

BREATH OF HOPE

a publication by the Mesothelioma Applied Research Foundation

Summer 2021



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**Thank you to everyone who submitted their photo for this collage!*

A COMMUNITY DIVIDED BY COVID UNITED IN SPIRIT (AND BY TECHNOLOGY)

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MOVING FORWARD WITH STRENGTH AND RESILIENCE

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

Even during the best of times, the mesothelioma community faces extraordinary challenges. Last year, many in our community were forced to navigate a mesothelioma diagnosis amidst a global pandemic — a herculean task, it turns out.

Our organization prides itself in helping patients, particularly when they have nowhere else to turn. During this pandemic, too, we have supported patients and their families, as well as the bereaved community as we always do. Our services have continued and in many ways expanded to accommodate new needs brought on by covid, whether it be adapting treatment options to not require air travel; or checking with providers in real time about which treatments are on hold and which are not; or providing additional support to our bereaved community, particularly those who during covid suffered a loss that they couldn't properly mourn due to pandemic mitigation restrictions.

Another way our services grew has been through technology. Aside from the fact that we've been able to provide pertinent and timely information about treatment options solely thanks to technology, our community also has become more accustomed to using technology to connect — whether for support groups, virtual get-togethers or workshops. While a far cry from in person connection, technology allowed us to keep in touch in ways never before possible. It certainly helped alleviate some loneliness and isolation, and provide an opportunity for sharing of crucial information, and for that, we are grateful.

However, we all miss that in-person connection and our hope is that in 2022 we will once again be able to resume in-person meetings like our Symposium and our Celebration of Life ceremonies. We will keep you posted as the pandemic evolves and as our plans develop.

Until then, thank you for being there for one another and for your support of this organization and its community always, but especially during these difficult times.

Stay safe my friends,

Mary

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BREAKING NEWS: MESO FOUNDATION AWARDS THREE NEW RESEARCH GRANTS BRINGING TOTAL FUNDED TO \$10.8 MILLION

In July 2021, the Mesothelioma Applied Research Foundation announced the selection and funding of three new research awards for mesothelioma research. The three grants, each funded at \$100,000, bring the total research funded by the organization to \$10.8 million.

These awards conclude the 2020 grant cycle which began last summer with a call for letters of interest that attracted 49 applicants of which 10 were invited to submit a full application.

"The uncertainty of the covid era continues, but through it we remain focused on the needs of our community and our mission," explained Mary Hesdorffer, expert nurse practitioner and the executive director of the Mesothelioma Applied Research Foundation.

The science advisory board of the Mesothelioma Applied Research Foundation, chaired by Tobias Peikert, MD of the Mayo Clinic, is responsible for reviewing and ranking all applications, then recommending the best ones to the board of directors for funding. This year's process also included a review by community members.

The three grants awarded through this most recent grant cycle include a study into the creation of a mechanism to keep the immune system active against peritoneal mesothelioma cells; a study into engineered natural killer cell therapy; and a study into understanding and separating immunotherapy's useful features from the side-effect inducing ones.

"My deepest gratitude goes out to our donors whose support is essential to our mission. Without them none of this work would be possible," added Ms. Hesdorffer.

THE GRANTS

The Anderson Family Grant

Peritoneal Mesothelioma Organoids for Generation of Adaptive Immunity

Konstantinos Votanopoulos, MD, PhD, FACS
Wake Forest University Health Sciences

Grant in memory of Sandy Robb

Mesothelin-targeted CAR-NK cell therapy for malignant mesothelioma

Qun Jiang, PhD, National Cancer Institute

Grant in honor of Rich and Lora Mosca

Immune checkpoint induced tumor and autoimmunity: Can we separate them?

Jonathan Chee, PhD, University of Western Australia

UPDATES FROM THE INTERNATIONAL MESOTHELIOMA INTEREST GROUP (IMIG)

The International Mesothelioma Interest Group (iMig) biannual meeting was initially scheduled for March of 2020 in Brisbane, Australia, but had to be postponed due to the pandemic. In the Spring of 2021, organizers held the event, albeit virtually.

