

The Mesothelioma Applied Research Foundation

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



BREATH OF HOPE

Summer 2005

INSIDE THIS ISSUE

Message from the Executive Director



Achieving important change at the national or global level is rarely easy. Indeed, for us here at MARF the past few months have been challenging.

Most difficult for each of us are the painful, almost daily reminders of the suffering and loss meso causes. We get an email that someone for whom we were full of hope is now entering hospice. A good friend we have journeyed with over the past months or years calls, grief-stricken, to tell us that their loved one has been taken. We learn the story of Erin Bradley, a beautiful young girl trying to live a normal teen-age life while battling meso.

Encountering these wonderful lives thrown into turmoil by meso drives us deeper and more passionately in our commitment to find a cure. But it is discouraging to see all around us so much disregard of this need. The asbestos injury trust fund bill has been considered and debated for years and was finally voted out of the Senate Judiciary Committee on May 26th. This extremely controversial and contentious bill is a disturbing example of one of MARF's central points: For decades, fighting over issues of liability and compensation has grievously distracted from the most important question - how will we relieve the suffering in the first place? *Tens of millions* of dollars have been spent lobbying for or against this bill, money that could have had a dramatic, life-saving impact had it been applied to the necessary medical research.

Proponents of the bill argue that it addresses "the national problem of asbestos disease." Opponents argue that it does not adequately "compensate the victims." But any real demand for the solution that current and future patients need most - development of effective treatments to reduce the suffering - has been mostly absent from the debate.

This solution is where MARF is intensely focused. We have developed and proposed a National Mesothelioma Research and Treatment Program (NMRTP), and are urging the government to adopt it, independent of any trust fund legislation. We are also urging that if the proposed trust fund bill truly aims to address the "national problem of asbestos" over the next thirty years, it must include research funding for meso *as a first priority*.

We cannot passively accept another thirty years of death and suffering as a given. We must act now to develop ways to reduce the suffering and extend patients' lives. Meso research is the appropriate place to start. Meso is the most gravely life-threatening of asbestos-related diseases, and also the one with the greatest promise of significant advances. The progress being made now even with relatively limited funding demonstrates this.

Therefore, we continue our dedication to investing in meso research, and we continue to call on the government to join in this investment. We resist the argument that we should have nothing to do with the trust fund bill. MARF is not taking a position on other aspects of the bill. But we will continue to demand that it or any asbestos legislation must address the critical need for research funding, because every meso patient's first priority is life. We also fight to keep the emphasis on meso research as the most urgent need and promising use of the NMRTP's proposed funds. Because these funds are so limited, we resist efforts by others to reapply them to broader, less urgent uses.

We keep going, inspired by our belief in a cure, the almost 12,000 people who have signed our petition to establish the NMRTP, the progress we see all around us, and our daily, painful reminders of the tragic consequences if we fail.

Yours,

Christopher E. Hahn

Message from Chris	1
Patient Profile	2
Focus on Research	3
MARF Symposium	4
Fight Meso All Year	6
Federal Funding Update	7
VNN	7

BELIEVE IN A CURE

MARF STAFF

Christopher Hahn
Executive Director
c-hahn@marf.org

Rob Grayson
Director of Development
and Volunteers
r-grayson@marf.org

Jill Wayne
Assistant Director
j-wayne@marf.org

Trish Cerin
Administrative Assistant
t-cerin@marf.org

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Patient Profile - Erin Bradley

At age 12 Erin Bradley was a normal little girl growing up in Tennessee. Her mother was a nurse and her father worked with brake shoes and brake repair. She played basketball, loved doing arts and crafts projects, did well in school, and spent a lot of time with her four older siblings who doted on her. Life was full of promise for the sweet little girl on her way to becoming a young woman. Then she started to lose weight. Her parents, Betty and Paul, thought nothing of it. Their little girl was maturing, growing up, and to them her weight change did not seem unusual.



Unfortunately, doctors who should have known better never considered that something serious might be involved, even when Erin began to experience increasing stomach discomfort. Her pediatrician remained in denial so Betty and Paul sought the advice of a family friend who was a surgeon. He discovered that fluid in her abdomen had built up to the point of causing a double hernia. Still no serious tests were undertaken before the surgeon tried to get approval for a hernia operation. The insurance company refused as he was not on their provider list and forced a change of doctors. Her original physician had never questioned why a 14 year old would get hernias, but the new surgeon did. He ordered a more thorough exam and a CT scan. These revealed that Erin had peritoneal mesothelioma.

