Our mission is to eradicate mesothelioma as a life-ending disease.

the MESOTHELIOMA APPLIED RESEARCH FOUNDATION, inc.
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Mesothelioma Takes Our Heroes

The Service-Connected Cancer Warrants Proportionate Federal Research Funding

Mesothelioma, a lethal, asbestos-related cancer, has plagued the members of "America's Greatest Generation" and their families, who were exposed while building the U.S., working in her factories, serving in her fleet, or when the dust was brought home on clothes. The disease's incidence is increasing, and ranges from national leaders to firefighters to young adults. One third of today's victims were exposed while serving the U.S. in Navy ships or shipyards.

In 2003, Congress has a unique opportunity to remedy this national tragedy by supporting mesothelioma research with funding proportionate to other cancers. MARF, the national mesothelioma science and advocacy organization, is already promoting the necessary research with its own seed-money grants, and major breakthroughs may be imminent. Federal partnership in this effort is critically needed.

Ron Simkins, a 60-year-old retiree, lives with his wife Janet in Palm Springs, California. His life was the picture of the American dream. He had worked hard and was now poised, in his golden years, to reap the rewards -- golfing, playing tennis and enjoying his grandchildren. In May 2002, Ron was his club's "Fitness Member of the Month." A few weeks later he was diagnosed with a cancer he had never heard of, mesothelioma.

A Service-Connected Disability

It turns out Ron served in the U.S. Navy from 1959 to 1962 as a machinist's mate. He served in the engine rooms, where he was exposed to asbestos, used to insulate high temperature pipes and equipment. Now, 40 years later, his doctors were advising him that mesothelioma, caused by asbestos, was "uniformly fatal," that there was no established treatment procedure, and that the average survival was less than 14 months.

In shock, Ron and Janet sought treatment through the Department of Veterans Affairs. The seeds of his cancer were planted while he was serving his country, making it a "service-connected disability."

Ron Simkins was a machinist's mate on the USS Maddox from 1959 to 1962. He was diagnosed with malignant mesothelioma on May 1, 2002.

Treatment Options Ring Hollow

Ron called the Veterans Affairs hospital in Los Angeles, but the V.A. offered no specific treatment for mesothelioma patients, only a chemotherapy protocol for lung cancer. It was up to Ron to do his own research to come up with a treatment plan. He soon learned that virtually all chemotherapy drugs had been tested in mesothelioma, and that the best of these achieved only a dismal 12% to 24% response rate. Even if he were one of the few whose tumor did initially shrink from the drugs, invariably it would soon recur.

With further research, Ron learned that most over two-year survivors had undergone surgery. The surgical options include an extra-pleural pneumonectomy, which involves the removal of the tumor-encased lung, the diaphragm and heart sac, or a pleurectomy/decortication, which seeks to scrape off all visible tumor while sparing the otherwise functioning lung. Either of these surgeries requires 4 to 6 hours, and a radical incision from the back all the way to nearly the center of the chest in front; only a handful of specialists in the United States perform these surgeries routinely.

Ron met with one of these specialists, but surgery was ruled out because the tumor was already advanced and because Ron's diagnostic biopsy -- performed by a non-expert -- had allowed the tumor cells to infiltrate the chest wall and lung.

In 1979, when Steve McQueen was diagnosed with mesothelioma and advised to "go home and tidy up your affairs," he had desperately turned to "alternative" treatments in Mexico. Now, more than 20 years later, Ron's medical options seemed just as hopeless, and he was just as desperate for something that might give him a chance.

After More Hurdles, a Glimmer of Hope

Ron Simkins finally got a break when he learned of a chemotherapy cocktail based on a new drug, Alimta, that in clinical trials had shown a 46% response rate, well above the typical 12% to 24% rate. He and his wife rejoiced at these statistics, even though the median survival in patients not eligible for surgery was increased only by a few months. But they met another barrier when they learned that FDA approval of Alimta would likely take over a year.

Despite lack of support from their HMO, the Simkins were eventually able to obtain Alimta on a compassionate use basis. Still, it remains to be seen whether the drug will shrink the tumor enveloping his left lung enough that he can undergo the surgery that Ron hopes for yet dreads.

