical nurse educator for a large pharmaceutical company, where she educated providers at cancer centers and hospitals about clinical trial data, upcoming indications, immunotherapy, PARP inhibitors (a special type of a targeted cancer drug), mechanisms of action of various agents, potential adverse events, and side effect management. Earlier in her career she was an oncology specialty pharmacy nurse educating patients, caregivers, nurses, and clinicians on oral oncolytics. She holds the Oncology Certified Nurse (OCN) certification and certification through the Oncology Nursing Society for chemotherapy, biotherapy, and immunotherapy.



Maja Belamaric, Director of Communications and Operations
mbelamaric@curemeso.org

Maja's work at the Meso Foundation encompasses several areas including marketing and communications, fundraising, event planning, data management, and other tasks as needed. Prior to joining the Meso Foundation, Maja worked with several non-profit organizations, including the Young Storytellers Foundation and AIDS Project Los Angeles. Maja holds a bachelors degree in Mass Communications from Colorado State University and a master's degree in business administration (MBA) from Purdue University.



Meghan Butler, Development Coordinator
mbutler@curemeso.org

Meghan's work at the Foundation includes supporting all aspects of fundraising related to the annual appeal, donor research and identification, grant research, database updating and check processing. She is also responsible for initiating and nurturing partnerships, cultivating donors, and implementing special projects. Prior to the Foundation, Meghan was at the USO where she worked in development and account management. She holds a bachelor's degree in business management from Virginia Tech.



Nicole Yost, Program Associate
nyost@curemeso.org

Nicki is the newest addition to the Foundation's team, where she started as an intern. Nicki's responsibilities include supporting all aspects of the organization's work, with a special focus on patient support and education. She holds a bachelor's degree from Alma College and a master's degree from the University of Chicago.



“My biggest fear was that my daughter wasn’t going to remember her mother”

Julie attended the 2006 International Symposium on Malignant Mesothelioma with her neighbor who is a medical doctor. She needed someone with her to hold her hand and translate the medical information she was there to gather. Her husband Dan stayed home, in St. Louis, to care for their 3-year-old daughter, Madeline. Julie was looking for hope while Dan anxiously waited for news. They didn’t have any time to waste. Their family depended on it.

Just a month or so prior to this event, Julie was wheeled into surgery for a hysterectomy to remove what her doctors thought was ovarian cancer. The prospect of facing ovarian cancer terrified her but, at least, she knew the enemy.

But then, plot twist. This wasn’t ovarian cancer after all.

Instead, pathology confirmed malignant peritoneal mesothelioma.

At 35 years old, Julie was told that no real treatment options existed for this cancer and that she probably had about 6-12 months to live. With chemotherapy, she could maybe live a few months longer.

“At that point, all I could think was that my daughter wasn’t going to remember her mother,” said Julie.

The answers

Peritoneal mesothelioma is the rarer of the two more common types of this cancer. Unlike pleural mesothelioma, which affects

most mesothelioma patients, peritoneal mesothelioma does not grow around the lung, rather it surrounds the abdomen and the organs located in the abdominal cavity.

At that conference in 2006, Julie was stumbling in a haze hoping someone would take her by the hand and lead her. To her bewilderment that is exactly what happened.

At dinner that evening, during patient introductions, Julie shared her newly acquired diagnosis with the rest of the attendees. Almost immediately, other patients with her diagnosis swarmed around her providing support and sharing their experiences. They introduced her to peritoneal mesothelioma specialists in attendance, which is how she met the medical team that eventually treated her.

Julie seemed to have found herself in the right place at the right time. Suddenly, mesothelioma was not some obscure cancer that nobody seemed to know anything about. At this conference, mesothelioma was the only thing discussed. Attendees were either experts who made it their life’s work to find effective treatments for mesothelioma, or they were other patients or their family members.

“The Foundation was the lifeline that got me where I needed to go,” she said.

The treatment

Over the course of the next year, Julie was prescribed a treatment protocol that consisted of several components. The first in line would be an almost 10-hour HIPEC surgery. (HIPEC, or hyperther-

mic intraperitoneal chemotherapy, is a two-part procedure where after tumor removal the patient's abdomen is filled with heated chemotherapy drugs.) Then for six months after the surgery, Julie would get intraperitoneal chemotherapy treatments three times per month, followed by another, this time 8-hour, HIPEC surgery. The tasks ahead felt insurmountable at times.