The iMig meeting is a unique scientific meeting in that it focuses solely on mesothelioma, and covers all aspects of mesothelioma. Sessions feature basic scientists who study biomarkers and molecular processes, but also pathologists, oncologists, surgeons, radiologists, nurses, and representatives from nonprofit organizations such as the Mesothelioma Applied Research Foundation and MesoUK.

THE FUTURE OF MESOTHELIOMA TREATMENT

The session, “The Future of Mesothelioma: What Might the Next Decade Look Like for our Patients” featured Dr. Bruce Robinson from the University of Western Australia, Dr. Michele Carbone from the University of Hawaii, Dr. Melvin Chin of NCARD (Australian National Center for Asbestos-Related Diseases), and Dr. Dean Fennell of the University of Leicester.

Dr. Fennell discussed genomic drivers of mesothelioma and the potential in the future to create therapies that target certain genetic mutations in mesothelioma patients. He detailed studies that have already seen promise in this area (see articles on the next page).

Dr. Carbone discussed the role of the BAP1 gene mutation in mesothelioma development and prognosis of patients with this characteristic. He also listed several clinical trials that will continue exploring this area.

Dr. Robinson’s presentation focused on the role of immunotherapy in how mesotheliomas are treated in the future. He believes that in the future, immunogenic chemotherapies will have a prominent role in treatment. This is a concept built on using chemotherapy to expose certain immune targets which then can be attacked by the immune system. (Put simply, chemotherapy, in the process of killing tumor cells, causes them to release certain protein byproducts. Those proteins are then recognized by the immune system and attacked). Radiation therapy may also provide a similar pathway for accelerating the immune response, although research into that is in the early stages.

“When you think of the future of mesothelioma immunotherapy, I think it’s about reducing guesswork,” said Dr. Robinson in his presentation.

“We have the tools now, very sophisticated immunotherapy tools just developed in the last few years,” he added.

Dr. Robinson concluded his presentation by emphasizing an area gaining consensus among mesothelioma experts – like many of his colleagues, he sees the future of mesothelioma therapy, including immunotherapy, tied to the patients’ specific genomic characteristics.



NURSING WORKSHOP

A second pre-conference workshop was the “ITONF at iMig 2021 Nursing Workshop.” While medical and scientific sessions tend to focus on the mesothelioma tumor and the impact of treatments on the tumor, the nursing session covers research into the patient experience as a whole, with a focus on quality of life and patient care.

Melissa Culligan, RN, MS, of the University of Maryland kicked off the session with a literature review of recent studies. She then profiled the mesothelioma nursing programs around the world, including the one at the Mesothelioma Applied Research Foundation.

Buerkley Rose, MSN, RN, of the University of Chicago discussed “The Clinical Trial Landscape of Mesothelioma.” She began her presentation by acknowledging the significant impacts of covid on clinical trials. They include delays in surgeries and other treatments, travel restrictions making it more difficult for patients to participate in clinical trials, and clinical trial pauses to conserve resources. Despite these challenges, since January 1, 2020, 26 new clinical trials specific to mesothelioma have opened.



(from left) Melissa Culligan, RN, MS (former board member), and Buerkley Rose, MSN, RN (current board member), during a session at the 2019 International Symposium on Malignant Mesothelioma, along with Erica Glass, CRNP, University of Maryland, and Alison Massey, NP-BC, Memorial Sloan Kettering Cancer Center.

NIVOLUMAB TRIAL RESULTS MAKE IT A PROMISING TREATMENT FOR RELAPSED (PREVIOUSLY TREATED) MESOTHELIOMA PATIENTS

On the heels of the approval of combination immunotherapy in the first line setting, this study featuring a single agent immunotherapy shows much promise for some patients.

A Phase 3 trial in relapsed mesothelioma patients showed a significant improvement in overall survival and progression-free survival when patients were treated with nivolumab. Nivolumab is an immunotherapeutic agent that works by blocking the tumor's ability to disengage the immune system, effectively enabling the patient's own immune system to attack the cancer. Nivolumab is commercially known under the brand name of Opdivo.