Battling An Orphan Disease

Ron's grim experience with mesothelioma is typical. Mesothelioma has been an orphan among cancers with regard to research efforts and funding. And its rarity, intractable symptoms, and dismal outcome have led to frustration and nihilism in the medical community. Few oncologists have been willing to treat the disease, with most simply making an immediate recommendation of hospice care only. Faced with this overwhelming hopelessness, many patients and family members retreat into isolation, as they attempt to follow their doctors' advice to "get their affairs in order and prepare to die."

Other patients, like Ron, seek treatment at one of the few centers throughout the country which specialize in mesothelioma care. But, like Ron, most of these patients will not be candidates for aggressive treatment, since usually the disease is diagnosed too late. Even for patients who do receive the best current treatment, the tumor virtually always recurs.

Mesothelioma is particularly horrible in terms of the pain it causes, its progression, and its manner of causing death. The patient cannot take a deep breath due to pain, and even if he could, his lung capacity is severely restricted because the involved lung is crushed by the weight of massive tumor or fluid. Unrelenting pain as the tumor invades the chest wall, coupled sometimes with the tumor's compression of the esophagus, lead to an inability to swallow. Direct involvement of the heart sac or the pressure from fluid build-up on the heart will eventually cause heart failure. Growth of the tumor in the abdomen will lead to abdominal distention, and eventual death through intestinal obstruction and wasting.

For these reasons, experts familiar with mesothelioma consider the physical and emotional suffering it causes to occupy the highest range on any scale of human suffering.

A Grim Story Destined to Recur

This toll of human suffering has occurred, unchecked, for decades. It will continue for years to come unless a commitment is made today to cure mesothelioma.

The tumor was described in the medical literature as early as the 1930's, and its link to asbestos confirmed by 1964. The first victims of mesothelioma were heroes from America's "Greatest Generation," men and women who inhaled asbestos on the job while helping to build this country or serving in the military. During WWII, in the industrial and building boom that followed, and up through the early 1970's, asbestos -- the "miracle mineral" -- was used virtually everywhere, and millions of Americans were exposed. Naval ships and shipyards used asbestos heavily, and over 30% of America's mesothelioma victims were exposed to asbestos while serving their country, either in uniform or while building and maintaining our fleet. Spouses and children were exposed when the workers brought the deadly fibers home on their skin, clothes and hair.

Beginning in the 1970's, asbestos use began to be curtailed. (Contrary to popular belief, the U.S. has never banned asbestos outright. The EPA banned asbestos from several thermal and refractory insulation products in 1973. It attempted to ban most remaining asbestos products in 1989, but asbestos companies successfully sued to overturn the ban. Congress itself has never outlawed asbestos.) Despite this curtailment, incidence of the disease has not subsided. In fact, the incidence of mesothelioma is expected to

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- *3000 Americans lost each year.*
- *Primarily U.S. servicemen (30% of all mesothelioma victims are exposed to asbestos on Naval ships and in shipyards).*
- *Also heavy industry workers, building tradespeople, firefighters, schoolteachers.*
- *24-year Congressman Bruce Vento.*
- *Former Chief of Naval Operations Admiral Elmo Zumwalt, Jr.*
- *9/11 rescue workers now threatened.*

Rear Admiral Zumwalt, Jr., hailed as "the Navy's most popular leader since World War II", succumbed to mesothelioma in 2000 within four months of his diagnosis.

increase for another 10 to 15 years at least. The cancer's latency period spans up to 50 years. Thus, millions of Americans age 40 and up, and who were exposed in the 70's or earlier, are still at risk; mesothelioma strikes several thousand Americans from this population each year; and it will continue to do so for another 20 years.

The heroes whose lives have been cut short by mesothelioma include the Honorable Bruce Vento, who served this country for 24 years in the United States Congress. He was diagnosed in January 2000, at just 59 years old. Over 30 years earlier, while earning his teaching degree, he had held a summer job working near asbestos-insulated boilers in a local factory. He died in just nine months, despite receiving the best treatment available.