By the time Erin went to Columbia Presbyterian for surgery with Dr. Taub, the cancer was widespread. She has had two surgical debulkings, multiple rounds of chemotherapy, and is currently on Avastin. While the tumor hasn't progressed since December, side-effects from the chemotherapy and the residual effects of the surgeries, along with a reduced appetite, are wearing Erin down. Betty believes "mothers need to be nagging mothers about their children; we were told for two years that she was just a growing girl."

Erin is determined to live as normal a life as she can. She still attends school half days and receives support from friends, family and the numerous professionals involved with her care. She traveled to Disney World recently and while she was there a group of her friends created an "extreme makeover" on her

bedroom, turning it into a haven for a teenager. They put in a plasma screen TV, new computer, and stereo system. They found a picture of a butterfly that Erin had painted in 5th grade, framed it and put it up on her wall. The only reminder of her struggle is the big cushy couch they added so she can lie down when she needs to rest. Her situation has shocked, energized and humbled those around her. She has endeared herself to all who know of her situation and so she is not alone in her fight.

Although Erin hadn't confronted her illness head-on until recently, she is now coming to terms with what this cancer will cost her. She recently went on-line to look up mesothelioma; afterward she asked her mom, "What stage am I in?" Betty isn't sure exactly how she answered that most difficult question; she only states "we go day to day." Betty is sure about one thing, she is adamant: "without funds, lots of funds for research, we can't eradicate mesothelioma."

Erin has dreams like other 16 year old girls. She would like to travel to New York in August with her youth group and Betty expressed doubt that she would be "up to it." Upon reflection, however, she added that "If Erin wants to go, she will go!"

Erin celebrated her 17th birthday on June 8th.

ERIN'S MOTHER IS SURE ABOUT ONE THING, SHE IS ADAMANT: "WITHOUT FUNDS, LOTS OF FUNDS FOR RESEARCH, WE CAN'T ERADICATE MESOTHELIOMA."

Focus on Research

"Know thy enemy." This is the basic principle that the immune system uses in its day-to-day operation. Immune cells are constantly scanning the body to kill things that do not belong, like bacteria and viruses that cause illness. These immune cells (Killer T-Cells) somehow learn to recognize or "know" these foreign enemies, so they can find them, distinguish them from normal cells, and kill only them. For years, scientists have been studying how to harness Killer T-Cells, and cause them to "know" and therefore kill the rapidly dividing populations of cells that make up tumors.

It turns out that Killer T-Cells know what to kill with the help of Dendritic Cells. Dendritic Cells carry small pieces of foreign particles (such as bacteria or viruses) to the Killer T-Cells to "teach" them to recognize these foreign particles as enemies.

With grant funding from MARF, Dr. Bart Lambrecht and his colleagues at the Erasmus Medical Center in the Netherlands are working on how to use Dendritic Cells to treat meso. Meso tumors secrete tiny vesicles or sacs called "exosomes" that contain many different proteins. Dr. Lambrecht's research team is loading these exosomes onto Dendritic Cells, to teach Killer T-Cells to identify and kill the meso tumor.

So far, the results look very promising. Dr. Lambrecht and his team began by injecting mice with an asbestos-induced meso cell line. This led to development of meso and rapid death. However, when Dendritic Cells loaded with the meso exosomes were injected before injection of the tumor cells, the mice developed anti-tumor immunity and had greatly prolonged survival. Even more importantly, when the loaded Dendritic Cells were given within a short time after tumor injection, this also caused tumor protection and prolonged survival. This tumor protection was associated with a strong tumor-specific Killer T-Cell response, apparently verifying Dr. Lambrecht's hypothesis. These findings could have important implications for designing a novel form of immunotherapy for human meso.

Dr. Lambrecht also made a surprising discovery. The loaded Dendritic Cells had a curative effect when they were given shortly before or shortly after after introduction of tumor cells. But when tumor cells and the loaded Dendritic Cells were injected simultaneously, tumor development was enhanced.

Dr. Lambrecht is investigating several explanations for this paradoxical effect. Understanding it may provide crucial information on the mechanisms meso tumors use to evade elimination by the immune system.

The significance of Dr. Lambrecht's findings has been widely recognized. They have been presented at the 100th International Conference of the American Thoracic Society, at the International Mesothelioma Interest Group's 2004 meeting in Italy, and at the Dendritic Cells 2004 meeting in Belgium. This March, The American Journal of Respiratory and Critical Care Medicine published Dr. Lambrecht's work.

Based on the success of his MARF-funded research, Dr. Lambrecht is now developing a Phase I clinical trial of Dendritic Cell therapy for pleural meso patients. He hopes to launch the clinical trial at the Erasmus Medical Center before the end of the year. This is another encouraging example of how MARF's grant funding can translate to promising, completely new forms of therapy for meso patients.



