



# CARD NEWS

Center for Asbestos Related Disease

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## CARD Receives Federal Appropriation in the amount of \$188,100!

These funds must specifically be used for a construction project only.

So stay tuned...

**We GREATLY Appreciate the Support of our Senators and Representative!**

## MSU, College of Nursing Reports Research Results

Many of you may remember that CARD staff and patients partnered with researchers from MSU's College of Nursing in the Libby Asbestos Health Status Study. They came to Libby in November of 2008 and presented their research findings to the community. In case you were unable to attend this wonderful event, we thought we would give you a summary.

Five-hundred and twenty-four (524) CARD patients participated in the study by completing a paper/pencil or electronic survey using a touch screen computer between February and October of 2007. Of the **sample** (*group of people who participated*), 69% lived in Lincoln County and 31% lived in another county in Montana or out of state; 54% were men and 46% were women; the average age of respondents was 59, and 64% were married. The **purpose** of the project was to establish a better understanding of the physical, psychological, and social health status, as well as health service needs, of people exposed to Libby asbestos. The **aims** of the project were (1) evaluate access, availability, and financial aspects of healthcare, (2) describe the health status of persons exposed to Libby asbestos through an examination of the patient's severity of chronic illness, depression, acceptance of illness, and stress, and (3) explore the relationships between all

of these factors in people exposed to Libby asbestos.

It is important to remember that **conclusions** are drawn from trends seen in the data collected. The conclusions from one study should not be considered absolute black and white answers; rather they are shades of gray. (1) Regarding satisfaction with access and financial aspects of care, distant and local CARD patients recorded similar answers to the survey questions, but together they were significantly less satisfied than other groups of chronically ill adults. (2) CARD patients also have more respiratory health effects and complications than the general populations and some persons with COPD. (3) One third of the participants reported depressive symptoms, and patients experiencing a period of disease progression have greater respiratory health impacts and depression. (4) During disease progression, there is also some evidence that acceptance of illness was less and stress was higher.

All of these findings suggest that disease progression (when symptoms are changing), not severity of disease alone, should be considered in providing a patient healthcare. Patients with disease progression appear to be in greater need of support to manage their health status.

These kind of research activities help us determine how we can improve care for patients and what other important research questions need to be looked at next. Without participation from all of you these important things could not be understood.

## W.R. Grace & the Criminal Trial

Although CARD focuses on asbestos healthcare, research and outreach, and NOT legal issues, we thought it might be helpful to give you a little summary about the criminal trial. On Feb. 7, 2005, W.R. Grace & Co. and seven of its executives were charged with crimes, which include one count of conspiracy, three counts of knowing endangerment under the Clean Air Act, and four counts of obstruction of justice. Since then, the case has been intensely litigated, making its way from Federal District Court in Missoula, MT, to the steps of the U.S. Supreme Court and back again. The defendants have pleaded not guilty to the charges and are presumed innocent until proven guilty beyond a reasonable doubt. The criminal trial started Feb. 19, 2009,

with jury selection.

At this point in the trial, players from both the defense and prosecution have taken the stand. Dr. Whitehouse is one of 10 expert key witnesses in the trial. He has been working with CARD since 2004 prior to which he had been a consulting physician for CARD for years. At the beginning of March he testified about the medical implications of exposure to asbestos. He described the disease process starting with the inhalation of a tremolite fiber to the resulting health effects on the lungs ranging from one pleural plaque to extensive pleural thickening, asbestosis and even death. He testified that Libby has the highest mesothelioma rate in the nation due to the history of asbestos exposure that occurred in the Libby area. He was confident in explaining to the jury that his knowledge of asbestos-

related disease is beyond that of a radiologist because he does a full examination on a patient and doesn't diagnose based on an x-ray film alone. CARD supports Dr. Whitehouse's testimony and applauds his ability, determination and strength to stand up for Libby residents and those suffering with an asbestos-related disease!

The criminal trial is expected to last about 2 more months. The University of Montana law and journalism students have combined forces to create a blog focusing on the trial day-by-day. It is a non-bias blog that also features "tags" and "twitters" pertaining to the case. If you would like to visit the site for updated trial information please visit <http://blog.umt.edu/gracecase/>.