"When I was very sick, I heard a saying, 'How do you eat an elephant? You eat it one bite at a time,'" Julie said.

Following this advice, one step at a time, she would begin chipping away at this grueling protocol which often seemed even more unattainable by the fact that Julie and her family lived in St. Louis, MO, while the treatment team was in New York City.

Julie and Dan were determined to make it work. They spent money on flights, food, transportation, and lodging in one of the most expensive cities in the world. Julie quit her job. Dan had to take extensive family leave. They did all of that knowing that their efforts may still not yield the results they hoped for. They had faith but were also scared.

"Faith is not a lack of fear. It is being afraid and doing it anyway," said Julie.

"I was scared every step of the way, but I was not going to let my fear stop me. Sometimes, even if the faith's voice was not stronger, I would just pretend that it was. Fear is an emotion; it is not a reality. I just needed to put it in a box and do what I knew I had to do anyway," she added.

But something still gave them pause and kept them wondering if they made the right decision.

"If I only have a year left, do I want to spend so much of it away from my family?" Julie questioned herself.

Their family was too young not to give it their best shot. So they soldiered on.

Over the course of those early treatment days, after the first surgery was completed, Julie timed her treatment trips with astonishing precision and no room for error. In the morning, in New York City, she would get 2.5 liters of fluid and intraperitoneal chemo administered through intraperitoneal ports directly into her abdomen.

"I would walk in a size 6 and walk out a size 12."

By midday, she would leave the hospital in New York City heading directly to the LaGuardia Airport to catch her flight back to St. Louis. The hope was that she'd arrive home by the time side effects kicked in. Delayed flights and other travel mishaps were not just minor inconveniences. A delay meant that she'd have to be in excruciating pain while squished in an airplane seat surrounded by strangers.

More Surgeries

The results of this first series of treatments were mixed. There was some good news and then there was bad news. Some parts of Julie's cancer were exceedingly aggressive and continued growing in less-than-ideal places.

On November 3, 2008, Julie underwent another major surgery. This time, complications arose. She nearly bled out and died on the operating table. The situation was so dire that she was put into an induced coma for five days to stabilize her. She spent nearly a month in the hospital.

However, even after that, the mesothelioma wasn't gone. It continued to grow, though slowly, giving her some time before another surgery became necessary. Julie's most recent surgery was in February

of 2014, memorialized by a hospital room Valentine's Day celebration with her husband. While the results of this surgery were promising, she still fell short of the NED distinction. In fact, Julie never heard the coveted term "NED" (No Evidence of Disease).

To this day, Julie travels out of state twice per year for CT and PET scans and check-ups.

Anger

The first few years after diagnosis Julie was angry. She was angry that she and her family were continuously exposed to a dangerous carcinogen without as much as a warning despite the dangers of asbestos being well known by that point. She is still angry that asbestos hasn't yet been banned in the United States, and that most people have no idea that asbestos from past uses is all around them, posing a danger to themselves and everyone else. Over the years, she focused that anger on political advocacy. She talked to anyone who'd listen, and when she talked, they did listen. The wrath of a mother fighting for more time with her child is not something that can be ignored.

Every year, Julie also attended the Foundation's conferences. It was an opportunity to give back by speaking with other patients, by advocating on behalf of patients, and she enjoyed gathering with her support group of other patients with whom she walked in stride. They became unexpectedly close, like a family, bonded by their unusual hardships. But mesothelioma is cruel. Each death was a new heartbreak. Each loss crushed her, and each loss simultaneously reminded her of her own precarious survival. It was time to make some changes.

"Cancer and asbestos stole years off my life. My life could not be about mesothelioma anymore. I didn't want to be the 'person with cancer.' I just wanted to be a 'normal person.'"

In an act of self-preservation, she pulled away from living with mesothelioma and focused only on living. She knew what she needed,

and at that time, it was normalcy – at least as normal as it could be.

Life

Over time, Julie learned not to make plans too far in advance and instead focused on each day and that day only.

"Then, you look back on doing that one-day-at-a-time thing, and all of a sudden you realize that you've accumulated a lot of days."

