

Breath of Hope

Summer 2007

Board Members Press for Meso Research Funding on Capitol Hill



Over the past several months, Meso Foundation Board of Directors members have had four opportunities to personally advocate in Washington, DC, for important legislation regarding mesothelioma.

On February 8, Meso Foundation Board members and staff individually visited their respective senators and all met with US Senator

Patty Murray (D-WA) to stress the need for meso research, public awareness and a ban on asbestos. Since then, Board members Dr. Harvey Pass and Susan Vento have testified before subcommittees regarding these important issues.

On March 1, Dr. Pass and Vento, along with long-time ban asbestos activist Barry Castleman and John Thayer, foreman of the Capitol Hill tunnel workers, testified before the US Senate Employment and Workplace Subcommittee. The subject of the hearing was The Ban Asbestos in America Act (S. 742), legislation proposed by Sen. Murray which would finally ban asbestos in this country, increase public awareness of the serious danger of asbestos exposure, and fund medical research for meso and other asbestos related diseases. Dr. Pass provided the perspective of medical professionals by giving very specific information about causation, diagnosis, and treatment. Vento's testimony was of a more personal nature, describing the diagnosis, treatment and death of her husband, Bruce, who died from meso in October 2000 in his 12th term as a member of the US House of Representatives from Minnesota. She also noted

several other meso patients, stressing that even limited, non-occupational exposure can and does cause illness and death.

S. 742 needs strong bipartisan support. Your political involvement is critical. Go to our website to see if your Senators have yet committed to support the bill, and if not, how to encourage them to do so.

US Representative Betty McCollum (D-MN) is authoring the House companion to Sen. Murray's bill. Congresswoman McCollum was elected to the seat held by Bruce Vento until his death. She saw first-hand the tragic effects of meso and is passionate about this bill. The Meso Foundation is working with her and her staff to recruit co-sponsors for the bill on the House side. We'll provide an update in a few weeks on the website.

On March 29, Vento testified before the US House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies, which oversees the National Institutes of Health. Vento's testimony articulated the need for federal funding from NIH for research into improved meso detection and treatment.

On May 16, Vento testified on the Meso Foundation's behalf before the US Senate Defense Appropriations Subcommittee, presided over by Senator Daniel Inouye (D-HI). Her testimony focused on the need to include meso among the "defense-related" diseases eligible for funding under the Department of Defense's \$50 million per year Peer Reviewed Medical Research Program. This will give researchers working on effective treatments for meso a critically-needed boost. Meso was actually added to the eligibility list last year, but the unusual year-end budget stalemate wiped out our work. So we are starting over, and this important effort also needs your support. Go to our website for the current status and what you can do to help.

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I love summer, and as I write, we are now halfway between two great summer holidays. While we enjoy the long warm days, the family time, and the recreation, both days are actually quite somber. Memorial Day is a time we remember the sacrifice of the patriots who served in our country's military. And on Labor Day we honor those whose hard work built our country and provided for our way of life, and we renew our commitment to their health and safety. Both days make me think about meso patients and their families.

I wonder about all those who now battle this disease, or will face it in the future, just because they served on or helped build our country's great Naval fleet, or because they got up every morning and went to work to keep our country going and to provide for their families. Beyond all the flag-waving, parades, and politicians' speeches, does our country really have a commitment to them?

This year, there are encouraging signs that it does. For the first time since she began her efforts six years ago, Senator Patty Murray's Ban Asbestos in America Act has a realistic chance of passing. Also, it looks likely we will finally succeed this year in making meso research eligible for funding under the Department of Defense's \$50 million per year Peer Reviewed Medical Research Program. For more detail on the progress of these efforts and what you can do to help, see the cover article.

For me, the most exciting part of this progress is the outpouring of advocacy we have seen from our grassroots. Responding to our email Action Alerts, patients, family members and other caring individuals have called and emailed their Senators and Representatives, met personally with them or their legislative assistants, and forwarded the Action Alerts on to their own email contact lists.

