

BREATH OF HOPE

a publication by the Mesothelioma Applied Research Foundation

Summer 2023

#MesoAwarenessDay
#LightTheWorldBlue



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Breath of Hope (Summer 2023 issue) is a periodical offered free of charge once per year by the Mesothelioma Applied Research Foundation 1717 K Street NW, 900, Washington, D.C. 20006

Update from the Foundation!



By Julie Powers
Executive Director, Mesothelioma Applied Research Foundation

Dear Friends,

It is my pleasure to share the Summer 2023 edition of "Breath of Hope" with you and to invite you to learn more about the Mesothelioma Applied Research Foundation's work. We have much on our schedule between now and the end of the year and I look forward to sharing it with you.

First and foremost — after last year's shortened version of our annual conference, **we are thrilled to finally, once again, plan a full three-day International Symposium on Malignant Mesothelioma.** As in years past, this year, we will again gather in Washington, DC. **The conference will begin with a much anticipated Advocacy Day.** As many of us might not have had an opportunity to meet with our elected officials recently, this year's event will be critical as we rebuild relationships in Congress.

The second day of the conference will be devoted to science. If you're a community member, you will learn about updates in mesothelioma treatment through presentations and panels. This year, we doubled down on panels in order to more easily provide you with a variety of viewpoints across the medical and scientific community. If you're a researcher or a medical professional, you will have the option to attend the concurrent scientific meeting just across the hall from the patient conference. We hope that having this time together with your peers will help you collaborate and build consensus on ways to accelerate the incredible advances we have seen in recent years.

Finally, **our third day of the conference, called Community Day, will be a day of connecting with one another, learning, and support.** I invite you leaf through to the centerfold, where we provide some additional details about the conference, but also please visit our website at curemeso.org/symposium to find registration and hotel booking information. I hope to see you in Washington, DC this fall!

But before coming together in October, we have another big event to rock in September! In fact, **Mesothelioma Awareness Day is just around the corner.** As we approach September 26, we invite you to help us once again raise awareness by turning your social media feeds blue with your blue t-shirts and selfies! And don't forget to participate in our #LightTheWorldBlue campaign to turn buildings and landmarks (with color changing capabilities) blue for meso awareness! A full list of actions to choose from is available on our website at curemeso.org/awareness.

In other news, please make sure to read about this year's research grant awards. **We are thrilled to fund \$400,000 in promising mesothelioma research.** On page 4 of this publication, we summarized the funded studies and hope you will take a few minutes to learn about them.

Ultimately, **this Foundation exists for you and because of you.** Our patient support and education services, research, and advocacy would not be possible without your support. I want to take this opportunity to thank you all for being a part of our community and I hope to cross paths with you soon!

Onward,



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NEWS: Meso Foundation awards \$400,000 to mesothelioma research projects

The Mesothelioma Applied Research Foundation announced the recipients of its most recent grants cycle's awards totaling \$400,000. This brings the total mesothelioma research funded by the organization to \$11.5 million. This funding is made possible by philanthropic support in the form of donations to the Foundation. To make a donation to the Foundation, please visit <https://www.curemeso.org/donate>.

The Foundation's research funding program, which was modeled after that of the National Institutes of Health, consists of a rigorous double peer review, a process that grades and ranks projects based on merit. Only the best and most promising projects advance to become funded. The peer reviewers are all leading mesothelioma experts who serve on the organization's Science Advisory Board. The review process also includes feedback from a panel of patients, caregivers, and those who have lost a loved one to mesothelioma.

The Foundation received 29 letters of intent, of which 11 were invited to submit a full proposal. Of those, the following projects were selected for funding.

"Transcriptomic analysis of mesothelioma-associated fibroblasts: a human-based study," Dr. Marcella Barbarino, SHRO Institute

Recent research has identified fibroblasts as crucial elements in the performance of tumor suppressive functions, or vice versa, in tumor-proliferating functions, depending on the molecular characteristics of different fibroblasts. In fact, these cells, which are present in abundance in the tumor microenvironment, are now thought to be part of the reason why some tumors are resistant to chemotherapy and/or immunotherapy. With this project, Dr. Barbarino seeks to study these cells in order to understand which ones hinder response to treatment and which support it. This knowledge would open the door to potential therapeutic strategies personalized to a patient's specific tumor and tumor microenvironment characteristics.

"Monoclonal antibody-drug-conjugate to target oncogenic ERK5 in mesothelioma," Dr. Emanuele Giurisato, Università degli Studi di Siena

The tumor microenvironment and the cells that comprise it are increasingly seen as the key to understanding why certain tumors respond to treatment while others don't. The researchers in this study

have already identified the process by which special cells present in the tumor microenvironment, called tumor-associated macrophages (TAMs), communicate with the tumor, and ultimately cause the expression of ERK5. This communication pattern consists of the activation of a series of pathways in tumor cells that have been identified as chemoresistant. This study will test an antibody-drug conjugate (a concept for drug delivery directly into certain cells, akin to a trojan horse, which first binds to the cell and then releases the drug molecule into it) that would inhibit the activation of those tumor-inducing pathways.

"Vaccine boosting to engage CAR T and endogenous T cells for long-term control of mesothelioma," Dr. Leyuan Ma, Children's Hospital of Philadelphia

Although CAR T cell therapies have shown much promise, just like other therapies for mesothelioma, they have faced significant challenges. Specifically, this type of therapy hasn't been able to produce the expected results due to several factors, one being that the engineered cells don't persist for very long in the body in the amounts necessary to make a difference, and the other is that the mesothelioma tumor itself may express mesothelin (the target of CAR T cells in mesothelioma treatment) in some parts of it, but not others. The team at UPenn has already identified a vaccine that works in conjunction with the CAR T cell process in other cancers that not only expands the CAR T cell numbers, but that also enhances the CAR T cell functionality and activates the patient's immune system against the tumor. This same team is now looking to apply this knowledge to develop the equivalent type of vaccine for CAR T cells targeting mesothelin.