When looking through photos to share with us for this profile, Julie said she was blown away at the amount of life she got to live in the last 16 years – Africa, Bali, Croatia, Venice, Mexico, Hawaii.

"But I was more moved by the pictures that didn't have me in them, mostly of Madeline. Soccer games, catching her first fish, 8th grade graduation, high school graduation, dates, prom, trips, Christmases, general kid goofiness... SO. MUCH. LIFE."

Earlier this year, 16 years after being told she had months to live, Julie sent Madeline, now 18, off to college. For most parents, this is a milestone that carries some inherent bittersweetness.

For Julie, this milestone was mostly sweet.

"That is without a doubt the miracle. Getting to see a life that I never thought I'd see."





Transforming patients' lives through science™

We are in the business of breakthroughs—our diverse, promising pipeline is focused on innovative medicines that transform patients' lives. Our scientists are addressing some of the most challenging diseases of our time, lung cancer among them. We will never give up our search for more hope, for more patients, around the world.



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Richard Mosca

Hedy Lee
Kindler, MD

Maria Towe

2022 AWARDS RECIPIENTS

THE PIONEER AWARD

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

Hedy Lee Kindler, MD, University of Chicago

Dr. Hedy Kindler is the director of the Mesothelioma Program at her institution where she has established one of the world's premier centers for the treatment of mesothelioma. Dr. Kindler has been affiliated with numerous scientific organizations and has served on the organization's Science Advisory Board. This year, she also served as faculty director for the community conference of the International Symposium on Malignant Mesothelioma. Throughout her career spanning nearly three decades, Dr. Kindler has been at the forefront of patient care as well as research. She has developed and led numerous clinical trials seeking to test the efficacy of novel agents against mesothelioma thus positioning herself as a true pioneer in this often overlooked cancer.

BRUCE VENTO HOPE-BUILDER AWARD

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

Maria Towe

Maria Towe came to the Foundation when her wife Cris was diagnosed with mesothelioma in 2017. Ever since her wife's passing in 2019, Maria has lent her time and (numerous) talents to the Foundation and its work. Leaning on her background in public health, she was instrumental in the development, deployment, administration, and analysis of a large survey of the Foundation's community. Currently, Maria is a member of the organization's Community Advisory Board through which she continues to contribute to the mission of the organization.

KLAUS BRAUCH ABOVE AND BEYOND AWARD

This award recognizes an engaged and exemplary individual who invests time and talent to advance the Foundation's mission.

Richard Mosca

Richard Mosca was diagnosed with mesothelioma in 2008. He, along with his wife Lora, became instantly involved in the Foundation's mission. Over the years, Rich served on the Foundation's board of directors and has provided countless patients with hope and support. Most recently, Rich became involved with the Department of Defense's medical research program, where he supplied the patient experience in his role as consumer reviewer. He later applied the knowledge and experience acquired through that program to establish a community review within the Mesothelioma Applied Research Foundation's own peer-reviewed research grant program.



Join us to

light the world blue

Mesothelioma Awareness Day,
this September*

*Locational details forthcoming

At Novocure, **we are inspired by patients,**
their families, caregivers, and advocacy
partners **in their dedication to re-define**
living with mesothelioma.

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MESOTHELIOMA AWARENESS DAY

SEPTEMBER 26 2022

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 18th annual Mesothelioma Awareness Day in the following ways:



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.



RAISE AWARENESS AND FUNDS

- ➔ Share our social media posts including infographics, facts, and tips.
- ➔ Organize an awareness or fundraising event.
- ➔ Start a Facebook Fundraiser
- ➔ Attend an awareness or fundraising event.



LIGHT THE WORLD BLUE

- ➔ Request that your local landmarks light up blue on September 26
- ➔ On September 26, visit a lit up in blue landmark near you and take photos
- ➔ If able to secure a landmark to light up blue, contact your local media and tell them about it!

VISIT curemeso.org/awareness FOR ADDITIONAL ACTIVITIES.



Nothing is not normal in grief

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"Almost nothing is not normal in grief. Not wanting to get rid of the person's clothes, or buying their favorite food even though you don't eat that food; all [of] that is normal processing even though people might feel like something is wrong with them."