This information was brought to you with help from their site!

## Ban Asbestos in America

Do you think asbestos has been banned in the United States? Many people would answer yes! When, in all actuality, anyone in the US can still buy and sell products containing asbestos.

Since 1975 manufacturing asbestos-containing materials including; insulation, wall and ceiling tiles, fireproofing spray, roofing, drywall, truck brakes, toasters, hairdryers, pot holders, and some children's toys in the United States has been banned. However, the United States still imports, sells, and uses asbestos-containing products from other countries. Roughly 8 million Americans may already have been exposed through various jobs such as; construction, industrial, and shipyard workers, asbestos mining and mill workers, and heating, ventilation and conditioning trades people. Furthermore, asbestos can still be found in 10-15% of schools. There's no known safe level of exposure to any form of asbestos. Yet asbestos is still legal in the US.

The US EPA attempted to ban asbestos-containing products in 1989, but that ban was overturned on legal technicalities in court two years later. Right now, industry lobbyists are pressuring Congress to institutionalize the allowance of up to 1% of asbestos in our industrial materials, consumer products, toys, and other products on American store shelves. Some of the asbestos-containing products that were made with Libby's amphibole asbestos, like Zonolite attic insulation, has less than 1%. 1% is too much! It's time for a total ban on asbestos in American products, and Congress is expected to hold hearings this year on whether to implement a total ban on asbestos.

The Committee to Ban Asbestos in America's (CBAA) was formed by public health advocates whose mission is to ban asbestos and fund federal medical and educational programs pertaining to the health impacts, including mesothelioma, caused by exposure to asbestos. This committee is led by the Asbestos Disease Awareness Organization (ADAO) and The John McNamara Foundation. The CBAA is currently petitioning to ban asbestos in the United States. If you would like to tell Congress that any amount of asbestos is too much, sign the petition to ban asbestos at <http://www.gopetition.com/petitions/totally-ban-asbestos.html>.

## Understanding the Cycle of Research

With all the talk about research these days, we figured it was important for everyone to understand the timeline and cycle of research.

1) An unanswered question exists. **Example:** what are the health effects of childhood exposure to Libby amphibole asbestos?

2) A funding opportunity, like a grant or contract, must be found to fund the research activities to address the question. **Example:** ATSDR (Agency for Toxic Substance and Disease Registry) announced that they would fund *The Libby Amphibole Health Risk Research Initiative*. The idea was announced in July of 2008 and then it took until January 15, 2009 for the official posting of the grant opportunity to be released for competition.

3) Organizations and Universities must apply for this funding and it is very competitive. A grant application is written and it must spell out every step involved and every dollar spent for the research activities that are proposed. Applications are typically 50-100 pages long and very complex. There is very little time to accomplish such an in-depth research plan. **Example:** *The Libby Health Risk Initiative* application deadline was March 16, 2009. CARD, University of Montana, and Idaho State University are all partners in an application with New York's Mount Sinai School of Medicine who is the lead institution in the application. It includes three different projects that will involve hundreds of people over five years.

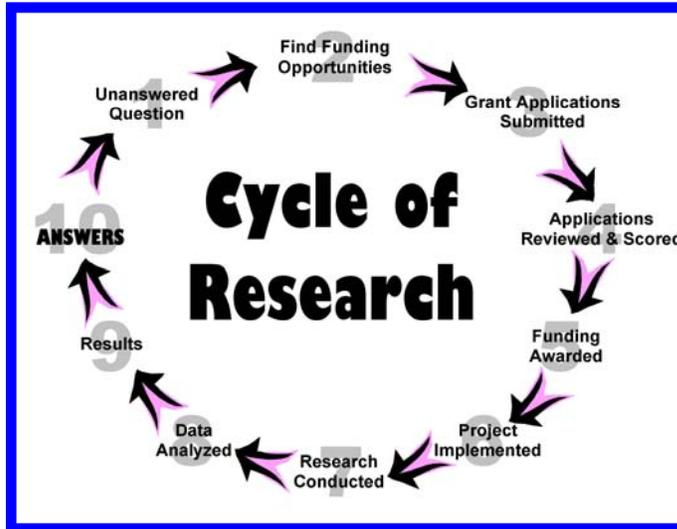
4) All applications for the specific research funds go through a review process. Typically there is a first round called "peer review" which is followed by "secondary review." Final scores are given to each application. **Example:** *The Libby Health Risk Initiative* applications will undergo peer review in May-June 2009 and secondary review in June-July 2009.