"Localized immunotherapy for malignant pleural mesothelioma," Dr. Dawen Zhao, Wake Forest University Health Sciences

This is another study aiming to bypass the challenges of the exceedingly complex tumor microenvironment. In fact, this study utilizes a new, just-developed, technique of delivering an immunostimulant directly into immune cells through a nanoparticle injected locally into the pleural or peritoneal cavity. In combination with FDA-approved immunotherapy (nivolumab + ipilimumab also known by the trade name of Opdivo + Yervoy), this nanoparticle therapy will be tested in mouse models to understand the immune effects on cells in the tumor microenvironment of mesothelioma.



Positive results reported from mesothelioma Phase 2/3 trial for sarcomatoid / biphasic patients

Recently, the Polaris Group announced positive results of its Phase 2/3 clinical trial evaluating the effectiveness of an arginine degrading enzyme agent called ADI-PEG 20. The study was conducted in patients with pleural mesothelioma who had not been previously treated, who were not candidates for surgery, and who had the sarcomatoid or biphasic type of disease. This group of patients traditionally does not respond well to standard chemotherapy treatment of pemetrexed (Alimta)/cisplatin alone.

In this study, patients were randomized into two groups. One group received the experimental drug ADI-PEG 20 in combination with pemetrexed/cisplatin. The other group received only chemotherapy. When results between the two groups were compared, the experimental group demonstrated a significant improvement in "Overall Survival" (OS) as well as "Progression Free Survival" (PFS).

"The top-line results from the ATOMIC-Meso study are nothing short of tremendous leveraging a novel area of cancer metabolism for patients by targeting arginine, specifically in non-epithelioid mesothelioma," said Peter Szlosarek, MD, PhD, the principal investigator of this study and a medical oncologist and researcher at the Cancer Research UK Barts Cancer Institute in London, England.

"[These results] come after more than 5 decades since the first clinical use of asparaginase – the paradigm for amino acid depletion in cancer – namely childhood leukemia. ATOMIC-Meso has now set the bar for future studies of arginine deprivation in tumors requiring arginine as an essential amino acid on account of low expression of argininosuccinate synthetase 1 (ASS1)," he added.

The ADI-PEG 20 agent is an enzyme targeted at non-epithelioid pleural mesotheliomas with low ASS1 expression (a feature seen in approximately 75% of mesotheliomas in this subgroup) that degrades the arginine fueling mesothelioma cells. Mesotheliomas

with this deficiency have been found to require arginine to grow, therefore Dr. Szlosarek and colleagues hypothesized that using this drug to restrict arginine would destroy the mesothelioma cells thus prolonging patient survival.

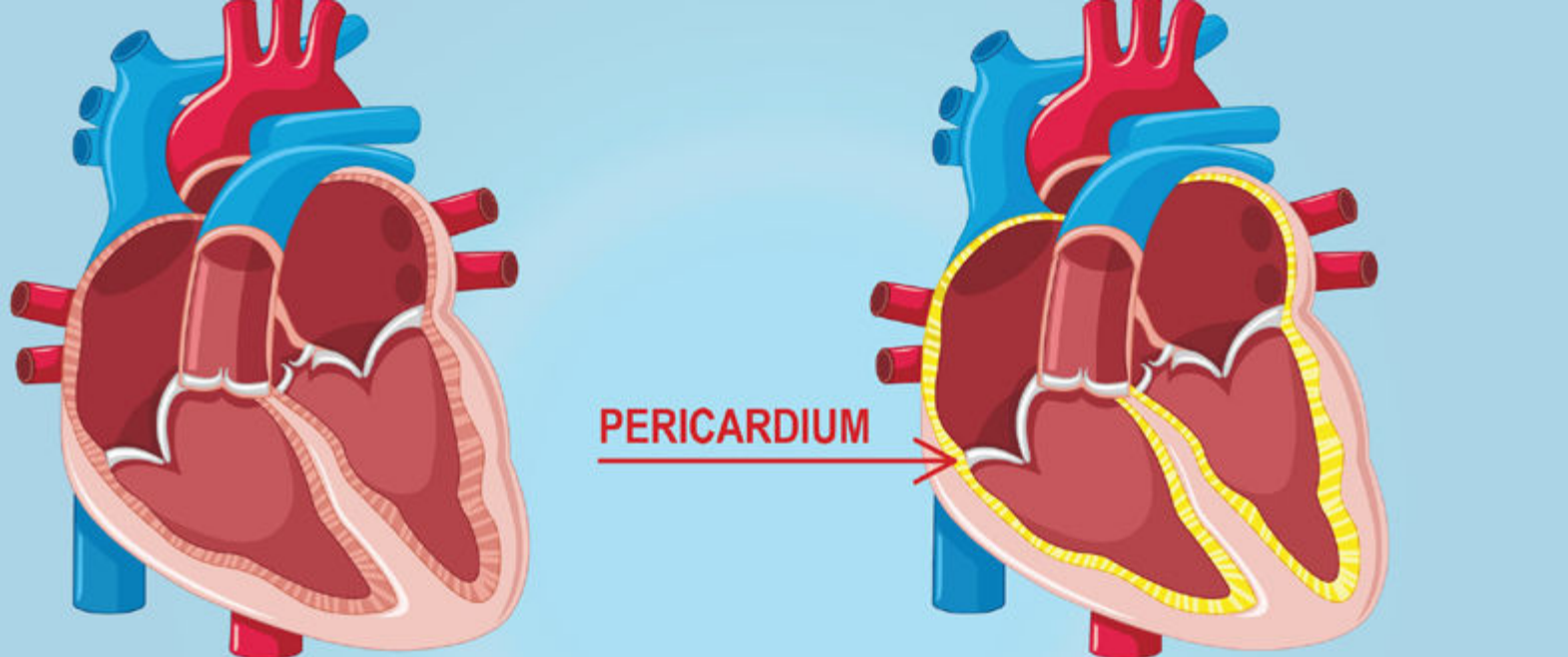
Sarcomatoid mesothelioma, and biphasic mesothelioma that is predominantly sarcomatoid, has traditionally been more difficult to control compared to its counterpart, epithelioid mesothelioma. Unlike epithelioid mesothelioma, sarcomatoid doesn't respond well to chemotherapy. For this reason, the results of this study in this particular subgroup are even more pronounced.