This grassroots advocacy is key to the progress we are making. And there is much more you can do. Check the website and stay up to date on our legislative efforts and how you can help. Continue to respond to Email Alerts (and make sure we have your correct email address), and forward them to your circle of contacts. And finally, attend this year's Meso Foundation Symposium.

The Symposium on Malignant Mesothelioma, 2007 will be held in Washington, DC, October 4 - 6. On Thursday the 4th, patients, families, doctors, researchers, lawyers and other Meso Foundation supporters will have an opportunity to meet personally with their Senate and House representatives on Capitol Hill to share their experience with meso and urge them to support S. 742.

Your personal stories regarding meso and the devastating impact it has on patients and families will provide Senators, Representatives and their staffs with an up-close, personal and very persuasive sense of why federal action is critically needed. This is an opportunity for you to have a major role in advocacy and we hope you can be a part.

At the Symposium we will also join together for a candlelight march to the Capitol steps to call for a cure, honor meso patients and remember our lost loved ones. As in years past we will hear from top meso experts on the latest advances in understanding meso and in treating it. We will also focus on how you can join more actively in the mission to cure meso through volunteer and advocacy opportunities with the Foundation. This promises to be our most exciting, most inspiring Symposium yet, and I look forward to seeing you in Washington.

Chris

Patient Profile

Bob Treggett knows what it means to prepare for battle. In the US Navy, Bob served aboard a nuclear submarine whose mission was to deter attacks on our country. Bob took his duties very seriously, and rose to a high level of responsibility. He viewed his naval service as a privilege, and constantly strove for perfection, making the defense of America and the welfare of his fellow sailors his top priorities.

After an honorable discharge in 1972, Bob looked eagerly forward to the next stage in his life. He anticipated smooth sailing, unaware that he had a deadly “stowaway” on board. Like so many of his fellows who served in the Navy or worked in shipyards, Bob had been exposed to significant amounts of asbestos.

In 2003, Bob was working, and attending Northwest College in his home state of Washington with the goal of obtaining a degree in Ministry. He began experiencing respiratory symptoms, and sought advice from his physician, who felt it was bronchitis. But his symptoms worsened significantly, including breathing difficulty and a fever. Worried that he had pneumonia, he went to the local Emergency Room. Fluid was discovered to be filling his right chest cavity. He was admitted to the hospital, and the fluid drained off through a needle inserted into his chest (thoracentesis). Examination of the fluid resulted in a verdict of malignancy, exact type unknown.

Stunned, Bob and his wife Linda consulted a local oncologist. Bob underwent a thoracoscopy – inspection of his pleural space using an endoscope. His pleural membranes were sealed to prevent fluid accumulation (pleurodesis), and biopsy specimens were obtained. The biopsy report was indecisive – Bob had either malignant mesothelioma or a benign mesothelial inflammation and fibrosis. An expert pathologist determined that Bob was indeed faced with meso, epithelioid type.

Bob Treggett suddenly found himself in a battle for his very life, with an enemy he had never even heard of. Determined to fight, he consulted a thoracic surgical oncologist with expertise in meso, who recommended aggressive tri-modality treatment involving chemotherapy, surgery, and radiation.

Bob’s treatment began with several rounds of Alimta and Cisplatin, which he completed in January 2004. He then underwent extrapleural pneumonectomy on February 23. Bob’s right chest was emptied of lung, pleural membranes, diaphragm, and pericardium, and the surgical defects patched with Gortex grafts. Finally, he had high dose radiation to try to kill off any remaining meso cells in his right chest.

This radical treatment carries the risk of numerous complications, and Bob had his share. He had problems with the function of his right arm, a rapid heart rate, and a recurrent left pleural effusion, among other things. Later, he

developed an infection in his chest cavity that required repeated surgical drainage. Some inevitable scatter of the hi-dose radiation scarred areas of his remaining lung (radiation pneumonitis), further reducing his breathing capacity. Bob’s recovery was a gradual process of finding ways to increase his activity tolerance, while minimizing pain and discomfort. He worked with a physical trainer to help regain some muscle strength and tone, and sought ways to modify his favorite activities to fit his new limitations. He managed his pain with medication, and his fatigue with rests.