These heroes also include Admiral Elmo R. Zumwalt, Jr., whose illustrious life was taken by mesothelioma on January 2, 2000. Only six months earlier, he had placed first in his age group in a 5k run. Many consider Zumwalt to be the architect of the modern Navy, and he was hailed by Time Magazine as the Navy's most popular leader since World War II. We can only wonder what might have been if Admiral Zumwalt had lived long enough to use his influence to obtain help for veterans suffering from mesothelioma, just as he did for veterans exposed to Agent Orange.

In the future, will more of America's heroes and citizens be lost because of exposures occurring after the 1970's? Unless a cure is found, the answer is yes. Today, the settings and activities which continue to cause release of air-borne asbestos are innumerable and common, and there is *no safe level of exposure*. Asbestos is still widely-present in homes, schools and -- as the 9/11 disaster has shown -- in office buildings. From just one mine in Montana came an insulation product sold from the 1940's through the 1990's, which was contaminated with an extremely lethal form of asbestos and which today is found in millions of homes, businesses and schools across America. As a result, the tumor is appearing in a frightening number of individuals who have never had the typical industrial exposure, and are much younger than the average patient of the past.

Mesothelioma does not respect innocence, youth or beauty. Elizabeth Clancy, exposed to asbestos in public schools, battled the tumor for 18 grueling months before dying at age 23.

Experts predict we will see firefighters, policemen and other heroes of New York City's 9/11 tragedy who were exposed to asbestos at Ground Zero develop mesothelioma. Will we offer them as little hope as was offered Steve McQueen two decades ago, or Ron Simkins, Congressman Vento and Admiral Zumwalt in the current decade?

Needed: A National Commitment Proportionate to the Problem

Since the first asbestos lawsuits were filed in the 1960's, about 56 billion dollars have changed hands. The Rand Institute for Civil Justice projects asbestos litigation will ultimately cost corporate America between $200 billion and $275 billion. Despite those staggering numbers -- and the vast human suffering and drain on the

economy which they represent -- there is at present no legal mandate or mechanism to invest any portion of these funds in eradicating the source of the misery in the first place.

In 2001, the National Cancer Institute, with a budget of over $3 billion, allocated less than $1.7 million for research on mesothelioma. This is a fraction of what most other cancers received, even when adjusted by number of fatalities.

The Department of Defense is also a major source of federal cancer research funding. Congress has appropriated more than $1.2 billion to fund peer-reviewed breast cancer research through the DoD, and $310 million for the DoD's Prostate Cancer Research Program. The DoD also conducts a research program for ovarian cancer, and as recently as 2002, established Congressionally-directed research programs for prion disease, tuberous sclerosis and chronic myelogenous leukemia.

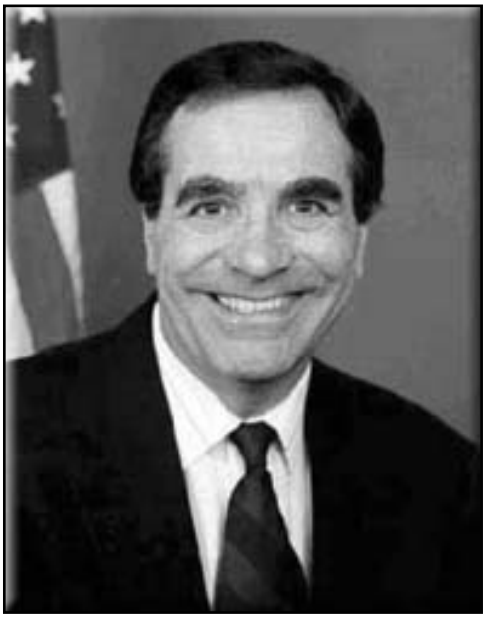
As a result of such federal funding, major advances have been made in breast and prostate cancer, and these and many diseases considered uniformly fatal just two decades ago can now be successfully treated. But, without any similar national commitment to mesothelioma, treatment has improved relatively little in the past 20 or even 40 years. America's heroes stricken with mesothelioma are offered little in terms of hope or effective treatments.