The CONFIRM study was a randomized trial that compared a nivolumab arm against a placebo arm. The trial was run in 24 centers in the United Kingdom and it enrolled 332 patients who were previously treated in a first-line setting. Patients were randomly assigned to each arm and stratified by cell type of mesothelioma (epithelioid vs. nonepithelioid). The epithelioid-type patients appeared to benefit most from this treatment.

The study was led by Dr. Dean Fennell, professor and chair of Thoracic Medical Oncology at the University of Leicester. Dr. Fennell indicated that nivolumab administered as a single agent is a safe and effective treatment option for malignant mesothelioma and should be considered as a new treatment option.

The official name of this study is CheckpOint Blockade For Inhibition of Relapsed Mesothelioma (CONFIRM): A Phase III Double-Blind, Placebo Controlled Trial to Evaluate the Efficacy of Nivolumab in Relapsed Mesothelioma.

This news comes on the heels of the October 2020 FDA-approval of combination treatment of nivolumab + ipilimumab in a first-line treatment setting.



Dr. Dean Fennell presenting at the International Symposium on Malignant Mesothelioma at the National Institutes of Health (NIH).

A HOPEFUL FOUNDATION FOR DEVELOPMENT OF PRECISION MEDICINE IN MESOTHELIOMA

The challenges of treating mesothelioma are well known to this community of patients, caregivers, bereaved, and the physicians who treat them. Particularly, researchers have been puzzled by this cancer's ability to respond extremely well to certain treatments in certain patients, but not respond as well, or at all, in others.

The answer to this phenomenon appears to be linked to information stored inside the exome (the part of the genome that stores proteins – also known as biomarkers) of the tumor. In a new study by Dr. Min Zhang and Dr. Dean Fennell, published Friday, March 19, the authors map out the tumor microenvironment in mesothelioma to identify features that could be exploited as targets for treatment.

In response to this study recently published in Nature Communications, Dr. Marjorie G. Zauderer, a medical oncologist at Memorial Sloan Kettering Cancer Center and the chair of the board of directors of the Mesothelioma Applied Research Foundation, argues that its results further support the need to focus future research on identifying predicting biomarkers for new therapies.

"Exceptional responders were identified in many early phase clinical trials in MPM (malignant pleural mesothelioma), but without a biomarker, these compounds were abandoned for lack of efficacy," wrote Dr. Zauderer in the article.

This concept is not new in cancer research. In fact, several previously difficult to treat cancers have seen monumental improvements in survival once researchers focused on personalizing treatment to match the molecular characteristics of the tumor. Similarly, Dr. Zauderer argues that these new discoveries should fuel inquiries into creating personalized therapies for mesothelioma patients, as well. She is hopeful that doing so will unveil much-needed opportunities for better outcomes in mesothelioma treatment.


"Work like this hails the dawn of a new age for drug discovery and development in MPM, and I am optimistic for what lies ahead," concluded Dr. Zauderer.

Nature Communications is a peer-reviewed, scientific journal.



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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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THE MESO FOUNDATION AND ITS TEAM

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

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

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

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

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

Mary Hesdorffer, Nurse Practitioner Executive Director



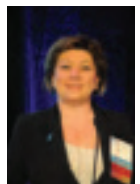
In addition to the responsibility of leading the organization in all of its areas of operation, Mary is also the head of our patient support department. She is an expert in mesothelioma treatment with over 25 years of experience specific to mesothelioma. She provides one-on-one consultations with patients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

Meghan Butler Development Coordinator



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.

Ivana Mihajlovic Administrative Assistant



Since her diagnosis in 2009, Ivana has not missed any Meso Foundation conferences. In fact, you may recognize Ivana from our videos and photos from our events where she's been featured quite prominently. She has also organized her own fundraising events and looks forward to helping the Foundation and our community in this new position.

