Asbestos Awareness Day Conference

The 2nd Annual Asbestos Awareness Day International Conference, held at the Mount Sinai School of Medicine (MSSM) in New York City on April 1, 2006, was a rousing success. Sponsored by ADAO, MSSM, and the New York Committee for Occupational Safety and Health (NYCOSH), the meeting drew registrants, speakers, honorees, and volunteers from Japan, Germany, Australia, Canada, and the United States.

Linda Reinstein, ADAO Executive Director, and Co-founder together with Dr. Philip J. Landrigan, MSSM’s Chairman of the Department of Community and Preventive Medicine, kicked off the day’s events with a welcome and brief overview. Before moving to the major sessions, participants paused to consider the human toll taken by asbestos — truly, the heart of the conference.

ADAO National Spokesperson Jordan Zevon presented the “Asbestos Kills” slideshow, featuring “Keep Me in Your Heart” by his father, singer-songwriter Warren Zevon. Warren died from mesothelioma just weeks after finishing his Grammy-winning album, “The Wind.” The slideshow features many photographs from “Breath Taken: The Landscape and Biography of Asbestos” by photojournalist and author Bill Ravanesi, who next took the stage. Marilyn Amento, ADAO’s National State Representative Co-Director and Pennsylvania Representative, wrapped up this segment of the conference with a heartfelt Tribute to Victims and their Families.

Top medical experts in the field of Asbestos-Related Diseases (ARDs) discussed Early Detection and Treatment of Nonmalignant and Malignant ARDs among Asbestos-Exposed Populations. Doctors, professors, nurse practitioners, and researchers from Mount Sinai School of Medicine, Columbia University Mesothelioma Center, the National Center for Vermiculite and Asbestos Related Cancers, Queens College, NYU School of Medicine and NCI Cancer Center joined to cover this important subject in its many aspects.

Before breaking for lunch, the conference paid tribute to the ADAO Asbestos Awareness Day Honorees.

The Selikoff Lifetime Achievement Award Recipients were Paul Brodeur, journalist and author who, in the late 60’s was among the first to spread the word about the dangers of asbestos; and Dr. Yasunosuke Suzuki a former co-worker of Dr. Selikoff, who officially retired from MSSM the day before the conference. Dr. Suzuki’s work has led to a global re-examination of asbestos use.

The Tribute of Hope Honoree was Senator Harry Reid, Democratic Leader of the U.S. Senate, who accepted his award via video; the Tribute of Inspiration Honoree was Chuck Strahl, Canadian Member of Parliament, and Mesothelioma Victim, and the Tribute of Unity Honoree was Jim Fite, Founder of the White Ling Association. Speaking prior to the luncheon was New York City Congressman Jerrold Nadler, whose district encompasses the World Trade Center site, and Keynote Speaker Paul Brodeur.

The afternoon was as productive as the morning, with experts covering global asbestos advocacy,
Canadian mining, and exportation of asbestos and victims’ support and resources.

The presentations and discussions throughout the day allowed an exchange of information as well as an education of the audience that was virtually unprecedented. There also were many opportunities for networking, face-to-face contacts that often prove to be invaluable. In fact, speakers commented that they learned more information about asbestos and ARDs at the conference by hearing from their peers.

It was wonderful to have several ADAO volunteers present. Aside from those already mentioned, also in attendance at Asbestos Awareness Day were Alan Reinstein, Doug and Kim Larkin, Dr. Richard Lemen, Dr. Arthur Frank, Mary Hesdorffer, RN, Bonnie Diana, Sharry Erzinger, June Breit, RN, Melissa Rose, Lynn Robinson, David Allgaier, Debra Swagart, Paul and Michelle Zygielbaum. It was nice to put faces to names.

Enough cannot be said about the hard work put into the conference by the many ADAO volunteers. We also want to give special thanks to Dr. Philip J. Landrigan and the MSSM staff including Alvara McBean, Lauri Boni, Laura Linker, Lucia Lee, Diane Stein, Erica Jurgel and Winnie Chan; also Joel Shufro and Jonathan Bennett at NYCOSH and Laurie Kazan-Allen from International Ban Asbestos Secretariat (IBAS).

It was wonderful to have several ADAO volunteers present. Aside from those already mentioned, also in attendance at Asbestos Awareness Day were Alan Reinstein, Doug and Kim Larkin, Dr. Richard Lemen, Dr. Arthur Frank, Mary Hesdorffer, RN, Bonnie Diana, Sharry Erzinger, June Breit, RN, Melissa Rose, Lynn Robinson, David Allgaier, Debra Swagart, Paul and Michelle Zygielbaum. It was nice to put faces to names.

