

2008 Asbestos Disease Awareness Conference—United States—3/28-3/30/08

The Barbara Ann Karmanos Cancer Institute (BAKCI) in Detroit was the site of Saturday's full day portion of the conference. This was an amazing conference that is only the fourth offered by a once fledgling organization that began with a short press conference in Washington DC in April of 2004. From the beginnings with a small group of volunteers the group has achieved worldwide recognition even as it remains a nonprofit group that is devoted to the victims of asbestos-related diseases and the needs of the future victims that are still there waiting to be diagnosed. Epidemiology and the latency period of the diseases say that the peak will not be seen for many years in European countries as well in the United States. There were speakers and attendees from several foreign countries as well as a wide range of professionals and activists.

The next wave will come from Southeast Asia and other countries where industries are using ever-increasing amounts of raw fiber to make building products such as asbestos-cement boards. And, there, too, is little concern over the waste produced in manufacturing and how the asbestos is used. All the speakers reiterated the urgent need to educate people, ban asbestos, prevent diseases, fund research and treatment, and provide support to the asbestos disease victims. Most developing countries have banned asbestos and the developing countries are increasing their manufacture of asbestos products. There is still much work to be done to prevent these diseases and halt the use of the "miracle fiber" that turned out to be such a toxic fiber.

SESSION 1. Dr. John C. Ruckdeschel, MD, president and CEO of BAKCI, welcomed the conferees to the BAKCI. He said that it is heartwarming to see so many persons working on the eradication of asbestos diseases, but unfortunately the therapeutic outlook is still very poor for victims. Dr. Richard Lemen, MD (retired admiral from the United States Public Health Service) provided a little history of asbestos disease associated with Canada's Thetford Mines. The evidence of mesothelioma was seen the 1950's, at the mines where chrysotile was mined. Dr. Lemen asserted again that all the fiber types cause asbestos disease contrary to what the Canadian government believes. Working safely with chrysotile in developing countries is not a reasonable option for workers who have no training, no protective equipment, etc.

SESSION 2. Drs. Michael Harbrut and John Ruckdeschel, co-directors of the National Center for Vermiculite and Asbestos-Related Cancers, provided the good news and bad news about the diagnosis and treatment of asbestos-related diseases (ARD). The HRCT (high-resolution computed tomography) is state of the art and provides good diagnostic information. The PET Scan is very good for looking at the stages of the cancer and in selecting good surgical candidates. Alimta and cisplatin are yielding good results as chemotherapeutic agents for mesothelioma along with Pleurectomy with Decortication that is very useful in the younger patients.

The bad news is that B readers are not useful for the diagnostician. Patients need to beware of the fraud being perpetrated by B readers. All cell types can cause lung cancer in those exposed to asbestos. The exposure to asbestos also increases the risk of other cancers e.g. kidney cancer. Dr. Ruckdeschel provided the grim statistics that the 5-year survival rate for those with mesothelioma is 30% of the 28% who can have the surgery. Those with the fibrosarcoma type of methothelioma have a very poor outcome while those with the epithelial type do better. The need is great for randomized treatment trials, a need for centers doing research and treating ARD with a well-documented track record, and for a tests that would provide early diagnostic information.

Dr. Warren Teel, a consulting physician with the Occupational Health Clinics for Ontario (Canada) Workers described their experience with ARD in Lambton county that has the most ARD of all Canadian counties. This is the site of the area known as Chemical Valley. Dr. Teel described the area with its high rate of ARD as a "Slow Motion Bhopal" Disaster (1984 release of methyl isocyanate gas that killed thousands). The Canadians have been doing annual screening of those highly exposed to asbestos in the hopes of finding cases early and they have done so for a few. The pleural plaques are a marker of exposure, cause pain, but the patient may not progress to full-blown ARD. They, too, have found that the biomarkers are not particularly useful.