Maja Belamaric, MBA Director of Communications and Operations



Maja's dual role touches on varied aspects of the organization's work, including business management of the organization, as well as overseeing public facing informational materials and campaigns across print and digital formats, and implementations of tech solutions across all areas of the organization's work.

Katie Jamieson, CAE Special Projects Manager



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

Tobias Rodriguez Communications Manager



Tobias' work at the Meso Foundation helps engage the community on all aspects of the organization's operations online and offline. These include writing for the website about all-things mesothelioma with a heavy focus on stories about patients and their families affected by mesothelioma. He tweets and engages on Facebook and Instagram.



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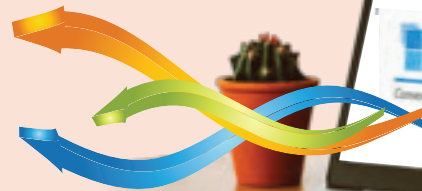
As we honor your efforts in working
for a cure, we join you in dreaming
of a better future for mesothelioma
patients and their families.

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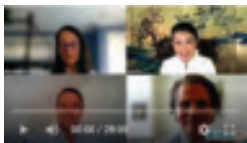
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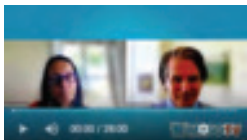
HOW TO WATCH

Watching MesoTV is easy. On any device with access to the internet visit our website at curemeso.org/mesotv or visit our YouTube channel directly at youtube.com/mesofoundation.

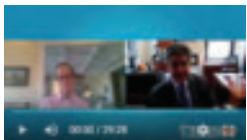
Make sure to subscribe to our channel in order to be notified as we post new videos. We list here some of our most recent episodes.



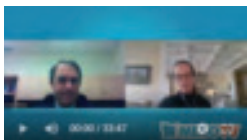
Chemotherapy + immunotherapy, another positive step in mesothelioma treatment



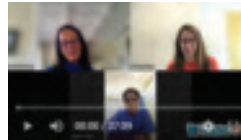
"Does staging matter in mesothelioma" with Dr. James Stevenson of the Cleveland Clinic



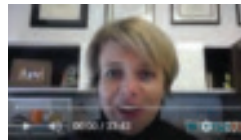
Pneumonitis in immunotherapy-treated mesothelioma patients



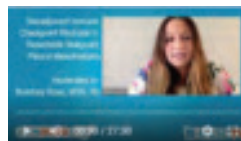
Peritoneal mesothelioma surgery and treatment at the National Cancer Institute



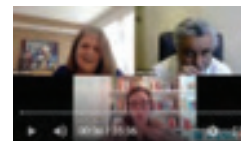
Toxicities, side-effects, from immunotherapy for treatment of mesothelioma



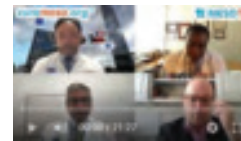
CLINICAL TRIAL: Engineered T-cell therapy (TC-210, gavo-cel) for mesothelioma



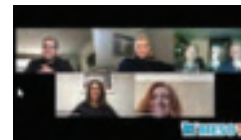
CLINICAL TRIAL OPEN: Immunotherapy prior to surgery for resectable pleural mesothelioma



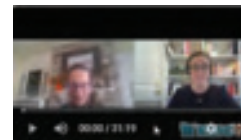
Current trends in mesothelioma treatment - discussion by thought-leaders in this disease



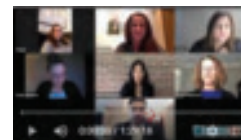
Pain management for mesothelioma patients by Baylor panel



Panel discussing survivors' guilt and other issues affecting mesothelioma survivors



NOW ENROLLING: Overview of CAR-T cell therapy trial targeting mesothelin



Having a baby after mesothelioma - a panel with cancer patients and fertility specialists

MESOTHELIOMA JARGON GUIDE AND GLOSSARY



We have heard this story from our patients over and over again: after their diagnosis, the patient and their family are catapulted into an intensive search for treatment options and information. Suddenly, folks with little or no medical background find themselves reading medical literature and searching through clinical trial descriptions. While we hope that our coverage of treatment options and advances helps patients make important decisions, we understand that much of the information presented is often complicated and made more so by the technical nature of the mesothelioma jargon.