"The results show a near 2-month median survival improvement for ADIPemCis (ADI-PEG 20 + Alimta + cisplatin) versus PlaceboPemCis (placebo + Alimta + cisplatin), which for a chemorefractory (chemo-resistant) subtype of mesothelioma represents a 30% reduction in the risk of death," added Dr. Szlosarek.

Recent clinical trials have shown that patients with this more aggressive type of disease tend to respond significantly better to treatment with nivolumab + ipilimumab (Opdivo/Yervoy) than the current standard chemotherapy of Alimta + cisplatin alone.

"Further studies will be needed to determine the most effective deployment of ADI-PEG20-based chemotherapy in light of the approval of nivolumab plus ipilimumab for mesothelioma, however, there are survivors from ATOMIC-Meso beyond 3 years who have not required immunotherapy pointing to arginine deprivation as a viable alternative treatment for a subgroup of patients," explained Dr. Szlosarek.

"As Chief Investigator I would like to thank all the patients and their families who participated in ATOMIC-meso, all the staff at research sites and Polaris Pharmaceuticals Inc., for their unwavering support. We look forward to further data being presented in 2023 with publication of the study in full," he added.



Chemo / immunotherapy study makes debut at ASCO 2023

Ultra-rare pericardial mesothelioma gets first hint of improved outcomes

Mesothelioma in and of itself is a misunderstood diagnosis. As a cancer that affects roughly 3,000 Americans per year, it is often mistakenly thought of as a type of lung cancer. In reality, mesothelioma is a cancer of the mesothelial lining that surrounds several organs, the lungs being the most common one. However, this cancer can also affect the lining of the abdomen, and in extremely rare cases, the heart and testes.

When mesothelioma affects the lining surrounding the heart it is called pericardial mesothelioma. This type of mesothelioma is so rare that it only affects between 10-15 Americans annually.

This month's issue of the *Journal of Thoracic Oncology* featured a new paper about a study following a series of pericardial mesothelioma patients at one institution over the course of 11 years. This type of mesothelioma is so rare that only 12 patients were identified – a fact that makes research extremely difficult. Because of this, the findings of the study should be interpreted with caution.

The study penned by Michael Offin, MD, and colleagues at Memorial Sloan Kettering Cancer Center was just published in the *Journal of Thoracic Oncology* along with an accompanying editorial which helped us contextualize the findings.

The twelve patients were predominantly female, which is not consistent with other incidence data, and were significantly young-

er than pleural disease patients (a median of 51 vs. 75). Nine, or 75%, presented with epithelioid disease, which is typical for mesothelioma in general. Overall, patients who underwent trimodal treatment (surgery, chemotherapy, and radiation) lived a median of 70.3 months compared with 8.2 months for those patients who were not treated with all three types of therapies.

The editorial accompanying the article pointed out that the very nature of selecting surgical candidates which tends to favor younger and healthier individuals may have had an impact on such promising results, but they nevertheless praise the results as “notable.” In fact, the median survival for the entire cohort of patients, including those who did not undergo trimodal treatment, was 25.9 months, which when compared to the 2-6 months overall survival previously reported, is equally remarkable.

Authors of both articles concur that the promise in the treatment of pericardial mesothelioma, just as with other types of mesothelioma, lies in the multi-disciplinary treatment approach, meaning that patients benefit when treated at centers with extensive mesothelioma expertise in a variety of medical disciplines.

The American Society for Clinical Oncology's (ASCO) annual meeting took place in June in Chicago, IL. As the largest oncology meeting in the world, ASCO is often where researchers announce research updates and new data.

This year, we were very interested in one study in particular – the Phase 3 Randomized Study of Pembrolizumab in Patients with Advanced Malignant Pleural Mesothelioma, also referred to as IND.227. We already covered the Phase 2 results of this trial, and in March of 2023, we reported that Merck announced that its Phase 3 counterpart was positive and that data would be forthcoming.

This study is one of the first completed studies looking into the efficacy of the combination of chemotherapy with immunotherapy. Since 2004, the chemotherapy regimen of pemetrexed (Alimta) and cisplatin was the only standard of care until 2020, when the FDA approved the immunotherapy combination of nivolumab and ipilimumab (Opdivo/Yervoy), making it only the second standard of care for the treatment of mesothelioma. In the last few years, the question has been whether combining these two standards can create an added benefit beyond what each treatment can do as a stand-alone.

Several studies were initiated to answer this question, most notably the DREAM (Phase 2) followed by the DREAMER (Phase 3) studies, and also, in the UK and Europe, the BEAT-meso study which adds bevacizumab to chemotherapy and immunotherapy, and, finally, IND.227, the results of which we cover in this write-up.

