SARCOIDOSIS NETWORKING ASSOCIATION

Volume XVIII SPRING 2011

POST 9/11 Sarcoidosis Exposure to Airborne Toxins

August 13, 2007 Elaine Moore

Studies show that exposure to the airborne toxins by the WTC attacks triggered the development of sarcoidosis and sarcoidosis-like respiratory diseases.

The death toll from 911 reached 2,750 when Felicia Dunn-Jones's name was added to the official death list. An attorney, Dunn-Jones fled her office, located a block away from the towers, and died of sarcoidosis 5 months after the attack. Dust from exposure to Ground Zero has also directly contributed to the death of others not yet on the list such as James Zadroga, a 34-year old police officer. Of the 10,000 clients represented by attorney David Worby involved in a lawsuit accusing the city of negligence, 5 have recently died of sarcoidosis.

The confirmation of Dunn-Jones's sarcoidosis came in a letter by Dr. Charles S Hirsch, the city's Chief Medical Examiner on May 18 stating that "Accumulating evidence indicated that in some persons exposure to WTC dust has caused Sarcoidosis or an inflammatory reaction indistinguishable from sarcoidosis."

Chemical Dust Exposure and Sarcoidosis

Sarcoidosis, which is also known as Besnier-Boeck disease, is an autoimmune disorder that usually starts in the lungs or the lymph nodes of the chest cavity. Sarcoidosis of the thyroid gland can also develop. Since its identification in the 1880's no direct cause of sarcoidosis has been identified.

Although airborne toxins had long been suspected, recent evidence that toxins, such as those that clouded the World Trade Center, can trigger sarcoidosis. A pathologist for Ocean County, New Jersey, concluded in April 2006 that the January 2006 death of James Zadroga was directly linked to 9/11 recovery operations.

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Spot a Stroke
Save a Life

If you think someone is having a stroke:

1. Ask the person to smile
2. Ask him or her to raise both arms
3. Ask the person to repeat a simple sentence like "It's sunny outside"

If he or she has any problems,
The American Stroke Foundation says think **FAST**:

1. ***F***acial droop
2. ***A***rm weakness
3. ***S***peech problems
4. ***T***ime—don't wait for symptoms to pass,
5. **Call 911 Immediately**

Remember, think *FAST!*

"Be kind, for everyone you meet is fighting a great battle."

Philo of Alexandria

Post WTC Sarcoidosis

As on May, 2007, twenty-six New York City Ground Zero firefighters and emergency medical service workers have developed evidence of sarcoid-like Granulomatous pulmonary disease. The condition, called *World Trade Center sarcoid-like granulomatous pulmonary disease,* consist of abnormalities in the pulmonary parenchyma, hilar and/or mediastinal adenopathies, clinical features resembling asthma, and, occasionally, involvement of the bones, joints, skin , or spleen.
Investigators has previously shown that even before 9/11, New York City firefighters and rescue personnel had an elevated incidence of sarcoidosis or sarcoid-like granulomatous disease linked to occupational or environmental exposures to organic dust, metal, chemical dust, silica, and wood dust or smoke.
However, since the incidence of sarcoidosis or sarcoid-like pulmonary disease increased significantly after 9/11 compared to the years before the World Trade Center dust exposure, particularly during the first 12 months following 9/11/2001.

The Proof

To determine whether prolonged, repeated exposure to airborne particulates might increase the risk to sarcoidosis or sarcoid-like granulomatous pulmonary disease in a population already at risk, the investigators followed the fire department employees. Those with chest radiograph findings suggestive of sarcoidosis underwent additional evaluations using CT imaging, pulmonary tests, airway challenge tests and, biopsies.
The investigators calculated an annual incidence rate of sarcoidosis and compared it with 15 years before the World Trade Center attacks. They found that 26 patients, all at the World Trade Center sites within 72 hours of the towers' collapse, when particulate levels were highest, had evidence of new-onset sarcoidosis.

Conclusion

Studies of the 26 firefighters showed 18 (69%) had findings that were consistent with asthma, and fifteen of those patients have clinical symptoms: cough, dispend, and/or wheeze exacerbated by exercise and/or irritant exposure, or improved by the use of bronchodilators. All patients had intrathoracis adenopathy, and six (23%) had extrathoracis disease, involving the spleen, abdominal and pelvic lymph nodes, bone, joint, skin, and, in one case, hematuria.

Half the patients were identified within the first year following exposure, indicating an annual incidence rate of 86 per 1000. The remaining 13 patients were identified within the second to fifth year after 9/11, showing an annual incidence rate of 22 per 1000.