Opportunity for Congress to Put Spotlight on Need for Cure

Congress now has an historic opportunity to address this national tragedy. In 2003, Congressional attention will be focused on asbestos issues as never before, with the likely introduction of two asbestos-related bills.

The first, a compensation bill which would limit the rights of asbestos claimants to file lawsuits, has sparked widespread interest and debate. In the first two months of 2002, insurance and manufacturers lobbyists reported spending $2 million to gain support in Congress for this bill. This is more in two months than the entire NCI budget for mesothelioma research in 2001. Millions more will be spent by lobbyists on all sides of the debate in coming months.

The bill's supporters talk about the need to compensate only the truly sick, such as the mesothelioma patients. They point out that the rash of asbestos-company bankruptcies has hurt shipyard and Navy machinists the worst, men like Ron Simkins, because most of the manufacturers of the products they were exposed to have declared bankruptcy. And they use words like "fatal" and "incurable" to describe mesothelioma. But little has been said about allocating any of the billions of dollars expected to be consumed by asbestos litigation and lobbying toward research on actually curing mesothelioma, or expanding treatment options. In this



Despite undergoing chemotherapy, a pneumonectomy and radiation, Bruce Vento, after serving his country for 24 years in the U.S. Congress, fell to the curse of mesothelioma within 9 months of his diagnosis.

Mesothelioma Must Be Cured; It Will Not Fade Away

- *Millions of tons of asbestos still present in modern environment.*
- *Asbestos used in virtually all office buildings, public schools and homes built before mid 1970's.*
- *Millions of U.S. homes, businesses and schools remain contaminated with extremely lethal form of asbestos present in insulation.*
- *Mesothelioma incidence is increasing; average age getting younger.*

way, the "incurable" label becomes a fait accompli. Mesothelioma becomes "incurable" only because of our apathy towards actually curing it.

The second bill comes in here. The Ban Asbestos in America Act, originally introduced in June, 2002 by Senator Patty Murray, would finally ban all commercial and consumer uses of asbestos. But the Act also recognizes that even after asbestos is totally banned, mesothelioma will persist for decades because of the millions of exposures which have already occurred and the millions of tons of asbestos still contaminating our buildings, machinery and appliances. Therefore, the Act would also, for the first time ever, compel the federal government to fund mesothelioma research and treatment programs. This is a critical first step. No matter what side one takes on the debate over the asbestos litigation "problem," everyone should agree that the human death and misery caused by mesothelioma is a problem more gravely unjust and even more in need of Congressional assistance.

"When are we going to finally launch an all-out assault on this damn tumor that has already taken too many good men and women down?"

Don Thorp, Chief Warrant Officer, US Navy, 1964 to 1985. Diagnosed with mesothelioma on December 4, 1999, underwent a pleurectomy January 25, 2000.

Now is the Time

In fact, there has never been a better opportunity for Congress to address this problem. For the first time in the U.S. history of asbestos and asbestos litigation, the private sector is uniting to cure mesothelioma. In 1999, a group of doctors, patients, lawyers and company representatives acknowledged that too much focus has been on fixing blame, and not enough on fixing the problem. Thus was born the Mesothelioma Applied Research Foundation (MARF), the national nonprofit whose mission is to eradicate mesothelioma as a life ending disease. MARF has now helped hundreds of mesothelioma patients find an appropriate treatment program. MARF has funded a pilot program to investigate the feasibility of a first-ever clinical mesothelioma database. And, funded entirely by private sources, including parties on both sides of asbestos litigation and thousands of friends and family of mesothelioma patients, MARF has now awarded $600,000 in peer-reviewed research grants.

MARF's seed-money grants are stimulating the much-needed smaller-scale, highly experimental projects which, once successful, become ideal candidates for larger federal funding. Thus, through MARF, the effort to fund mesothelioma research and develop a cure is receiving a crucial kick-start. The time is right for the federal government to partner in this effort.

