



CARD NEWS

Center for Asbestos Related Disease

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**CARD Database
Scheduled to go
LIVE May 5th 2008!**

We are all in this together & teamwork is the key! And of course *patience* is golden, as we adapt to the new way of doing things.

Why these changes?

- Improved Healthcare
- Building the Database
- Facilitating Research

Understanding LAMP II

You may have heard the talk about the 1.5 million dollars that the State of Montana has given to Lincoln County to provide benefits to persons suffering from exposure to tremolite asbestos until June 30, 2009. Both LAMP and ARD NET will receive a portion of these funds.

ARD NET will receive \$375,000 and their program will continue to provide services as it has for the past four years. They provide case management and home assistance services to anyone diagnosed with an asbestos related disease. They also provide travel reimbursement for asbestos related medical care for people that live within a 250 mile radius of Libby. ARD NET can be reached at 406-293-4600.

LAMP will receive \$1.125 million and their programs will continue with a few minor changes. In managing the LAMP benefits, it is important to keep separate the LAMP funds received from EPA due to the settlement with WR Grace in 2002 and the recent funds received from the State of Montana. These funds must be administered separately so as of April 15, 2008 the only LAMP benefits that exist will be LAMP II. LAMP II has a \$25,000 lifetime limit per person as long as these limited funds last.

If you are currently receiving *LAMP Screening Only* benefits nothing will change.

If you are receiving *LAMP Supplemental* benefits things will continue as before with two minor changes. 1) There is now

a \$10,000 maximum allowed amount for inpatient stays and 2) the maximum amount of home assistance for people on oxygen is now 5 hours/week (different limits apply if a person has an asbestos related cancer, thoracic surgery, or a hospice determination).

A new category of benefits is also being established called *Asbestos Related Disease Denied by Grace for Benefits*. This benefit category will cover services typically covered by the Grace Libby Medical Program administered by Health Network America/Triveris plus the benefits offered under LAMP Supplemental. To be eligible for this benefit you must be diagnosed with an asbestos related disease by a medical provider, have applied to the Grace medical plan and have documentation that you were denied. Because this is an entirely new category of benefits, it will be most important to review the benefit package you receive from LAMP II to fully understand these benefits.

LAMP II funds are limited! The *LAMP Asbestos Related Disease Denied by Grace for Benefits* benefit is only effective to cover claims until 2/1/09 or when LAMP II runs out of funds. Submitting a claim to LAMP II does not guarantee that it will be covered. All claims will be paid on a first come, first serve basis depending on the date LAMP receives them. If you have *LAMP Screening Only* or *LAMP Supplemental* benefits when LAMP II runs out of money you will be switched back to LAMP I.

For more specific information or questions on LAMP contact LAMP at 1-877-889-8405.

The Asbestos Disease Awareness Organization

The 4th Annual Asbestos Awareness Day Conference, hosted by the Asbestos Disease Awareness Organization (ADAO) was held in Detroit Michigan this year and it was a great success. People came from across the country (from Libby, Montana to the Capital Hill tunnel workers in Washington, D.C.) while others came from around the world (including Canada, England, South Africa, Bangladesh and many other countries experiencing the health effects of asbestos). All involved are working together to increase awareness of the dangers from asbestos and to make positive changes. Dr. Brad Black of CARD presented on *Libby, Montana -8 Years Later*, as everyone in the room knows the story of Libby, Montana and sees hope for the future in our community's strong resolve in addressing the issues and our focus on research for the future.

ADAO is an independent non-profit volunteer organization founded by Linda Reinstein and Doug Larkin on April 1, 2004. It serves as a resource for people impacted by asbestos exposure and disease and facilitates awareness and activist activities nationally and globally. They host a website with resources, contact information, and involvement opportunities www.asbestosdiseaseawareness.org. They also have a website called www.adaotv.com with several video channels that when selected, provide a list of presentations. Categories include asbestos exposure, patient information, and physician information, among others. You definitely need a DSL internet line to watch these videos, but having an opportunity to view these presentations is very valuable as they are from the ADAO annual conferences and feature the leading asbestos medical providers, researchers, and activists.