The American Journal of Pathology has just published, and featured on its cover, the work of two MARF-funded researchers, Gavin J. Gordon and Raphael Bueno.

Drs. Gordon and Bueno (featured in earlier Breath of Hope issues) have developed a sophisticated network of molecular pathways identifying genes likely related to mesothelioma tumor development. This is important work to help identify targets for therapy. That this work is featured on the journal's cover demonstrates that the high quality meso research now occurring is bringing meso out of the shadows as "an orphan disease," and into the attention of mainstream scientific research. This will further accelerate development of effective treatments.



Second International Symposium on Malignant Mesothelioma

By Dr. Nicholas Vogelzang - Director, Nevada Cancer Institute and Member, MARF Board of Directors

It is with great excitement that I, as Co-Chair with Dr. Harvey Pass, invite you to MARF's Second International Symposium on Malignant Mesothelioma, to be held at Caesars Palace in Las Vegas Thursday, October 6th to Saturday, October 8th, 2005. Last year's Symposium was a tremendous success, and this year's program will build on that momentum and follow a similar format, to unite, educate, and encourage the entire meso community.

Day one begins with experts discussing the growing scope of the meso tragedy and general issues regarding the effort to eradicate it. This will be followed by presentations designed specifically for patients, caregivers, and those coping with loss, including clinical aspects of meso, pain management, and social/emotional issues. Building on one of the most popular elements of last year, there will be extended break-out sessions for each of these groups to meet on their own, fostering discussion of shared concerns, problem-solving, and friendship. Day one's program will conclude with a special tribute ceremony. All those who wish to help honor and remember those we have lost to this disease are invited to participate.

Days two and three focus on the science of the effort to cure meso. Leading meso researchers, surgeons, oncologists, and radiation oncologists, as well as experts in gene therapy, immunotherapy and other developing approaches will come together to exchange the latest ideas and information and discuss how to move forward in effectively treating meso.

These are high-level presentations, aimed at advancing the science and educating the medical community - including front-line physicians - on the current status of meso research and treatment. However, last year the patients, family members, and MARF volunteers and other advocates also found these presentations extremely informative. This year, we are designing the presentations to be more interactive, and they will be even more interesting for both experts and non-experts.

All of this will again take place in Las Vegas. The city is more than just casinos and entertainment, as it is becoming a major population center, the Nevada Cancer Institute is now located here, and it is increasingly a destination for high-level conferences. By holding the Symposium here again, we gain world-class convention space, ease of travel from all over the U.S., good affordability, and great October weather.



I heard personally from many of those who attended last year that the Symposium was extremely informative and did a great deal to strengthen the meso community. Participants gained valuable treatment, research, and life-skills information, and were grateful to have extensive access to the knowledgeable and extraordinary panel of specialists. We are working to make the Symposium even better this year.

I sincerely hope that you will join us.

The Second Annual Symposium on Malignant Mesothelioma
will be held at
Caesars Palace in Las Vegas, NV
October 6 - 8, 2005.

To reserve your room at MARF's discounted rate of \$185.00 per night
call: (800) 933-7110 and use reservation code SCMES5. The Symposium is
listed under the name: Mesothelioma Applied Research Foundation.

Make your reservation early as space is limited.

THE SYMPOSIUM
PROGRAM
ANNOUNCEMENT
WITH DETAILED
AGENDA WILL BE
DISTRIBUTED SOON

RESERVE EARLY...
REGISTER NOW!

Second International Symposium on Malignant Mesothelioma

Symposium Registration

Name _____

Add _____

City _____ Prov/State _____ Country _____ Zip/Postal Code _____

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Please Check Appropriate Category

Before September 15 / After September 15

Group I Patient • Family Member • Care Giver

\$150

\$175

(Financial aid scholarships are available, contact MARF.)

Optional:

If you are a person living with meso would you like to be included in the special recognition of patients planned for the Symposium? Yes No

If you have lost a loved one to meso would you like them to be honored in the special tribute ceremony planned for for the Symposium? Yes No

Name of loved one: _____

Group II Allied Health Care Practitioner • Fellow in Training

\$150

\$175

Group III Medical/Academic/Scientific • Government • Nonprofit Advocacy

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\$1000

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**A cancelation fee of 75% will be assessed on registration refunds requested after September 27th, 2005. No refunds will be made after October 4th, 2005. (Not applicable if due to patient medical needs.)