For this reason, in conjunction with our release of the MesoTV episode titled “Current trends in mesothelioma treatment – discussion by thought-leaders in this disease” (to watch, visit our website at curemeso.org/mesotv) we have compiled below, in one place, some mesothelioma jargon terms along with their lay definitions, to make the information in the episode easier to understand.

While we simplify these terms to make them as easy to understand as possible, please be reminded that cancer treatment is incredibly complex and nuanced. If you need any help understanding your diagnosis and treatment, please contact the Mesothelioma Applied Research Foundation.

Anti-angiogenesis = inhibition of blood vessel growth with goal of starving the tumor of blood flow

Bev = short for bevacizumab, drug that inhibits the growth of blood vessels (inhibitor of VEGF-A which stands for vascular endothelial growth factor A), also known as anti-angiogenesis or angiogenesis inhibitor agent; has been studied in mesothelioma in combination with pemetrexed/cisplatin; see MAPS study below

Biphasic = cellular type of mesothelioma determined by histological analysis (a detailed look into the microscopic structures of the tumor) to contain both epithelioid type cells and sarcomatoid type cells

Cis = stands for cisplatin, a platinum-based chemotherapy most often used in combination with pemetrexed, which in turn is known by brand name Alimta

Carbo = stands for carboplatin, a platinum-based chemotherapy drug, sometimes used in combination with Alimta (pemetrexed) particularly when cisplatin is not well tolerated

Checkmate 743 = a phase 3, randomized study of 713 patients that compared a group of patients treated with combination nivolumab/ipilimumab (combination of two immunotherapy agents) to patients treated with standard platinum + pemetrexed chemotherapy; the study showed a significant improvement in survival among the group treated with immunotherapy and led to the October 2020 FDA-approval of combination nivolumab/ipilimumab for mesothelioma treatment

Doublet = treatment combination of pemetrexed / platinum chemo

Durvalumab = immunotherapy agent that blocks PD-L1 from binding to PD-1, known as a checkpoint inhibitor; currently used in randomized, phase 3 trial of combination chemotherapy/immunotherapy

Epithelioid = cell type in mesothelioma, determined by histology, less aggressive as compared to sarcomatoid; 78% of mesothelioma patients present with this type

Gemcitabine = chemotherapy drug; used in mesothelioma when pemetrexed is not suitable, often in combination with a platinum agent

IO = immunotherapy

Ipi = short for ipilimumab, immunotherapy drug that interrupts the CTLA-4 receptor thus enabling the immune system to attack the tumor

MAPS study = randomized, phased 3 study of combination pemetrexed/cisplatin/bevacizumab that found that the triplet combination improved survival over doublet combination, however with additional toxicity

Nivo = short for nivolumab, immunotherapy agent that blocks the PD-1 protein from binding to the PD-L1 protein, also known as immune checkpoint blockade, allows the immune system to attack the tumor cell

PD-1 = a protein found on the surface of t-cells, stands for programmed cell death protein 1. When connected to the PD-L1, it suppresses the immune system. Utilizing a PD-1 or PD-L1 inhibitor drug, prevents the two proteins from binding (connecting), thereby removing the suppression (brakes) from the immune system allowing it to attack the tumor.

PD-L1 = a protein found on the t-cells, when connected to PD-1, it suppresses the immune system

PD1, PDL1 expression = does the tumor express these proteins and in what quantities?