The goals of ADAO are: 1) Serve as the united voice for all asbestos victims; 2) Unite asbestos victims; 3) Educate the public and medical

community about asbestos related diseases; 4) Support research that leads to early detection and prevention and a cure, 5) Ensure equitable compensation for victims and their families; 6) Ban the use of asbestos.

ADAO Will: Seek to give asbestos victims a united voice to help ensure that our rights are fairly represented and protected including: 1) Our right to medical research and treatments aimed at early detection, prevention, and a cure for asbestos related disease; 2) Our right to file suit based on the merits of our individual asbestos related injustices; 3) Our right to fair compensation; 4) ADAO strives to implement an asbestos national asbestos disease database registry – to help unite victims of these tragic asbestos-related diseases; 5) ADAO also works to support the efforts to ban the use of asbestos and help protect future generations.

So, check out ADAO and ADAO TV on the web. If you don't have a computer at home, you can always use one at the library!

Working with Steve Levin

Steven Levin, MD in Occupational Medicine is making several trips to Libby this spring to work with CARD. He is an Associate Professor at Mt. Sinai School of Medicine and Director of the Selikoff Center of Occupational Medicine which has a long history of addressing asbestos issues in New York.

While in Libby he presented to the local medical staff about asbestos exposure and the health affects he has seen in his clinic population whom are insulators heavily exposed to asbestos. Compared to the health effects he has seen, he notes that Libby's asbestos disease has unique features including its rapid progression, obstructive airway disease component (like asthma), and pleuritic (chest) pain.

Dr. Levin was also a key facilitator in setting up the medical monitoring program for the World Trade Center responders after 9/11. At Libby High he presented to Mr. Reckin's research class about the respiratory problems experienced by the responders who worked so dedicatedly towards saving lives that they did not protect themselves. With all of the dust and debris in the air around the site, they were exposed to high levels of crushed cement and other hazardous materials including Monocote. Monocote was one of the two trade names under which Libby vermiculite was marketed. It was a fire proofing material used to coat all of the steel beams in the construction of the World Trade Center and of course it was heavily contaminated with Libby asbestos.

Dr. Levin's experience in setting up the medical monitoring program and database for the World Trade Center Responders, plus his extensive experience in treating asbestos exposed patients, makes him a great asset to CARD. He has provided a valuable service helping to create the CARD database and will work with us to analyze health data. These are critical steps towards understanding exposure/risk and to facilitate research to find new treatments and a cure.

CARD Believes in Holistic Care!

Here at CARD we provide excellent quality healthcare within our realm. We are a clinic that specializes in asbestos related healthcare, but we strongly believe it is important to look at, and treat, all aspects of health.

Primary Care

Our physicians all specialize in lung related healthcare. We provide annual screenings, help people manage their asbestos related disease, respiratory symptoms, and encourage you to be seen if you are catching a respiratory infection. However, a lot of patients we see have other healthcare needs that we do not address at CARD. We strongly encourage every patient to have a primary care provider. This is a healthcare provider that considers all aspects of a person's health. They coordinate care of different specialists and manage things like general health, blood pressure and cholesterol. They provide annual physicals and general screenings such as: colon, prostate, and breasts. Your primary care provider, and all of your medical providers, should be people you are comfortable with and trust, so don't be shy to find somebody new if you are not happy with your current medical providers. A good fit is important.

Exercise

Yes, we all know we need to, and should. We encourage a regular routine that increases your breathing

rate and lets the lungs know you haven't forgotten about them. Exercise is different for everyone. Some people have bad hips, knees, problems with their back or other health issues that hinder their ability to get a strenuous work-out. That's okay! We can't all work out in the same way or at the same pace. The bottom line is to find a routine that works best for you and stick with it!