Dr. Rebecca Kline, PhD, a senior scientist at BAKCI, described the psychosocial impact of ARD on patients. She has done research at Libby and found that the victims of ARD feel they have a stigma that is like the stigma felt by those with HIV. The patients keep the information secret from even close friends. The victims ask all the same questions that victims ask, why me, why here, etc.

Linda Reinstein, the Executive Director and Cofounder of ADAO with her late husband, Alan Reinstein, provided a moving overview of what she did when her husband was diagnosed with mesothelioma in 2003. Alan had the EPP surgery, but the disease returned in 2005 and he died in 2006. Linda described the process of dealing with mesothelioma and from this she formulated the ten points of the Reinstein School of Hard Knocks that she recognized while dealing with Alan's illness. Part of these ten points was the acronym, LIFE that stands for legal, insurance, financial, and end-of-life requests. Her take away points were to ask for help, be organized, ask questions, read all you can about the disease and treatment options, and join a support group or at least network with other caregivers in the same position. Perhaps the most important point is that the caregivers take care of themselves as they have a long tough road ahead and need to lessen their stress and maintain their own health.

SESSION 3. This session summarized the status of what is happening in North America with asbestos. This past year saw an historic event, the US senate passed unanimously a bill to ban asbestos. The previous ban was overturned in 1991! However some last minutes changes allowed the ban only of greater than one percent (1%) asbestos containing materials, **not the ban of asbestos products**. Several other last minute changes make the bill less acceptable and it differs from the companion bill introduced in the House of Representatives. Resolving these differences will take some time.

The situation in Libby, Montana caused by the WR Grace vermiculite mine has not been fully resolved. In fact Grace has reached a settlement with the EPA for \$250 million dollars. Dr. Brad Black, MD, who was instrumental in founding the Center for Asbestos-Related Diseases (CARD) for Libby residents described and showed pictures of the contaminated areas that are still in Libby. He pointed out that in the last eight years there have been 31 cases of mesothelioma diagnosed in the 10,000 residents of Libby, an extremely high rate for this disease. This environmental and health disaster is not over yet as cleanup is not finished and people are still being diagnosed with asbestos diseases. There may be a further loss in funding for the CARD clinic with the Grace settlement.

Dr. Aubrey Miller, MD, a senior scientist and toxicologist at the Environmental Protection Agency (EPA) described the current situation with the asbestos. In the United States, many people think it is still banned, and it has taken seventeen years since the overturn of the ban for the US senate to pass a ban. In the meantime there are many sites such as Libby that still need to be cleaned up. There is also the problem with naturally occurring asbestos such as that found in El Dorado, California that when disturbed by children or adults playing exposed them to detectable asbestos fibers. Elsewheres, naturally occurring asbestos problems have shown up in China, crocidolite in Da Yao, erionite in North Dakota, etc. Dr. Miller again stated the need the ban asbestos in asbestos products. He also reiterated the statements made by other speakers that **all fiber types cause asbestos disease**. Dr. Miller was awarded ADAO's Tribute of Hope for his ***“commitment to Libby and his determination to remove the asbestos scourge from society”***

Paul Zygielbaum, ADAO Project Manager and mesothelioma patient, provided an update on asbestos testing of products commercially available to consumers. Surprises were found in many items such as the CSI fingerprint kit, a toy that was created as a result of the popularity of the popular television programs that feature the forensic aspect of criminal investigations. This fiber was tremolite, the same fiber that caused such devastation in Libby MT. Other consumer items included a sealant and a high performance duct tape.

This product testing by ADAO has provided more “ammunition” for the advocates of a total asbestos ban. The information about the testing especially the information on the fingerprint kit garnered a great deal of attention from the public and congress with the press release.