The IND.227 protocol included 440 patients enrolled in Canada, France, and Italy, who were randomly assigned to two different groups. One group was treated with standard chemotherapy (Alimta/cisplatin or carboplatin) AND pembrolizumab (Keytruda). The

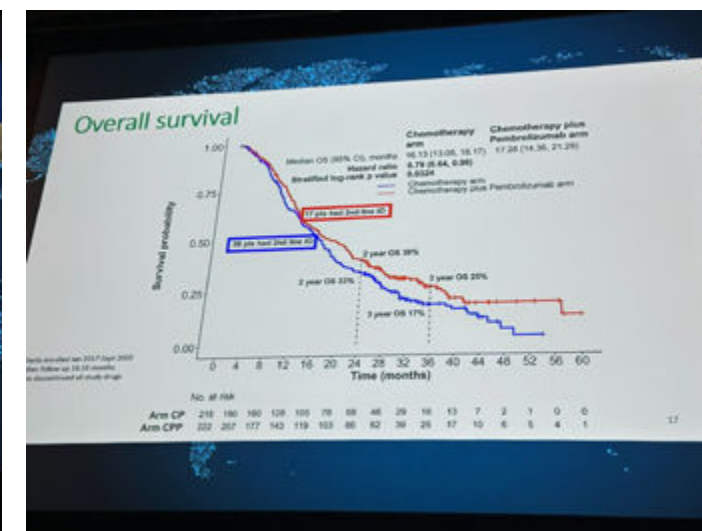
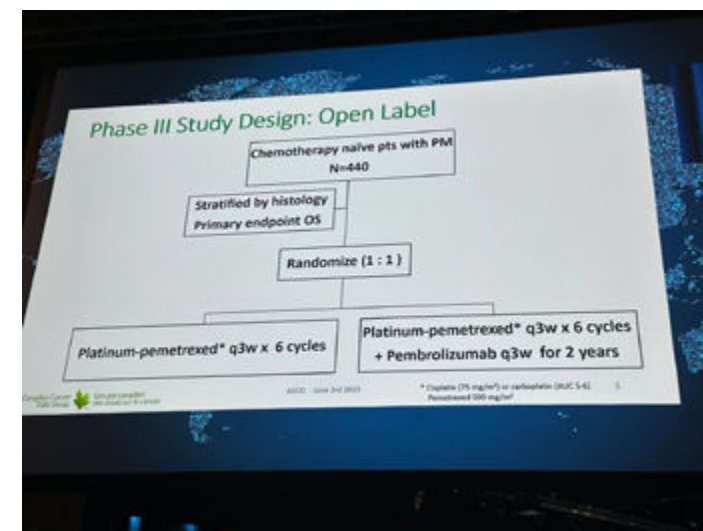
second group was only treated with standard chemotherapy. All patients were treatment naïve, meaning that they had not received any previous treatment. Pembrolizumab is an immune checkpoint inhibitor that binds to the PD-1 protein found on T cells which, by doing so, signals to the immune system to attack the cancer cell.

The study results didn't see an association between benefit and levels of PD-L1 expression, which is in line with results from previously reported immunotherapy studies.

Ultimately, overall survival (OS) was this study's primary endpoint. The median OS was 17.28 months for patients treated with both chemotherapy and immunotherapy and 16.13 months for those treated only with chemotherapy.

Consistent with data from other immunotherapy studies, patients with sarcomatoid or biphasic mesothelioma appeared to gain the most from the addition of immunotherapy. In fact, these patients saw an improvement in median overall survival of over four months, while epithelioid patients' improvement in median overall survival was 1.6 months.

The change in survival benefit between different subtypes of mesothelioma reinforce the notion that treatment for epithelioid, sarcomatoid, or biphasic mesotheliomas might require a different treatment modality. Moreover, as clinicians work with patients on treatment decisions, the increased toxicity profile of this combination will need to be considered. In this case, chemotherapy plus pembrolizumab might not be the best option for all patients, but it could be an option for some. As such, the focus on patient selection by the mesothelioma medical community seems to be a hopeful next step.



From iMig: Surgery, radiotherapy, neoadjuvant and adjuvant therapies, and what is the best combination for multimodal treatment, and much more



The second day of the conference began with a session addressing questions of vital importance to mesothelioma patients called "Surgery, radiotherapy, neoadjuvant and adjuvant therapies, what is the best combination for multimodal treatment?" The good news is that much work is being done to determine if there is a preferred order to the administration of therapies before and/or after surgery. The bad news is that the answer is not so simple. The work done by Dr. Marc DePerrot with the SMART, SMARTER, and SMARTEST trials, suggests that radiotherapy before surgery is an interesting concept that leads to better outcomes than surgery without radiotherapy.

Mesothelioma clinicians and researchers came together at the end of June in Lille, France, for the International Mesothelioma Interest Group's biannual meeting known as iMig to discuss mesothelioma treatment updates.

This is a unique meeting where all disciplines come together in one place to discuss all advances, regardless of specialty, in a comprehensive manner. This cross-education of clinicians and scientists is incredibly valuable to future research and patient care.

The first day's sessions included discussions about mesothelioma treatment updates in epidemiology, imaging, pathology, surgery standardization, and an overview of reported advances from other meetings.

Although so much of the meeting was incredibly technical as it dealt with molecular biology, biomarkers, tumor genetics, etc. during this conference the convergence of advances in biology of mesothelioma and clinical practice was more evident than ever before.

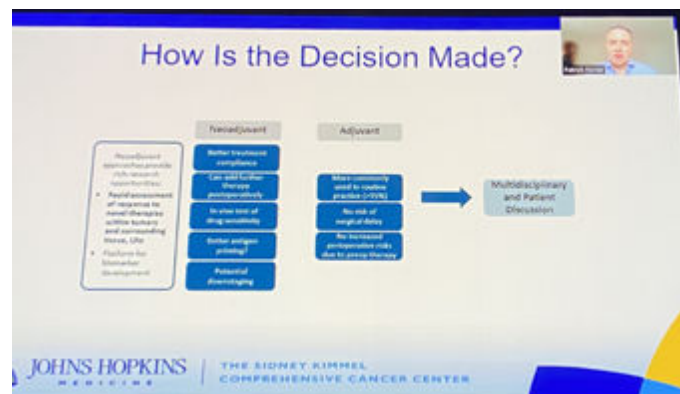
What this means for patients is that as our collective knowledge of mesothelioma and its behavior deepens, clinical researchers take note as they design future clinical trials, and interpret data acquired through previous clinical trials.