A second historical development also makes this a critical time for the government to commit to funding mesothelioma research. Thanks to the persistence of a small cadre of mesothelioma experts, decades of hopelessness are beginning to yield to a "cautious optimism" regarding development of effective treatments. Alimta is an example of this progress. Dr. Nicholas Vogelzang, head of the University of Chicago's Cancer Center and a member of MARF's Board of Directors, led the largest Phase III clinical trial ever conducted in mesothelioma, showing that patients treated with Alimta improved significantly. While this is not yet a cure, it represents real progress for mesothelioma patients, and demonstrates the potential for further breakthroughs if the government joins in and applies the necessary resources.

Indeed, these breakthroughs likely will not be limited to mesothelioma. Funding mesothelioma research will advance the battle against cancer generally, because the mesothelioma tumor is a microcosm of many other solid tumors. In fact, since mesothelioma is more active and

grows faster than most other tumors, it can actually serve as a better, more effective subject of research and experimentation, *even with regard to improving treatments for other cancers*.

Declare War on War Related Disease

MARF therefore urges Congress to support the Ban Asbestos in America Act. Beside the outright ban, the Act's call for funding mesothelioma research as a priority at the federal level is a giant step in the right direction. Also critically important is the mesothelioma registry/database which would be initiated under the Act. While experts now consider mesothelioma an epidemic, the U.S. -- unlike most European nations -- does not maintain a registry for mesothelioma as a reportable disease.

Further, as Congress considers asbestos tort litigation, it should consider creative solutions to ensure that at least a fraction of the billions spent on litigation is invested in finding a cure. Mechanisms include establishing a trust fund that will award grants to meritorious researchers after rigorous peer review.

But more must be done. Ultimately, to build a weapon that will finally knock the tumor out, the Federal Government must create a dedicated mesothelioma research program, with funding proportionate to other cancers. For the sake of the many mesothelioma patients who served in the Navy, natural vehicles for such a program include the DoD, which already administers research programs for breast and prostate cancer and a number of other diseases, and the Department of Veterans Affairs. Other potentially appropriate agencies include the Agency for Toxic Substances and Disease Registry, the Centers for Disease Control, and the Office of Rare Diseases within the NIH.

MARF advocates therefore that Congress appropriate $20 million to create a national Malignant Mesothelioma Research Program.

For the government to step up now and partner in the development of a cure for mesothelioma is the proper way to honor the sacrifice and public service of heroes like Admiral Zumwalt and Congressman Vento. It is the just responsibility owed to the unsung heroes like Ron Simkins and Donald Thorp. They have served their country proudly, and deserve effective treatments which can help them live long enough to attend their grandchildren's high school graduations. And it is a public health necessity with regard to the millions of Americans who have been and continue to be exposed to asbestos and potentially may develop mesothelioma in the future.

Now Is The Time

- *Unprecedented Congressional focus on asbestos issues.*
- *MARF research grants now kickstarting the search for a cure.*
- *New "cautious optimism" replacing decades of hopelessness.*
- *Alimta and other recent advances indicate breakthroughs may be near.*
- *Mesothelioma research broadly applicable to other cancers.*

Paul Coyle was a boiler tender on the USS Arnold J. Isbell from 1960 to 1963. He died of mesothelioma at the age of 57, within four months of his diagnosis.

Research Dollars by Various Cancers
(in millions)

	2000	2001 Est.
Total NCI	**$3,311.1**	**$3,753.7**
Brain & Central Nervous System	71.9	75.5
Breast Cancer	438.7	463.8
Cervical Cancer	67.0	74.2
Colorectal Cancer	175.8	190.0
Head and Neck	47.0	50.8
Hodgkin's Disease	9.4	10.0
Leukemia	141.7	150.4
Liver Cancer	46.2	50.1
Lung Cancer	175.0	189.0
Melanoma	67.9	72.0
Non Hodgkin's Lymphoma	70.4	74.4
Ovarian Cancer	65.5	69.4
Pancreatic Cancer	20.0	21.5
Prostate Cancer	203.2	258.0
Stomach Cancer	6.8	8.5
Uterine Cancer	16.0	16.5

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MARF

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