John Thayer, the subject of the video, ***Tunnel Rats***, released at last year's conference brought attendees up to date about the asbestos situation in the utility tunnels under the US Capitol in Washington DC. Since then all of his men and he were fired and all are now training for new jobs. They were awarded a small settlement for their exposures to asbestos while working in the tunnels. However, the future is very uncertain for these men because they show signs of asbestos disease and had very heavy exposures. For his efforts, John Thayer truly deserved ADAO's Tribute of Inspiration for ***his courage, honesty, integrity and determination to speak out about a serious asbestos situation, and to speak out for his co-workers and not just himself.***

SESSION 4. This session highlighted how far we have come in fighting the asbestos problem and how far we still have to go in achieving a global ban. Mr. Lyle Hargrove, Director of the Canadian Autoworkers' (CAW) Asbestos Campaign, described what asbestos has done to the autoworkers in Canada. There is an uphill fight to ban asbestos because the Canadian government actively promotes the "safe" use of asbestos in products and exports asbestos worldwide.

Dr. Barry Castleman, a well-known authority on the legal and medical aspects of asbestos, described the shortcomings of the Ban Asbestos Act that was passed in October of 2007 by the US Senate. These changes to the original bill were very last minute and allow products that contain up to one per cent (1%) by weight. There are many differences between the House and Senate bills to be worked out such as whether violations are a misdemeanor or a felony, provision in House bill for companies to apply for an exemption from the ban if there is no substitute for asbestos followed by full regulatory procedures to grant the exemption, etc. He did have a bit of good news, the Vanderbilt talc (ore contains asbestos, too) mines in New York are closing this year.

For all of his work both at home and on the international scene Barry was awarded ADAO's Selikoff Lifetime Achievement Award *for his dedication and commitment to the global ban asbestos campaign*. He has been part of organizing international asbestos conferences, especially the 2000 Global Asbestos Conference in Brazil, consulting with federal and international organizations on asbestos issues, and wrote *Asbestos : Its Medical & Legal Aspects*, a most important resource for the asbestos community.

Dr. Bishakha Ghose, Head of the Department of Community Medicine at BGC Trust Medical College in Bangladesh showed the group just what happens with one source of asbestos waste. These are the ships that are bought by brokers and are dismantled on the beaches to recover all scrap materials. The government sees this as an economic boon for the country and does not feel the work is dangerous. This is belied by the pictures that describe an utter lack of safety and health protection for these workers. The workers are not aware of the hazards, don't know anyone with asbestos diseases and are very glad to have jobs. Besides the asbestos hazards there are environmental hazards as wastes leak into the water from the ships that are broken apart.

Robert Jones, a consultant and researcher, has been working in South Africa on projects assessing the asbestos situations in communities that were the sites of asbestos mines. Not surprisingly, there is a high level of contamination in the areas around the old mines. In the study areas, 82% of the homes, 59% of the schools, and 53% of the roads are contaminated with asbestos dust and tailings. Mr. Jones aim with these studies is to assess the extent of the contamination in order to devise workable remediation projects.

Ms. Laurie Kazan-Allen, founder and coordinator of the International Ban Asbestos Secretariat wrapped up this session by summarizing the roadblocks that the ban asbestos campaign faces with the companies that proclaim that their asbestos products cause no harm, the pro asbestos governments that fund asbestos research projects, the concerted efforts of the Chrysotile Alliance to assure everyone that chrysotile is safe to work with. There are six (6) countries that account for 98% of the asbestos exports. Ms. Kazan-Allen's latest publication, *Killing the Future: Asbestos Use in Asia* shows us just how far we have to go in achieving a worldwide ban on asbestos and repairing the damage that is being done with this most toxic "miracle" fiber.

The conference ended on Sunday with a Remembrance Brunch to honor and remember those who have died. Eric Jonckheere, with the Belgian Asbestos Victims Association (ABEVA) provided a very moving account of how asbestos has affected his family. His father was an engineer at an Eternit facility (asbestos cement products) and was required to live close to the factory. As the result of this work, Eric's father, his mother, and two brothers have died of mesothelioma. He and his brothers of course were exposed and are waiting to see what happens to them. Before his mother died she was instrumental in founding ABEVA in 2003 because she saw the devastation in her family and wanted to prevent this from happening to other families.