Similarly, Dr. Forde argues that systemic therapy before surgery can be beneficial. One reason is that it allows two options for treatment, one before and the other after surgery. But also it may serve the purpose of "priming" the antigens for subsequent treatment, which would theoretically make it more effective. Finally, treatment before surgery could help downgrade the stage of the cancer making the surgery more effective. One potential downside to treatment before surgery to keep in mind is that it could delay the surgery itself, which is not ideal.

The next session featured the Mesothelioma Applied Research Foundation's executive director, Julie Powers, as she spoke about the work of the Foundation and how the Foundation meets the needs of mesothelioma patients it serves (including their families).

Presenters also discussed targeted therapies, T cell therapies, peritoneal mesothelioma, patient care and quality of life.



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Despite all the ads, odds are people around us don't know what mesothelioma is



When I tell people I battled mesothelioma and lived to tell about it, they often ask: Oh, is that the disease they have commercials for on TV? Yes, my name is Rich and I have that cancer you see on TV.

For those unfamiliar, mesothelioma is a form of cancer directly related to asbestos exposure, and it's as deadly as they come. There is no cure. Treatment options have very limited effectiveness, and long-term survival prognosis is not good. The five-year survival is less than 10%. A diagnosis like mesothelioma will stop you in your tracks.

In the fall of 2006, I was 54 years old and living a textbook life. My wife Lora and I had recently become grandparents, our youngest child was getting married the following year, and we were just about to embark on our dream vacation: a two-week Mediterranean cruise.

I had been feeling a little bloated around that time, and more often than not I would wake up in the middle of the night in a severe sweat. I felt as if I had gone directly from the shower to the bed. I self-diagnosed it as another diverticulitis attack and was going through it unencumbered, as usual.

During my annual physical, I didn't even think to mention it to my doctor until he asked the routine question: Is there anything else you want to discuss? His eyebrow shot up when I told him my symptoms, and he immediately sent me for, what I now know would be, the first of countless CT scans.

My first scan was scheduled for the following Monday at 8 AM. That same Monday evening Lora and I were supposed to fly to

Spain to start our cruise. I chugged that disgusting contrast, laid motionless in a CT scanner for an hour, and thought about what I still needed to pack. Did I remember the sunscreen? Were my walking shoes packed? Needless to say, the question "do I have mesothelioma?" never crossed my mind.

I was barely home when the phone rang. Little did I know that day was indeed the start of a journey, but not the one Lora and I had planned—they found fluid in my abdomen.

At this point neither my doctor nor I suspected mesothelioma. Fluid was not a good symptom, but my hopes were it was nothing. I was thinking simple fix, take a few pills or have a quick surgical procedure and it will be over within a couple of weeks. I never imagined I wouldn't even get a diagnosis for another three months.

If you've ever waited for important news, you understand the anxiety I was experiencing during that three-month time frame. What was wrong with me? Why couldn't they figure it out? The mental anguish of waiting and wondering was nearly as painful as those biopsies. Not knowing, feeling powerless, wanting so badly to make yourself whole again turned out to be worse than getting that final diagnosis.

Then, in true mesothelioma fashion, when I least expected it, a new symptom suddenly appeared. When you're waiting for a diagnosis, you'll be amazed at how in-tune you become with your body, no matter how loud or how subtle a signal occurs. So when I felt a golf ball-sized lump at the base of my neck, I knew my body just sent me a loud signal.



TV commercials". That form of cancer that currently has no cure and has few viable treatment options. That form of cancer that, for now, my doctors and treatments have kept on the back burner.

Rich Mosca has been an active member of the mesothelioma patient community since 2006. He became involved with the Mesothelioma Applied Research Foundation after attending his first International Symposium on Malignant Mesothelioma. He has advocated on behalf of mesothelioma patients on Capitol Hill, and through a nomination by the Mesothelioma Applied Research Foundation, he regularly participates in the Congressionally Directed Medical Research Programs' grant panels. Prior to retiring, Rich spent 35 years working in the IT industry.

As I went for yet another CT scan, I was almost excited about it. Finally, this will give us the answer we've been looking for. This was the one clue to the crossword puzzle we needed. This was the one turn needed to get out of the labyrinth.

What they found was a blood clot in my neck and inflammation in my abdomen. I was sent to the emergency room and admitted to the hospital the same day.

Having so much time to think is dangerous. My excitement had turned to fear. Fear that I wouldn't see my grandchildren grow up. Fear that my job of being a father would be cut short. Fear that Lora and I would not be able to fulfill the many dreams and plans we made together. I would have given anything to leave that hospital room and run with the bulls in Spain or tandem jump off a skyscraper—something just dangerous enough to take my mind off the unknown and the uncertainty of a daunting diagnosis.

More biopsies, more doctors, more questions. In just three months I had visited more hospitals than I had in my entire 54 plus years. But just when the repetitive cycle of 'see a doctor and get a test' started to feel like a way of life, something miraculous happened. I found a surgeon without an ego (which surgeons themselves will tell you is a rarity). Even though the biopsies were initially inconclusive, he knew what he was looking at. His words of wisdom still reverberate in my head: You need to see a mesothelioma specialist!

Seeing the mesothelioma specialist finally delivered a definitive diagnosis, and in a strange way, a sense of control I hadn't felt over the past three months. Having that diagnosis, made me feel active, almost triumphant. It also let me know I had a new journey ahead of me—one that I never expected.

When people refer to my disease as "that one on TV" I laugh and nod. Yes, "that one from

**MESOTHELIOMA NEWS
DIRECTLY FROM THE SOURCE**

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oncologists
who treat
and study
mesothelioma!**

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INTERNATIONAL SYMPOSIUM ON MALIGNANT MESOTHELIOMA

OCT 19 – 21, 2023 WASHINGTON, DC

The Meso Foundation's International Symposium on Malignant Mesothelioma is a unique conference that brings together the entire mesothelioma community. We invite patients, their families, caregivers, and the bereaved community, to learn about the latest in treatment options, speak face-to-face with top mesothelioma experts, and find community and support with others walking in their shoes.