PD1, PDL1 inhibitors = a class of immunotherapy drugs that inhibit the ability of the PD-1 and PD-L1 to connect to one another thereby allowing the body's own t-cell to attack the tumor

Pembrolizumab = immunotherapy agent that, also known by its brand name Keytruda, blocks PD-1 receptor from binding to PD-L1

Pemetrexed = also known as Alimta, chemotherapy drug approved by the FDA for mesothelioma in combination with cisplatin

Platinum = platinum-based chemotherapy agents such as cisplatin or carboplatin

Ramucirumab = anti-angiogenesis drug, similar in activity to bevacizumab, but instead of inhibiting only the VEGF-A, it inhibits all VEGFs, therefore with a different benefit vs. toxicity profile

Sarcomatoid = cell type in mesothelioma, as opposed to epithelioid, is considered more aggressive

Significant = statistical term used in studies to convey that an occurrence in the study was tested and shown statistically to not have been random; the term itself does not convey quantifiable benefit – the actual statistics in the study do that (overall survival statistics, progression-free survival statistics, etc.)

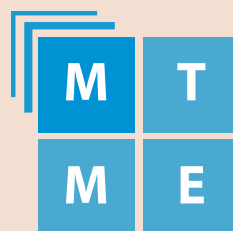
Triplet = treatment combination of pemetrexed / platinum-based chemo / bevacizumab



As part of the Meet the Mesothelioma Experts (MTME) series, the Meso Foundation invites specialists in the field of mesothelioma to discuss their current research interests as well as promising developments in the treatment of mesothelioma.

You can view our full library of interviews at curemeso.org/MeetExperts.

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



**Meet the
Mesothelioma
Experts**



COMMUNITY PROFILES

Colors of Hope: Inspiring the meso community

Peter Liman, 82, is passionate about life. His goal has always been to live life to the fullest. But nine years ago, just as he embraced his early 70s, Peter received a diagnosis that turned his life upside down. He was told he has malignant pleural mesothelioma, an aggressive cancer that affects the lining of the lung. Peter, an accomplished artist, decided at that moment that his art would be his coping mechanism and his hope was that as he helped himself he could also inspire others.

As a boy growing up in New York and New Jersey, Peter was introduced to art by his sculptress mother. He watched her spend hours working on her craft, while she, in turn, encouraged him to follow his own passion for painting.

“She saved my “masterpieces” throughout the years, most of which I felt she should have discarded long ago,” Peter said.

As Peter matured professionally, his studies at the University of North Carolina and Harvard would lead him on a path of world travel. Working in marketing, he visited many countries where he was introduced to new artists and galleries.

However, it wasn’t until retirement and his mesothelioma diagnosis that he figured out his talent for painting could be inspirational.

“Anywhere I can try to give hope to people, I try to do that,” he said.

Like hospital halls, for example.

Over the years, Peter spent many hours walking hospital halls in New York and New Jersey. Before he even knew he had mesothelioma, he frequently sought medical help to drain the mysterious fluid that was regularly building up in his chest and was

making it difficult to breathe. At the time, doctors told him it was pleurisy, but after switching medical providers, Peter underwent a biopsy which revealed the mesothelioma diagnosis. Then, after his diagnosis, he found himself once again pacing up and down hospital halls as he underwent treatment through a major surgery, then several rounds of radiation, and countless rounds of chemotherapy. In those halls he felt many emotions, but anxiety seemed to rise above them all.

“People don’t realize that because they look at you and you’re talking and walking and nothing seems wrong, but it’s not always the physical part of it, but the mental part of it,” Peter said.

To counter that, Peter has at this point shown around 60 paintings at various hospitals in New Jersey. Painting and making art became his lifeline – a way to disconnect from the stark reality and find peace. Now, his hope is that his creations can do the same for others and hopefully can alleviate at least some of the anxiety and fear patients endure wandering hospital halls.

This year, Peter has completed a new project. As a legacy to his wife, daughter, and grandchildren, he compiled into a book his impressionistic art, along with pictures of his family, two of the things Peter loves most. It’s called “The Monet of the Mountain Top.”

“I hope I will be a survivor to see [my family] achieve their dreams,” Peter said.

He feels optimistic thanks to doctors, the prescribed treatment, and the support of other mesothelioma survivors. If he had one piece of advice in return for the optimism this community has given him, it’s to find a passion and pursue it.

“Whatever it takes to lead a normal life, do it,” Peter said.