United Airlines is the official airline of the Second International Symposium on Malignant Mesothelioma. Reservations booked by you or your travel agent on United, Shuttle by United or United Express 30 days prior to travel will receive a 10% discount on the lowest published fare, or a 5% discount if booked less than 30 days prior. **Call United's Specialized Meeting Reservation Center at 1-800-521-4041 and reserve using Meeting ID Number 529CG.**

For additional information contact MARF at 805-560-8942



Fight Meso All Year Long

Each Fall, MARF sends a fundraising letter. Besides responding to this annual letter, you can support the mission to eradicate meso all year long, and there are a number of ways to do so. Your generosity helps MARF throughout the year as we fund critically needed research, organize the annual meso research Symposium, provide patients and families with the latest information on meso treatments and clinical trials, raise awareness of the meso tragedy, and lead the fight in Washington, D.C. for federal funding of meso research. Here are some of the ways you can support this work:

Cash - A tax-deductible gift of cash is the simplest way to contribute to MARF. It's as easy as writing a check or going on-line to our website and making a secure credit card donation. Your gift starts working immediately to help patients.

Gifts of Stock - Transferring stock is an excellent way you can support the life-saving mission of MARF. Appreciated stock donations provide tax advantages in two ways. You can avoid capital gains tax on your earnings by making a charitable donation of the stock (provided you have owned the stock for a required period). And, you can take an income tax deduction for the stock's full market value at the time of your gift.

Charitable Remainder Trusts - If you have a significant asset, either property or money, you may want to do something good with it but still need to use it or its income for yourself or your children. Setting up a charitable remainder trust (CRT) allows you to donate the asset to MARF, yet you or your beneficiaries continue to use it and/or receive its income while living. The asset then will revert to MARF. You avoid any capital gains tax on the donated asset, and also get an income tax deduction for its fair market value. In addition, the asset is removed from your estate, reducing subsequent estate taxes. If you are 70 years or older, you might want to consider a gift annuity, which offers higher payouts over a shorter period of time.

Pledge from Litigation - If you are involved in mesothelioma litigation, you might consider pledging to MARF a small percentage of the litigation proceeds to help find a cure for the disease. Families that have done this appreciate the opportunity to fight the disease, help many people, and bring some justice to an otherwise very unjust situation. You may be able to get your attorney to match your pledge, or to agree to calculate attorneys' fees net of your pledge.

Fund A Grant/Naming Opportunity - With a gift of \$100,000 (made all at once or spread over two years), you can fund a new MARF grant to a deserving researcher through our rigorous peer-reviewed grant process. And you can name the grant in honor or memory of a loved one, so that all journal articles or academic presentations resulting from the grant refer to it by this name. For example, last year the children of Alvin Rehbeck funded "The Mesothelioma Applied Research Foundation Alvin Rehbeck Memorial Grant" which MARF awarded to renowned chemo-resistance researcher Dr. I. David Goldblum for his study of chemo resistance to Alimta.

Designated Gifts - MARF's peer-reviewed, competitive grant process is the best way to promote the highest quality meso research projects. The rigorous peer review process ensures that the most meritorious projects are the ones which receive funding. However, you may be extremely grateful to a specific doctor or center and wish to further that doctor's or center's meso research or treatment programs. In appropriate circumstances, MARF will allow you to make a gift designated for a particular use like this.

Bequests - By remembering MARF in your will or estate plan you can leave a legacy of hope for others.

Monthly Giving - No checks, no envelopes, no hassles! Monthly gifts by automatic withdrawal from a credit card support MARF's continuous battle against meso. Joining our sustainer gift program is secure, efficient and lowers our administrative costs. It's a real win-win program.

Matching Gifts - Many corporations will match donations given to MARF by their employees. Why not double your contribution by asking your employer if they offer a Matching Gifts Program?

Volunteer Fundraising Event - Discover your hidden talents while creating a fun and easy way for you to partner with us in our common goal of finding a cure for meso. Ask for a copy of our Volunteer Handbook.

Special Occasions - Having a birthday? Anniversary? Wedding? Ask the guests at your special occasion to give, in lieu of customary gifts, a donation toward what we all want most, eradicating meso.

For more information on any of the ways you can help support MARF, please call our office so that we may assist you. 805.560.8942.

Senators Embrace Meso Research Funding

The fight to obtain national recognition of the need for meso research funding made an historic step forward in May. Senator Harry Kohl, a member of the Senate Judiciary Committee considering the trust fund bill (SB 852), recognized that the trust fund bill's focus on economic issues wrongly ignores the need to address the human suffering itself. He persuaded the Committee's leaders, Senators Arlen Specter and Patrick Leahy, to include MARF's proposed National Mesothelioma Research and Treatment Program (NMRTTP) as an amendment to the bill, as it was being voted out of committee on May 26th.