WHO SHOULD ATTEND

- Patients, their families, caregivers, friends
- Those who have lost a loved one to mesothelioma
- Anyone else interested in making a difference

LOCATION AND HOTEL

The conference will take place at the Omni Shoreham Hotel in Washington, DC where we also secured a room block for our attendees.

Omni Shoreham Hotel
2500 Calvert St NW, Washington, DC 20008

CONFIRMED SPEAKERS

- FACULTY DIRECTOR:** Marjorie G. Zauderer, MD
Memorial Sloan Kettering Cancer Center
- Prasad Adusumilli, MD, Memorial Sloan Kettering Cancer Center
 - Samuel Armato, PhD, University of Chicago
 - Jennifer Bires, MSW, LCSW, OSW-C
 - Andrew Blakely, MD, National Cancer Institute
 - Keith Cengel, MD, PhD, University of Pennsylvania
 - Ibiayi Dagogo-Jack, MD, Massachusetts General Hospital
 - Joseph Friedberg, MD, Temple University
 - Joseph George, RN, Memorial Sloan Kettering Cancer Center
 - Raffit Hassan, MD, National Cancer Institute
 - Chuong Hoang, MD, National Cancer Institute
 - Alexandra Lebensohn, MS, CGC, National Cancer Institute
 - Melina Marmarelis, MD, University of Pennsylvania
 - Garret Nash, MD, Memorial Sloan Kettering Cancer Center
 - Michael Offin, MD, Memorial Sloan Kettering Cancer Center
 - R. Taylor Ripley, MD, Baylor
 - Charles, Simone, MD, NY Proton Center
 - Daniel Sterman, MD, NYU Langone
 - Christopher Straus, MD, University of Chicago
 - Kiran Turaga, MD, Yale

SCHEDULE OVERVIEW

- October 19:** Advocacy Day
- October 20:** Community Conference / Scientific Conference, Awards Dinner
- October 21:** Community Conference

Read the full agenda at curemeso.org/symposium

AGENDA HIGHLIGHTS

- Sessions about currently-available treatment options at diagnosis, first recurrence, second recurrence, and beyond
- Overview of surgery, chemotherapy, immunotherapy, VEGF, target therapies, precision medicine, combination therapies, supportive care
- Clinical trials
- Side effect management
- Life during treatment: management of disease effects and treatment side effects, nutrition, treatment options as symptom management
- Support groups
- Tribute ceremony and sessions specific to those who suffered a loss.



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Are you a mesothelioma patient or caregiver?

The Mesothelioma Applied Research Foundation provides free-of charge services for mesothelioma patients and caregivers regardless of stage of disease. We encourage all patients to join our community whether they are receiving help, providing help, or even just reading our news occasionally. Involvement can take many different shapes and forms, but being connected ensures a bigger and, thereby, stronger community.

If you a newly diagnosed mesothelioma patient or their caregiver, you may be interested in these services.

For many newly diagnosed patients, finding the best (for them) treatment team and accessing treatment is vital as they navigate their diagnosis. Our team is here to help with:

- One-on-one personalized guidance services with a mesothelioma nurse
- Financial assistance for travel to clinical trials, or a first consultation to an expert
- Identifying clinical trials
- Support groups for the patient and caregiver
- Peer to peer support
- Educational programming



Patients who already have have a medical team or whose disease is stable can still benefit by being connected to the Foundation.

Sometimes, patients have already identified their treatment team by the time they find us. Or other times, patients have already undergone treatment and are in remission. Even for these patients, the Foundation might still be a useful resource.

- Hear it here first: news about treatment options, reporting on their efficacy, what's next.
- Sometimes the best clinical trial for a patient is not offered at their center of treatment. In that case, we can facilitate trial enrollment by connecting your treating oncologist with the trial investigator to create a bridge between insitutions.
- Management of treatment and disease side effects. Our community as a whole has seen it all and has tried it all. No one is better equipped to suggest solutions than someone who has been there, done that.
- Survivorship support
- Educational programming
- Socialization opportunities



JOIN THE COMMUNITY!

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Announcing our Science Advisory Board co-chairs



Cara Haymaker, PhD, MD Anderson Cancer Center, and Tobias Peikert, MD, Mayo Clinic

The Science Advisory Board (SAB) of the Mesothelioma Applied Research Foundation is an entity tasked with reviewing and scoring grant applications submitted through the Foundation's research grants program. It is comprised by a group of medical professionals and scientists who are deemed experts in the field of mesothelioma.

As of the summer of 2023, Cara Haymaker, PhD, MD Anderson Cancer Center, and Tobias Peikert, MD, Mayo Clinic, will lead the SAB as co-chairs.

The composition of the Science Advisory Board as of July 2023

Cara Haymaker, PhD, MD Anderson Cancer Center
Tobias Peiker, MD, Mayo Clinic

Joseph Friedberg, MD, Temple University

Madhavi Ganapathiraju, PhD, University of Pittsburgh

Jonathan Greer, MD, Johns Hopkins Medicine

Travis Grotz, MD, Mayo Clinic

Chuong Dinh Hoang, MD, National Institutes of Health

Fabian Johnston, MD, MHS, Johns Hopkins

Hyun-Sung Lee, MD, PhD, Baylor College of Medicine

Steve Mutsears, PhD, University of Western Australia

Michael Offin, MD, Memorial Sloan Kettering Cancer Center

Manish Patel, DO, University of Minnesota

Emanuela Taioli, MD, PhD, Mount Sinai

Kiran Turaga, MD, Yale University

Polaris Group
is a biotechnology company
focused on developing novel
anti-cancer therapies.

We proudly stand with the
**Mesothelioma Applied
Research Foundation**
in our common quest toward new
and better cancer treatments.