Peter with his wife Reggie



Fatherhood and mesothelioma

These days, Patrick Maholland is doing something you might not expect from a mesothelioma patient. He has been busy assembling a crib and a bookshelf as he counts down the days until his son, Julian, is born. Patrick and Ashli, his wife, cannot contain their excitement as they think about what life will be like when their baby boy arrives. Reality is still setting in for Patrick, that, in just a few months, he will become a father.

"I guess the first time it really hit me was when I heard his little heartbeat. I don't think I have been able to wipe this smile off my face since," Patrick said.

Father's Day will be a day to celebrate for Patrick and Ashli. It's a symbol of their love and their future. But, their past has been a roller coaster of emotions starting with Patrick's pleural mesothelioma diagnosis.

In February 2019, Patrick was experiencing recurring issues – a nasty cough and a drip down his throat. The 39-year-old English teacher's primary care physician recommended him to a local Charlotte, NC pulmonologist for an asthma test.

An x-ray showed a cloudy right lung. Numerous tests, scans and a biopsy later, an oncologist confirmed Patrick's diagnosis: what he had been dealing with was pleural mesothelioma.

"Within 48 hours, I had my wife's family and my family in our apartment," he said.

Patrick's life was on the verge of huge changes with his wedding and a big move on the horizon. The diagnosis added a whole other level of stress to it. In a few short days, he packed his belongings and made the eight and a half hour move from North Carolina to Philadelphia. In March, he started 14 rounds of chemotherapy, which took him right up to his wedding day.

"It was a lot thrown at me at once. It was like swimming in an abyss for like two weeks," Patrick said.

The dark days of his diagnosis followed by grueling treatment are now beginning to look brighter with fatherhood just around the corner and an easier treatment regimen that now only includes bevacizumab every three weeks at UPenn. Worry still sets in at times, but navigating it all is bearable knowing there can be a light at the end of the tunnel.

Ashli keeps Patrick accountable as she reminds him to take life one day at a time.

"She is a constant source of love, compassion and strength," Patrick said.

Despite having mesothelioma, Patrick thinks he's mostly feeling the same as any parent, except for the fact that he and his wife have to think about the "what ifs" sooner than others.

"I can't wait to spend every single moment with Julian. Of course, I have anxiety about not being here forever, but if the last few years have taught me anything, it is that my wife and family are amazing. The love and strength they share has shown me that, no matter what, Julian is going to be in great hands," Patrick said.

This Father's Day, Patrick will be in his son's nursery recording his favorite children's books and literature for Julian, just in case he can't be there to read them to him himself. But make no mistake, this time next year, Patrick wants nothing more but to be in that same nursery with his wife by his side holding their son.

"I get goosebumps just thinking about her rocking our little boy in her arms," he said.

Mental health impacts

Just like the rest of Americans, our community similarly suffered through the inability to spend time with family members and friends. The Mesothelioma Applied Research Foundation's Symposium was also canceled taking away what is often the only opportunity for patients and their families to socialize with others who have "walked in their shoes." Feelings of isolation, depression, anxiety were common among respondents. A recurrent theme was that our patients felt that they wasted a year of precious time.

"Too much isolation, and too much time wasted while health was at a level when life could have had so much more joy."

"Biggest impact on terminal patient is lack of family time."

Double heartbreak for our bereaved community

Family members of patients who passed away during the early stages of the pandemic found themselves largely alone through every step of their loss, including in their grief. Interpersonal support wasn't possible for most, and funeral and memorial services had to be postponed, thus also postponing the grieving process.

"Having my husband so ill during covid was difficult. I had to screen everyone who wanted to visit us. Our own children had to visit with us while talking through our screen door visiting their Dad. I had to be extremely careful for I knew that if he contracted covid and had to go to a hospital, he would die alone."