Diet & Nutrition

Believe it or not eating too much may hinder your ability to breathe. The diaphragm lies between your stomach and chest cavity. If a person is carrying too much fat on their stomach it can hinder the diaphragm's ability to move up and down during breathing. We all know that we breathe in oxygen and breathe out carbon dioxide (CO₂). But, if you have COPD or emphysema you do not expel CO₂ appropriately, rather your lungs "traps it". Thus, in regards to your diet, it is important to be aware that when the body breaks down carbohydrates they release CO₂. So, if you are somebody who already has too much CO₂ in their lungs you may experience further breathing difficulties when eating too many carbohydrates. In addition to being mindful of these things that make breathing more difficult, it is also important to be aware of what you are eating so you get adequate nutrition from the food you do eat. We all know the basics, 5 fruits/vegetables for vitamins/minerals, enough protein and fiber and a limited amount of fats/sweets. So if we know what we should be eating, make our best effort to do it!

Thoughts & Feelings

Now we are not just talking about warm and fuzzy; different people need different things to feel balanced and satisfied on the inside. It is just as important as good physical health. Feeling good mentally can be accomplished by utilizing appropriate stress management skills and making time for fun, whether it be laughing with friends or having a little quiet time alone to read a book or go fishing. We all have our own unique sense of balance, so know yourself and make it a priority to find the time to take care of your mind, emotions, and spirit too.

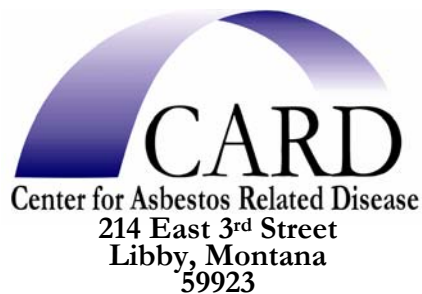
Your Voices Were Loud & Clear!

During the months of February and March the Voices of Libby Survey Project was in full swing. Of the 1100 randomly selected community members 52% responded, and of the 100 randomly selected CARD patients 79% responded. In the world of survey research a 33% response rate is considered acceptable, and the response rate from our community was considered to be AMAZING!

Thank you everyone who participated! We are already demonstrating to the world the CARD Research is a Community Project in Libby, Montana!



If you have questions or comments about this newsletter, or would like to receive it by mail or e-mail: Contact Tanis Hernandez at the CARD: tanis@libbyasbestos.org or 406-293-9274 x29.



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THE BIG CARD NEWS of SPRING 2008

CARD Database Goes *LIVE* May 5th!

So you may be wondering, what does it mean now that the CARD database has gone live? It means that your next visit will be a little bit different. It is important to remember that healthcare will always be the number one priority at CARD. A lot of your health information will now be collected and managed electronically, but this does not mean that it is automatically part of the research database. At the time of your healthcare visit you will be informed about the research activities and you will have the option of giving **informed consent** to be a part of research. Informed consent serves as a wall dividing your electronic health information from the research database and it is only through your informed consent that your de-identified health “data” will be pushed through the wall to be used for research activities.

Regardless of whether you participate in research, or not, there will be some changes to your annual CARD visit (not sick visits) now that we have gone live with electronic health information collection and the research database. For your first visit after we go *LIVE*, you will need to plan about two hours because extensive health and exposure histories will be taken. We will send you a preadmission packet of forms to serve as the framework and we will help you with any you were unable to complete. Future visits will be a lot quicker after the baseline information has been collected. We will just update your health history and symptom changes each year, if any. The flow of your visit may also be different. You will still see the same people, (doctor, nurse, respiratory therapist) but the order in which you see them might be different. You will also be given the opportunity to participate in research either by consenting to have your health information included in the database or by donating blood. The choice is yours! Please be patient as we iron out the kinks in providing improved asbestos healthcare while also building the database that will help us translate healthcare into research to find new and improved treatments.