These are words by Claudine Benmar who lost her husband, Pete, to peritoneal mesothelioma three years ago.

"You have an idea about who you will be spending your life with and when you lose that person, it changes your entire life, and that is a traumatic loss," she said.

Claudine, an assistant director of communications and public relations for the School of Law at Seattle University, became acquainted with the Mesothelioma Applied Research Foundation and its services through her mother-in-law who did extensive research to find treatment options for her son. When Claudine settled with her grief, the leadership team at the Foundation invited her to host the "Young Widows and Widowers Support Group."

"It is hard to call myself young," smiled Claudine. "I am 53; I often think when you are in your 50's, cancer is the only reason anyone calls you young, because it is a young age for cancer, but I don't know if people consider it young ordinarily."

Mesothelioma, even more so than cancer in general, tends to affect an older demographic that is most often in their 70s and 80s, and less frequently in the 60s, 50s, or younger.

Certain challenges after a loss are different at various stages of life

Even though there is already a loss support group, the Foundation saw the need for a separate group for young widows and widowers because they face different challenges than the older members.... challenges like dating, careers and children.

The group meets monthly, and "it is just a safe space where people feel like they can talk about anything that is on their mind and we don't judge them or try to give them clichés. We are just there because we all need support. It is just showing up for each other every month," said Claudine.

During their meetings, the group discusses grief, trauma, and some less obvious logistical issues like, "how long you keep wearing your wedding ring?" Some newer members lost their loved ones during covid, so they struggle not being able to have a memorial service for them or to gather with loved ones for support.

"Grief is a horrible thing," she said, but she has learned much about it.

"I learned that it is not linear, and that almost nothing people say to you really helps. It's just, are they there for you? People always think that saying something is comforting, but really just their presence is the most important thing," she explained.

"I learned that you can't distract yourself away from it and when you feel it you got to just feel it and let yourself feel it – we talk a lot about this in the group actually – when that wave of grief comes, try not to push back against it. Just letting it come and consume you for the time that it needs and just trust that it will end at some point, even if it feels like you are standing on the edge of this dark abyss," she added.

The role of family and community

Family support and bonding with her two daughters, 22 and 19 years old, are what helped Claudine the most with moving forward.

When asked about the role of the bereaved community within the bigger mesothelioma community, she paused to hold back tears:

"I think it is important that the bereaved community stay engaged to the extent they feel emotionally capable because we don't want any other family to go through what we've been through," she said. "By engaging, we make sure that the Foundation stays active in its mission, whether through financial support or logistic support. Curing cancer is a difficult mission but it's sort of like when you graduate from a university, and you continue to financially support the university so that other students can get scholarships. When we stay engaged, even though we lost our people, I think it makes it easier for people in our same situations. We try to make the path easier for the next person who comes along."

Claudine is always looking forward to seeing the members of the group, and it is comforting for them to be together. They meet on the third Thursday of the month at 7 p.m. ET. The "Young Widows and Widowers Support Group" is for members under the age of 55 who have lost a spouse to mesothelioma.

If you would like to join this support group call, contact the Mesothelioma Applied Research Foundation at info@curemeso.org or 703-879-3797.





FUNDRAISE FOR MESO

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This fall, don't miss the Fundraise for Meso events in your neck of the woods! Year over year, our dedicated community members devote time and resources to raise awareness and funds in their local communities. We are deeply grateful for these efforts and wish to support their kindness in every way possible.

Below is a list of upcoming fundraisers/events. Please note this list was current as of print time but may have been updated since. For the most accurate list, check our website directly.

Interested in hosting your own event?

Contact Meghan Butler at mbutler@curemeso.org or 703-879-3824.

UPCOMING EVENTS

John Slagle Memorial Golf Tournament

September 24
River Falls, Wisconsin

Mesothelioma Race for Justice

September 24
Chicago, IL

Steve Torrey Memorial Golf Outing

Saturday, September 17
Vassar, Michigan

The Em' for Emily

Saturday, October 10
Greer, South Carolina

Mesothelioma Awareness Day

September 26
Global

Kick Out Mesothelioma 5-Miler & 2.5 Mile Walk

November 13
Portland, Maine

curemeso.org/fundraisingcalendar



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