SUPPORT GROUPS

Telephone support groups allow for group participation monthly:

- Patient Support Group
- Caregiver Support Group
- Survivor Stories (quarterly)
- Spousal Loss Conversation Group: Compassionate Conversations with Olga and Friends
- Young Widows and Widowers Support Group
- Young Adult Support Group

We also moderate **Facebook Support Groups** for those who would rather interact online or wish to supplement their monthly calls with additional opportunity for support.

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.

Please contact Meghan Butler at mbutler@curemeso.org or 703-879-3824 to join the groups.



NEW! EXPANDED TRAVEL GRANTS PROGRAM

OFFERING FINANCIAL ASSISTANCE FOR TRAVEL EXPENSES
INCURRED WHILE SEEKING TREATMENT

GRANT AWARDS

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 \$1,000 grant can cover the costs of travel, lodging and meals. To receive a grant, patients are required to complete an application and document financial need. The grant is paid by check directly to the patient.

QUESTIONS?

Contact Meghan Butler at (877) 363-6376



Join us to

light the
world blue

Mesothelioma Awareness Day,
this September*

*Locational details forthcoming

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MESOTHELIOMA AWARENESS DAY SEPTEMBER 26 2021

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:

VISIT curemeso.org/awareness FOR UP-TO-DATE INFORMATION AND LINKS.

PAINT THE WORLD IN MESOTHELIOMA BLUE

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

SHARE THE MESO FOUNDATION'S SOCIAL MEDIA POSTS

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

VISIT THE LANDMARKS LIT UP IN BLUE

- We will make a list of landmarks scheduled to light up in blue available on our website. Visit the one close to you, take photos, send them to us, and post them on social media.

UPDATE YOUR FACEBOOK PROFILE PICTURE

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

OBTAIN A MESOTHELIOMA AWARENESS DAY PROCLAMATION FROM YOUR STATE OR LOCALITY

- Download the how-to guide at curemeso.org/awareness

ATTEND A THIRD-PARTY FUNDRAISER BENEFITING THE MESO FOUNDATION

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

CONTACT YOUR LOCAL MEDIA AND REQUEST A STORY ABOUT MESOTHELIOMA

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





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FUNDRAISE FOR MESO



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

Below is a list of upcoming fundraisers. Please note this list was current as of print time but may have been updated since. Please check our website for a most up to date list. Interested in hosting your own?

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

UPCOMING EVENTS

Bruce A. Waite 5k Run/Walk

Sunday, September 19
Ontario, Ohio

John Slagle Memorial Golf Tournament

Saturday, September 25
River Falls, Wisconsin

Third Annual Mesothelioma Race for Justice

September 1 – September 25
Virtual

Second Annual Steve Torrey Memorial Golf Outing

Saturday, September 25
Vassar, Michigan

The Em' for Emily

Saturday, October 9
Greer, South Carolina

Music for Meso

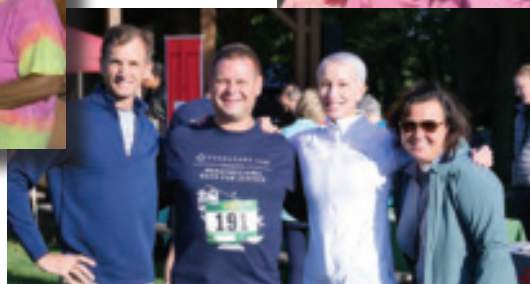
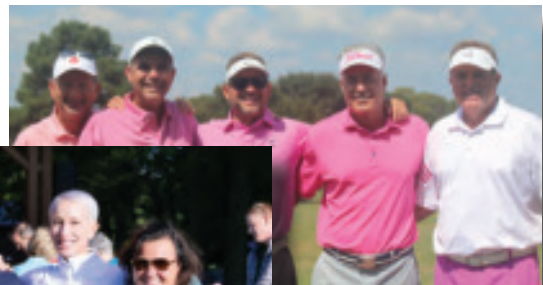
Saturday, October 23
Minneapolis, MN

Mesothelioma Awareness Day

Saturday, September 26
Global

Kick Out Mesothelioma 5-Miler & 2.5 Mile Walk

Sunday, November 14
Portland, Maine



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