Considering all he has endured as a consequence of serving his country, Bob Treggett would be justified in griping, but that’s just not his way. His optimism, bolstered by a deep and abiding faith, helps him to find the positive aspects of every experience, and sustains him in his ongoing battle with meso. Bob feels very strongly that maintaining a positive attitude is essential to supporting his body’s efforts to heal itself and keep its malignant enemy at bay.

He and Linda maintain their optimistic viewpoint by keeping themselves informed of advances in meso treatment. They have been proactive in making progress happen, donating generously to the Meso Foundation to fund new research. “Things are progressing rapidly with meso,” Bob says, “and as progress increases, so does hope.” He points to new treatments that “didn’t exist a year ago,” and to his having access to the best experts in the field.

Bob’s faith and optimism extend to every aspect of his life. Once an avid sailor and skier, he has found new ways to stay active by golfing, painting, and model making. He guards his resources and energy, and protects his remaining lung, but balances prudent caution with openness to exploring new paths for his life. Having completed his degree in Ministry Leadership (and graduating with honors), Bob now participates in international Christian Leadership conferences. He’s been to South Africa, Kenya, and Colombia, with a trip planned to Argentina this fall. He plans to speak nationally as well, and to include asbestos awareness in his presentations. Bob hopes that spreading the word about meso will help others obtain early diagnosis and treatment.

For himself, Bob knows that there’s no guarantee of smooth sailing, but then there never is in life. Bob is optimistic and determined to face future hurdles as they come. With hope in his heart, and Linda at his side, he’s determined to keep on moving!

Mary Hesdorffer Joins Meso Foundation



Many of you know and love Mary from her years caring for meso patients at Columbia Presbyterian, her presentations at the Foundation's annual symposium, and her passion to help and share her medical knowledge with members of the meso community generally. We are thrilled that Mary has joined the Foundation as our Medical Liaison. In this position she will wear many hats, but most central will be that of Patient Navigator. Mary is now available full time to discuss with patients and their families any medical issue, including treatment decisions, meso specialists and clinical trials, and pain, symptom and side-effect management. You can call Mary at (877) 363.6376 or email her at mhesdorffer@curemeso.org.

"It is with great excitement and enthusiasm that I have accepted this position with

the Meso Foundation. I have spent the past eleven years working as a Nurse Practitioner, actively treating and conducting research in both peritoneal and pleural mesothelioma. I was fortunate to be trained in this field at an academic institution, which exposed me to some terrific researchers. In clinical collaboration I was permitted to observe both pleural and peritoneal surgical procedures and actively participate in the recovery process. I was part of a team responsible for administering intravenous, intrapleural and intraperitoneal chemotherapy, and for monitoring the side effects and response to therapy in a large cohort of meso patients. I was privileged to work with basic scientists, pathologists, surgeons, and medical oncologists who were focused on understanding and treating this disease. This prior experience will allow me to provide you with accurate medical information, assist you in some of the complex decisions that you face, and most importantly I hope to become a trusted friend."



Special Thank You

In our Symposium Issue of Breath of Hope we thanked the sponsors that helped make the event possible. However, we neglected to thank one sponsor and we are genuinely sorry for the mistake.

*The Foundation is grateful to the **Kazan Law Firm** for its generous support of the International Symposium on Malignant Mesothelioma - 2006.*

Let's Rock Meso Awareness Day!

Meso Awareness Day is September 26th and the Foundation is gearing up to raise awareness through music. Foundation staff and volunteers are contacting radio stations across the country asking them to commit to play the music of Warren Zevon on Meso Awareness Day followed by a short 15 second Public Service Announcement. The PSA is being produced by the Foundation and will be available to any volunteers or radio stations that would like to participate.