Enough cannot be said about the hard work put into the conference by the many ADAO volunteers. We also want to give special thanks to Dr. Philip J. Landrigan and the MSSM staff including Alvara McBean, Lauri Boni, Laura Linker, Lucia Lee, Diane Stein, Erica Jurgel and Winnie Chan; also Joel Shufro and Jonathan Bennett at NYCOSH and Laurie Kazan-Allen from International Ban Asbestos Secretariat (IBAS).

With gratitude and respect, ADAO would like to thank the ADAO Asbestos Awareness Day Conference Sponsors and Bonnie Diana and Sharry Erzinger and their committees for their excellent teamwork and bringing this vision to fruition.

Marilyn Amento
Gayla Benefield
Jonathan Bennett
Brad Black, M.D.
Michael Bowker
Paul Brodeur
James Brophy
Kathleen Burns, Ph.D.
Barry Castleman
James Fite
Kimberly Flynn
Arthur L. Frank, MD, Ph.D
Michael R. Harbut, MD, MPH, FCCP
Mary Hesdorffer
Laurie Kazan-Allen
J. Brent Kynoch
Richard Lemen, Ph.D.

Stephen M Levin, MD
Jerrold Nadler, Congressman New York 8th Congressional District
Steven Markowitz, MD
The Honorable Patrick Martin, Member of Parliament, Canada
Harvey Pass, MD
Bill Ravanesi, MA, MPH
The Honorable Harry Reid, United States Senator
Abe Reinhartz, MD
Linda Reinstein
Barry Robson
The Honorable Chuck Strahl, Member of Parliament, Canada
Yasunosoke Suzuki, MD
Scott Swanson, MD
Robert N Taub, MD, Ph.D.
Jordan Zevon
Paul Zygielbaum

Lee Giannini
Debra & Glenn Swagart
Jill & Bud Vaughan
Tim Devlin
Warren Zevon’s Fans and Friends

Raye Black
Janet Simkins
The Henneuse & Tornese Families
Center for the Visual Arts

Fujirebio Diagnostics, Inc.
Critical Therapeutics, Inc.
Schering-Plough Corporation
Henry Schein, Inc.

Asbestos Awareness Day Conference Sponsorships and Tributes

The Asbestos Disease Awareness Organization
1525 Aviation Boulevard, Suite 318 · Redondo Beach · California · 90278
“United for Asbestos Disease Awareness, Education, Advocacy, Prevention, Support and a Cure.”
www.AsbestosDiseaseAwareness.org
April 28th 2006
International Workers Memorial Day

Dr. Jukka Takala, Director, SafeWork ~ International Labour Office (ILO)

“About two million people are killed by their work every year.”

“That is a global figure, drawn from the most recent estimates of the International Labour Office (ILO). Massive though they are, these work-related deaths are just a small fraction of the suffering caused. An estimated 160 million people on this planet have work-related diseases. Some 355,000 fatal accidents take place every year and for every fatal accident at work, some 500 - 2,000 other non-fatal injuries occur, depending on the type of job.” To continue reading Dr. Takala’s article, visit http://www.hazards.org/haz81/twomillionkilled.htm

“Hundreds die in work place “accidents. Tens of thousands die of occupational diseases. Prevention is the only cure.” To read the entire Hazards Magazine issue dedicated to asbestos visit http://www.hazards.org/wmd/

Send a message of support:

Rochdale was the birthplace of the multinational asbestos group Turner & Newall. Jason Addy and his colleagues in the campaign: Save Spodden Valley, have prepared a memorial card, which they are asking people to print off and send to the campaign. Their intention is to paste all the cards received from all over the world up in the Rochdale Town Hall to demonstrate the global nature of the asbestos epidemic.

Online card: http://www.spodden-valley.co.uk/WorkersMemorialDay-April2006.htm

Sign and support a Global Ban Petition:

http://www.thepetitionsite.com/takeaction/878671812

ADAO wishes to thank the “Save Spodden Valley” Organization for sharing their incredible IWMD graphic.

ADAO Volunteers

ADAO has put a face on these hideous diseases and now it’s time for Congress to meet US. Margy Urmberg and Marilyn Amento work tirelessly to
April/May Newsletter
coordinate volunteer efforts. To volunteer, email action@AsbestosDiseaseAwareness.org

Our ADAO State Representatives:

- Reduce the intense feelings of victims’ isolation, especially upon first diagnosis of disease
- Represent strength and unity in Washington D.C. and at a State and Local level (as needed)
- Disseminate ADAO information to our members via Serve as a state contact person for the press (as needed)

Please join us in welcoming our new ADAO State Representatives:

Lynn (TN) and Melissa (AL), who are sisters, along with their niece Kim Babin, attended the AAD Conference and Kim took hundreds of pictures, Lynn video taped much of the conference, and Melissa was taking lots of notes. They will be sharing with us soon. Valerie (FL) has joined us from Florida.