We're inspired by a single vision:

Transforming
patients' lives
through science™

Each day, the Meso Foundation works to offer hope and support to patients and families affected by mesothelioma by providing the most up-to-date information and resources, funding the highest quality and most promising research, and raising awareness in both the public and private sectors, all in an effort to one day lead to a cure for mesothelioma. None of this would be possible without the continued support from the meso community. **When you donate to the Foundation, you help us help our community!**



How we help patients, caregivers, family members

- One-on-one patient navigation with a mesothelioma expert
- Clinical trial information and guidance
- Patient travel grant program
- Online support groups
- Telephone support groups
- Peer support
- Conferences
- MesoTV
- Meet the Mesothelioma Experts Interview Series



How we help those who have lost a loved one

- Support groups
- Private gatherings
- Informational materials
- Opportunities for socialization



How we help scientists, physicians, medical professionals

- Peer-reviewed research funding
- Scientific conferences
- \$11.5 million in mesothelioma research grants funded
- 119 studies funded through the research grant program
- Scientific workgroups
- Development of educational materials for patients and caregivers
- \$22.5+ million in government funding directed to mesothelioma research

As the demand for the Foundation's resources grows and the ever-present need for new research grants continues, we work to meet the needs of our patients, caregivers, and their families. It is the generosity of like-minded individuals coming together that helps us meet these growing demands. Whether you are new to this community or a long-standing member, your continued support is valuable and impactful.

Thank you for sharing in our mission and your active engagement in our meso community.

DONATE ONLINE



Make your gift today by scanning the QR code, or visit curemeso.org/donate to see all of the ways to show your support.

DONATE BY MAIL

Mesothelioma Applied Research Foundation
PO Box 24041
New York, NY 10087

Get to know the 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 with her rescue dogs Maggie and Millie, enjoy hiking, dragonboating, and needlework.



Maja Belamaric, MBA, 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.



Melissa Gerard, Community Events Coordinator
mgerard@curemeso.org

Melissa's responsibilities at the Meso Foundation encompass coordination of community-based services such as support groups and educational events, including the International Symposium on Malignant Mesothelioma. She provides support to the Community Advisory Board as well our third-party fundraisers, and assists with the Foundation's marketing and communications efforts. Melissa came to the Meso Foundation with ten years of experience in marketing and communications in the non-profit industry. She previously worked for The Center for Courageous Kids and Hope Harbor, a sexual assault recovery center. She holds a bachelor's degree in Advertising and Non-Profit Administration from Western Kentucky University.



Carolyn Shields, MBA, Development Manager
cshields@curemeso.org

Carolyn Shields joined the Foundation in March 2023 as its development manager. Carolyn will be working with our donors and will manage our fundraising campaigns. She has a background in higher education development and was most recently at Xavier University, where she specialized in annual giving. Carolyn holds a bachelor's degree in Marketing and Management from Drury University and an MBA from Xavier University. She spends time working on DIY home projects, enjoying time with family, and playing with her dog, Magnolia.



Nicole Yost, Program Coordinator
nyost@curemeso.org

Nicki joined the Meso Foundation team in 2022, first as an intern and then full-time after finishing graduate school. Nicki's responsibilities include supporting all aspects of the organization's work, with a special focus on patient support and education. She also takes on a significant administrative role in the Foundation's research grant cycle. Nicki holds a bachelor's degree from Alma College and a master's degree from the University of Chicago.



Losing a loved one to mesothelioma

Just like a mesothelioma diagnosis, losing a loved one to mesothelioma can be an equally isolating and traumatic experience. To help our bereaved community through the hardship of loss, we provide support through groups and opportunities for meeting others experiencing similar circumstances. Just like our patient and caregiver groups, the bereaved groups are offered through video-calls, via Facebook, and occasionally in-person at our Symposium. (A full list of support groups is listed on pages 22 and 23 of this publication.)

While the full name of the Symposium implies a medical nature to the information shared, please note that we take great effort to ensure that all community members are welcome. For our bereaved community, we this year, we carved a special program that includes:

- A Celebration of Life ceremony
- A special memorial activity
- Grief support groups
- Socialization opportunities with other bereaved members of the community



Fundraising events by the community, for the community



Over the years, mesothelioma-community-members turned event-organizing-extraordinaires, have held hundreds of events across the United States and abroad. Have you ever wondered how they do it or whether you could do the same yourself?

We've seen walks, runs, kayaking, poker tournaments, corn hole tournaments, birthday gifts, happy hours and much more. And the good news is that we can help coach you through every step of planning from concept to execution, and provide access to the tools and resources you'll need to plan a successful event!



But even if you're not the event-organizing type, you can still support the Foundation and your fellow community by attending their events. Every year, our event organizers hold anywhere between 10-30 events across the country, and one might just be available in your next of the woods. While we do our best to list all of the remaining 2023 events below, we do add new events to our calendar often, so make sure to check our website!

CONTACT US AT INFO@CUREMESO.ORG IF YOU WOULD LIKE TO ORGANIZE YOUR OWN EVENT.



Saturday, September 2
Mesothelioma Race for Justice 5K
ILLINOIS



Saturday, September 23
John Slagle Memorial Golf Tournament
WISCONSIN



Saturday, September 23
Steve Torrey Golf Outing
MICHIGAN



Sunday, September 24
Ride Miles for Meso honoring Jeff Glassman
CALIFORNIA



Monday, October 9
The Em' for Emily
SOUTH CAROLINA

MESOTHELIOMA AWARENESS DAY SEPTEMBER 26

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 19th annual Mesothelioma Awareness Day in the following ways. More information, along with links, is available on our website at: curemeso.org/awareness.

PAINT THE WORLD BLUE FOR MESOTHELIOMA AWARENESS



- 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.