Warren Zevon was a legendary singer/songwriter who died of meso in September 2003. Warren Zevon wrote and recorded hundreds of songs such as "Poor Poor Pitiful Me," "Hasten Down the Wind," and "Carmelita." He scored his biggest hit with the 1978 album "Excitable Boy," which contained the top-20 single "Werewolves of London."



Following in his footsteps is his son Jordan Zevon who is quickly becoming a well know recording artist himself. Jordan has been working very closely with the Foundation to raise awareness. With his help and your help we believe we can really make an impact by raising awareness about this terrible disease and pushing the search for a cure forward.

If you would like to get involved, please contact the Foundation office for a Meso Awareness Day "press kit" and a list of radio stations in your area. Together we can make a difference!



Farewell Dear Friend... You Will Be Missed.



Klaus Brauch, long-time meso survivor, beloved friend to the meso community, and devoted Meso Foundation volunteer, passed away peacefully at home on May 2, with his entire family at his side.

For the last five years, Klaus shared his journey, in his journal and personally – one to one – in countless conversations with meso patients and family members. He has been an inspiration for so many, giving

them hope and information, and encouraging them in dealing with their own disease.

From the time Klaus was diagnosed, his focus was on educating himself about meso: the treatment options available, centers of excellence, clinical trials, and novel therapies. With great determination and diligence, he did the research, weighed the options, and always, with his wife Susan, made his own decisions about which course to take.

In September of last year he chose to have an aggressive surgery to deal with a small recurrence of meso in his chest. He suffered a rare, very severe complication and had been struggling with the after-effects since that time.

As he had always done, Klaus did the research, looked at the options available to him, evaluated his current state of health, and with dignity, made the decision to enter into hospice care. Just before his passing the staff of the Foundation visited with him and it was comforting to see that his sense of humor, wit, and above all, concern for others had not been abandoned to his own situation. While he understood that his own battle was over, he remained optimistic that with research the larger battle against meso would soon be won. He was proud to have been a part of that battle.

Klaus played a pivotal role in the development of the Foundation's website and was a regular contributor to the Breath of Hope Newsletter. All of us at the Foundation will miss him greatly.

International Symposium on Malignant Mesothelioma

October 4 - 6

Thursday - Advocacy

8:00 - 9:00 AM	Registration & Breakfast
9:00 - 10:00 AM	Capitol Hill Orientation
10:30 - 4:00 PM	Capitol Hill Meetings
6:30 - 7:30 PM	Capitol Hill Candlelight Vigil & Tribute
8:00 - 10:00 PM	Reception

Friday - Science

8:00 - 8:30 AM	Registration & Breakfast
8:30 - 8:45 AM	Welcome & Opening Remarks
8:45 - 9:45 AM	Basics of Meso Biology and Treatment Targets
9:45 - 10:30 AM	Multi-Modal Treatment of Pleural and Peritoneal Meso
10:30 - 10:45 AM	Break
10:45 - 11:45 AM	Alimta and First Line Therapies
12:00 - 1:15 PM	Lunch
1:30 - 2:30 PM	Second Line Treatments and Clinical Trials
2:30 - 3:15 PM	Developing Research
6:00 - 7:00 PM	Reception
7:00 - 9:00 PM	Gala Dinner & Awards

Saturday - Community

8:00 - 8:30 AM	Breakfast
8:30 - 10:30 AM	Activism - Joining the Mission to Cure Meso
10:30 - 11:00 AM	Break
11:00 - 12:30 PM	Breakout Sessions
	A. Patients
	B. Caregivers
	C. Coping with Loss
12:30 - 2:00 PM	Lunch & Closing Remarks
4:00 - 6:00 PM	Sightseeing Tour

HOTEL RESERVATION INFO
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1400 M Street, NW
call (202) 429-1700
reservation code: Mesothelioma

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INTERNATIONAL SYMPOSIUM
ON MALIGNANT MESOTHELIOMA

WASHINGTON, DC
OCTOBER 4 - 6

SPECIAL CANDLELIGHT VIGIL - OCTOBER 4



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