We hope that you will take a few minutes to ”meet” each other. We appreciate those of you who have sent us pictures and information about yourself and invite all of you to do so. This document is always a work in progress and will be updated periodically. We will be posting these bios to our website with your ADAO email address.

Our conference program will also be posted on-line soon, so check back often.

Legislative

As Congress returns to The Hill, ADAO is gearing up for more meetings with the Senate and House to discuss the need for a fair and balanced bill that takes into account the voice of the victims’ and the need to increase funding for education, prevention and research.

Key opposition points to Senate Bill 852:

- Faulty medical criteria used for determining compensation
- Inordinate compensation delays and ineligibility for the victims

Volume 2 Issue 1

- Inadequate funding for not only compensation, but also research, education, prevention and outreach
- Inadequate funding model that will lead to insolvency of trust fund
- No opt-out clause for the victim

Tributes

ADAO is committed to honoring the courageous victims who have lost their fight against asbestos related diseases. Margy, our ADAO Nevada Representative lost her father to mesothelioma. In honoring his memory, she has provided a name/photo tribute website for all victims. If you would like Margy to add a photo of your loved one, please email her directly at Margy-NV@asbestosdiseaseawareness.org

The tribute can be viewed at: http://www.asbestosdiseaseawareness.org/patients_supporters/tribute.html

Scientific Advisory Board

Asbestos Disease Awareness Organization is pleased to introduce our Science Advisory Board, lead by Dr. Richard Lemen and Dr. Arthur Frank. Their combined safety and medical experience represents more than fifty years.

Asbestos Disease Awareness Organization Scientific Advisory Board Goals:

- Raise public awareness about asbestos exposure and asbestos related diseases and their prevention.
- Educate the public about diagnosis and treatment of asbestos related diseases.
April/May Newsletter

- Provide accurate and newly emerging independent asbestos related disease information and analysis.
- Review ADAO medical educational and prevention materials.
- Facilitate patient support groups.
- Advise regarding new treatment and research needs for asbestos related disease.
- Support the ban on asbestos and asbestos containing materials worldwide.

ADAO Volunteer of the Month

Ellen Tunkelrott
Webmaster

Ellen Tunkelrott is a Contract and Grant Administrator for the original think tank, and resides in Redondo Beach, California. She became friends with Linda and Alan Reinstein through local community volunteer activity. Linda and Ellen collaboratively brainstormed the virtual non-profit site www.asbestosdiseaseawareness.org, and Ellen developed the original site based on the concepts and direction from those sessions. She has a B.A. in Psychology from California State University, Long Beach, and an MBA from Loyola Marymount University. She is a Certified Paralegal and is licensed by the County of Los Angeles as a Legal Document Assistant. She is self-taught in web design and development. In her spare time, Ellen is an avid photographer, gardener and is a magician member of the prestigious Academy of Magical Arts, located in the world renowned Magic Castle in Hollywood, California.

ADAO Volunteer of the Month

Ellen Tunkelrott
Webmaster

ADAO Important Links

- Read Senator Harry Reid’s Floor speech
- Read U.S. Senate Asbestos Awareness Day Resolution
- Find an ADAO Representative
- Find Educational Resources and Patient/Caregiver Support
- View “Asbestos Kills” slideshow
- Buy a wristband
- Make a donation
- Contact ADAO

Personal Note from Linda Reinstein

Newsletter Returns from Hiatus

On April 28th we honor and remember more than 56,000 workers who have died. Asbestos is the world’s leading cause of workplace cancer.

I wish to dedicate our April/May Newsletter to Alan Reinstein and the hundreds of thousands of victims who continue to battle and to victims who have lost their fight to asbestos diseases. In May 2005, Alan was diagnosed with a recurrence of Mesothelioma. Courageously, he and others battle chemotherapy, surgery and radiation to extend their lives. An asbestos victim is the antithesis of the traditional definition of victim. Victims, families and friends are anything but submissive and passive.

ADAO represents more than 3500 supporters around the world and has 100 active volunteers and partners. As we walk together, our unity and committed to asbestos disease awareness has enabled us to accomplish great steps in education, prevention, and advocacy. To read a summary of our accomplishments, please visit http://www.asbestosdiseaseawareness.org/about_adao/adao_accomplishments.html

ADAO is an all volunteer organization, powered by the people. Each Newsletter will feature a volunteer’s story. My personal thanks to each of you. ~ Linda