Senator Kohl's amendment allocates \$29 million per year for 10 years to meso research. Central to the program is a system of ten national meso medical centers, geographically distributed throughout the country, to provide the most current treatment to patients, advance research, and facilitate essential clinical trials in meso.

Of the \$29 million per year, the companies would pay \$17 million, and the government \$12 million. MARF

believes the total funding should be higher. Our NMRTTP petition advocates that because of its own role in the meso tragedy, the government should itself contribute \$30 million per year. And for years we have called on the companies responsible for the problem to contribute to curing it commensurate with their wealth and knowledge of the problem. This would be much more than \$17 million per year.

Still, the approval of Senator Kohl's amendment is a major step forward. It is an historic acknowledgement in the Senate that the companies involved in causing the meso tragedy should help to cure it. It also builds on key work of Senator Patty Murray in acknowledging the federal government's own responsibility.

In other respects, the trust fund bill remains highly controversial, and MARF is not taking a position on it. We are continuing to emphasize the need for a true national commitment to curing meso. We are grateful that the Kohl amendment begins to recognize this need.

VNN

(Volunteer Network News)

In our last newsletter we were excited to tell you that soon we would be offering Believe in a Cure Meso Awareness Bracelets. Well, as expected they arrived... but what we did not expect was the response that they would receive from the meso community. The bracelets have been an overwhelming success and volunteers all over the country have begun selling them and making them a part of their fundraising and other special events. If you have not ordered your awareness bracelets it's not too late. Bracelets come in packs of 10 and sell for \$3 each. Give us a call and we will be happy to send you some today.



Volunteers Karen Mirante and Chuck Barber are working overtime preparing for The Fred Mirante and Rudy Barber Memorial Golf Classic that will be held at the Foster Golf Links in

Tukwila, Washington on Saturday, September 17th, 2005 at 2:00 PM. The event is in honor of Karen and Chuck's fathers, who both died of meso. The tournament will be followed by a dinner and awards presentation. For more information contact Karen Mirante at: karenmirante@hotmail.com.

Are you thinking about planning your own fundraising event? Well, give MARF a call. Our staff has years of event planning experience and can help you plan and produce the perfect event. We can also provide you with materials about MARF, announce your event on the website and in the newsletter, and provide you with many other tools to help you have the most successful event possible.

ADD YOUR VOICE
TO THE CALL FOR
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OF MESO
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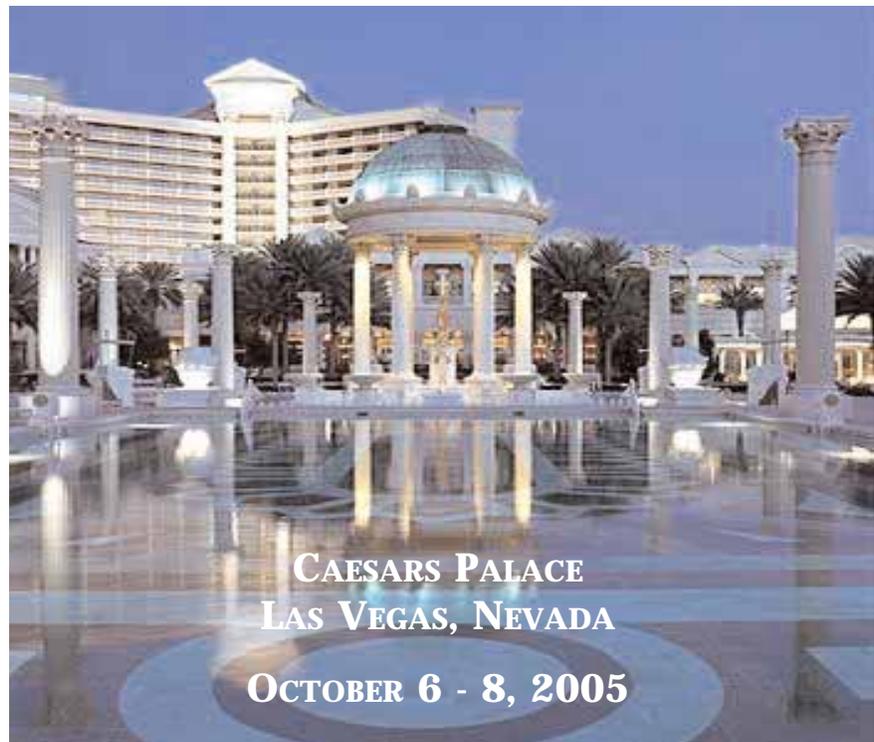
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