5) Funds are then awarded to the Organization/University who had the highest scored application and sometimes notification of this award can be delayed by unexpected circumstances in the review or award process. **Example:** *The Libby Health Risk Initiative* funding participants would be fully informed about what participating involves and only people who choose to participate would be involved after they gave "informed consent." **Example:** *The Libby Health Risk Initiative* project will involve data collection from the Fall of 2009 through the Fall of 2013.

8) After data collection is complete, the data must be analyzed. Experts in the field can work for many months to analyze the data in order to discover the initial findings, and often the same data can be analyzed and used in different ways for years after the project is over. **Example:** *The Libby Health Risk Initiative* plans to conduct data analysis throughout year five of the project (2014).

9) Results emerge out of the analyzed data.

10) Conclusion are drawn from the results that provide partial or complete answers to the question(s) that were initially asked. There is also the possibility that some questions answered will lead to new questions being asked and thus the research cycle begins again.



opportunity announcement states "Earliest anticipated start date (is) September 1, 2009."

6) It takes a couple months to get the projects started. You must hire staff, purchase all necessary supplies and equipment, figure out how best to implement the projects and develop consistent protocols. **Example:** If CARD and partners are awarded the funds for *The Libby Health Risk Initiative* all of the project implementation prep work will occur in the fall of 2009.

7) Then the research is conducted, this is also called *data collection*. Participants are recruited to participate in research activities. It may be a one time event or it may require a person to have a follow up visit one month or two years later; each project is different. All

participants would be fully informed about what participating involves and only people who choose to participate would be involved after they gave "informed consent." **Example:** *The Libby Health Risk Initiative* project will involve data collection from the Fall of 2009 through the Fall of 2013.

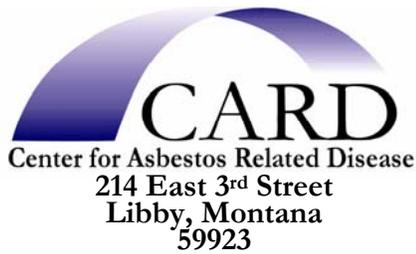
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*The Libby Health Risk Initiative* is a current project that was a good example of how the research cycle works. Research takes time, patience, and dedication but that is how answers are found. Remember that all proposed research questions go through this process. Currently CARD is a partner in 4 other research applications that have been submitted, but don't forget you must "win" the grant before you can do the research. CARD believes that working with as many great researchers as possible is the best way to find the answers that will directly benefit everyone affected by Libby amphibole asbestos. But CARD can't do it alone, we need all of you to help us along the way! We look forward to working with you!



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## **THE BIG CARD NEWS of April 2009**

### **CARD HAS A NEW WEBSITE!**

With a grant from the Gilhousen Family Foundation, CARD was recently able to update our website! As stated in CARD's mission, one of our main goals is outreach. Because technology plays such an important role in today's world, our website is very important for communication and providing information to our patients, researchers, other professionals, donors, and the public at large.

Through our new website, patients and the public will be able to find out information about Libby amphibole asbestos, asbestos related diseases, healthcare resources and educational materials. The site will also direct patients to CARD for healthcare services, and will be a resource to find out about Libby amphibole asbestos health related research activities, findings and opportunities to get involved.

This is the first phase of many that are planned for our website. Once funding is secured we will add many more visual and video elements to the site and expand resources for medical professionals and researchers.

Lastly, this website will serve as a forum for online giving to the Foundation, for donors interested in giving to CARD. The Foundation is in the process of creating their own separate website, which will be linked to CARD's. The Foundation website will be directed towards individuals and organizations interested in sharing a gift with the Foundation in order to assist CARD in serving all people affected by Libby amphibole asbestos through healthcare, research, and/or outreach.

Please check us out online: [www.libbyasbestos.org](http://www.libbyasbestos.org)