LIGHT THE WORLD BLUE FOR MESOTHELIOMA AWARENESS



- 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. List of confirmed locations is on our website at curemeso.org/awareness.
- If able to secure a landmark to light up blue, contact you local media and tell them about it!



- This is a campaign in conjunction with our friends at **Novocure** who envisioned it, and who, every year, provide the staffing necessary to make the bulk of the requests and grow our reach!

AMPLIFY THE MESSAGE

- Share our social media posts including infographics, facts, and tips.
- Organize or attend an awareness or fundraising event.
- Share proclamations from your states and localities.
- Contact your local media and ask them to cover your efforts.



Join us to
light the
world blue

Mesothelioma Awareness Day,
this September 26

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

Learn more: Novocure.com



SCHEDULE

Support groups for mesothelioma patients, caregivers, and those who lost a loved one

The Mesothelioma Applied Research Foundation (Meso Foundation) is a non-profit organization that provides support, education, and advocacy for individuals and families affected by mesothelioma, a rare cancer associated with asbestos exposure. The Foundation is also the leading funder of peer-reviewed mesothelioma research.

One of the key services provided by the Meso Foundation is patient support, which includes support groups and conversation groups. These support groups provide an opportunity for patients, caregivers, and those who have lost a loved one to mesothelioma to connect with others who understand the challenges of this specific cancer and the experience of its impact.

Some of the benefits of participating in a mesothelioma support group can include:

- **Emotional support:** Talking to others who are going through similar experiences can help reduce feelings of isolation and provide a sense of community.
- **Information sharing:** Support groups provide a platform for patients and caregivers to share information about treatments, resources, and coping strategies.
- **Encouragement:** Being in a supportive environment can help boost morale and provide encouragement for patients and caregivers as they navigate a mesothelioma diagnosis.

Meso Foundation's support groups are held in-person (at the organization's annual conference), by Zoom, or through Facebook groups, and are facilitated by trained professionals who understand the challenges of living with mesothelioma. The conversation groups are led by community members.

The Foundation also provides access to educational resources such as its MesoTV interview-based program with mesothelioma specialists, and support services such as treatment guidance and financial assistance.

To join the support groups, patients, caregivers, and the bereaved community can contact (703) 879-3824 or info@curemeso.org. All participants are vetted to ensure the groups are safe for everyone.

To join the organization's Facebook groups, search for these group names and request to join. Make sure to answer the required questions!

Mesothelioma Straight Talk: General Discussion (by US nonprofit). This a group for all members of the mesothelioma community to discuss topics of interest, ask each other questions, and connect.

Mesothelioma Straight Talk: Patient Support (by US nonprofit) This group is for those who have been diagnosed with mesothelioma who wish to share and connect with others on this journey. It is a private room where all conversations are welcome, no subject taboo but will be held to a kind and gentle format in an attempt to alleviate some of the stress, celebrate some of the victories and seek comfort on those difficult days.

Mesothelioma Straight Talk: Caregivers – Advanced Disease (by US nonprofit) This group is for caregivers of patients with advanced disease. It focuses on symptom management and treatment of advanced disease while still providing hope to those who are struggling with a multitude of caregiving challenges.

Mesothelioma Straight Talk: Caregivers – Early Disease (by US nonprofit) This group is for caregivers of patients who are in the early stages of mesothelioma requiring little in symptom management, who wish to focus on hope, support and navigating through treatment and decision-making.

Mesothelioma Loss Support Group (by US nonprofit) Losing someone you love at any time from anything is tragic enough, but losing someone to mesothelioma adds levels of emotion not experienced outside this unique circle. This group is a supportive community for everyone who has lost a loved one to mesothelioma.



Tuesday, September 5, 8 PM - 9 PM ET
ZOOM: Spousal Loss Conversation Group
 Compassionate Conversations with Olga and Friends



Monday, September 11, 7 PM - 8 PM ET
ZOOM: Patients Stronger Together Meet-Up
 w/ Bill Ziegler



Tuesday, September 19, 8 PM - 9 PM ET
ZOOM: Spousal Loss Conversation Group
 Compassionate Conversations with Olga and Friends



Thursday, September 21, 7 PM - 8 PM ET
ZOOM: Moving forward with loss - challenges facing younger widows and widowers, w/ Claudine Benmar



Sunday, September 24, 7 PM - 8 PM ET
ZOOM: Community Social Hour (leading up to Mesothelioma Awareness Day)



Tuesday, September 26, 7 PM - 8 PM ET
ZOOM: Caregivers' Professionally Moderated Support Group
 co-hosted by Jennifer Bires, MSW and Lora Mosca



Thursday, September 28, 7 PM - 8 PM ET
ZOOM: Patients' Professionally Moderated Support Group
 w/ Jennifer Bires, MSW



Tuesday, October 3, 8 PM - 9 PM ET
ZOOM: Spousal Loss Conversation Group
 Compassionate Conversations with Olga and Friends



Monday, October 9, 7 PM - 8 PM ET
ZOOM: Patients Stronger Together Meet-Up
 w/ Bill Ziegler



Tuesday, October 10, 7 PM - 8 PM ET
ZOOM: Caregivers Circle of Support
 w/ Lora Mosca



Tuesday, October 17, 8 PM - 9 PM ET
ZOOM: Spousal Loss Conversation Group
 Compassionate Conversations with Olga and Friends



Saturday, October 21 @ Symposium
IN-PERSON: Patients' Support Group
 Professionally Moderated



Saturday, October 21 @ Symposium
IN-PERSON: Caregivers' Support Group
 Professionally Moderated



Saturday, October 21 @ Symposium
IN-PERSON: Bereaved Support Group
 Professionally Moderated

Contact (703) 879-3824 or info@curemeso.org for information on how to join or RSVP.



Mesothelioma Applied[®] Research Foundation

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INTERNATIONAL SYMPOSIUM ON MALIGNANT MESOTHELIOMA

OCT 19 – 21, 2023 WASHINGTON, DC



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