The average annual incidence rate of sarcoidosis among firefighters during the 15 years before the World Trade Center attacks was 15/1000, and among controls (rescue personnel with out exposure to fire conditions) the rate was 12.9/1000

www.elaine-morre.com www.suite101.com

Celiac Disease

by Kristi Anderson

This past January, the Portland Oregon Sarcoidosis support group was honored to have guest speaker, Nadin Grzeskowiak, RN CEN, founder of GlutenfreeRN.
I was very surprised to receive a phone call from Katy McHenry, asking if Nadine could come and speak to our group about gluten intolerance/celiac disease because it is extremely unusual to be approached by people to speak to our groups. We quickly set the date for her to come.

Celiac disease is a typical autoimmune disease in that it is attributed to genetics and environment. It is chronic and multi-systemic. Some frequent symptoms are: bloating/gas/ abdominal pain, bulky or loose stools, diarrhea or constipation, fatigue, anemia, itchy skin rash, tingling or numbness in hands and feet, discolored teeth or loss of enamel, canker sores, joint pain, irritability or behavior changes, significant unexplained weight loss, poor weight gain, delayed growth in children, migraines, missed menstrual periods, fractures or thin bones. Symptoms can affect people differently from children to seniors.

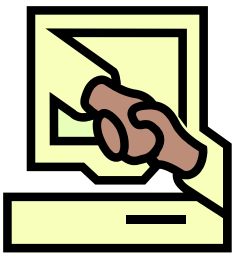
Some atypical symptoms Nadine mentioned were neurological, cardiac problems, respiratory problems and psychiatric issues. 40—60% of people with CD say they have no symptoms or that their symptoms vary. It can flair with stress or illness. When people with Celiac Disease (CD) eat foods that contain gluten, "it creates immune-mediated toxic reaction that causes damage to the small intestine. It does not allow food to be properly absorbed." (The Celiac Disease Foundation) Some of the tests done to support a diagnosis are: Total IgA, Iga antissue transglutamimase (tTG), IgA antiedomysial antibody immunoflurescence (EMA).

Many of the symptoms of CD may sound like other autoimmune diseases which can make diagnosis complicated, however, several of the support group members were able to relate to the symptoms and more were willing to try to go gluten-free for a time as a self test.

If you look in any store, you will find more and more gluten-free foods, however once you start looking it is amazing the scope of foods that have gluten in them. According to a pamphlet Nadine gave us from the Celica Disease Foundation, Gluten is the generic name for certain types of proteins contained in common cereal grains, wheat, barley, rye and their derivatives.

Foods such as soy sauce, some medications, soup bases, self basting poultry, imitation bacon, syrup, beer, malt vinegar and lunch meats can contain gluten; even the glue on back of stamps. Some foods to avoid if you are diagnosed with CD are barley, rye, triticale, wheat (durum, graham, kamut, semolina, spelt), malt and malt flavorings. Often people with CD can tolerate oats.

A key to keeping gluten-free is to read labels and to remember that just eliminating wheat from your diet doesn't mean you are gluten-free. I found it interesting to find that even though a restaurant advertises a gluten-free menu, it is important to ask of they prepare the food on a separate grill and preparation area. Many people are so gluten sensitive that just a utensil or cutting board used with gluten foods can make them sick. Don't be afraid to ask your waiter or chef



A BIG THANK YOU TO OUR CONTRIBUTING GUESTS:

Kristi Anderson

Elaine Moore

"Three grand essentials to happiness in this life are something to do, something to love, and something to hope

Symptoms

Symptoms of Sarcoidosis:

- Fever, sweats, chills
- Enlarged lymph nodes
- Shortness of breath, cough, wheezing
- Chest pain
- Skin rash, tiny red nodules
- Joint pain and swelling
- Visual disturbances with redness of the eye and pain
- Seizures

For more information on Sarcoidosis, contact:

Sarcoidosis Networking Association
5302 S Sheridan Ave
Tacoma, Washington
98408-3535

Phone: 253-826-7737
www.sarcoidosisnetwork.org

Pain nourishes courage. You can't be brave if you've only had wonderful things happen to you.

-- Mary Tyler Moore (1937-)
American Actress

Celica Disease by Kristi Anderson

You may ask, "what can I eat?" Some foods that are gluten-free are fruit, Vegetables, plain meat, fish, beans, nuts, rice, corn, potatoes, safe grains and Dairy products. There are also gluten-free bread and pastries.

As you can tell, this can be difficult to sort out on your won. If you suspect you have an intolerance to gluten, speak to your doctor, however, this is something you can try just be eliminating gluten from your diet for a time and see if there is a difference.

Some websites to learn more:

www.GlutenFreeRN.com This is Nadine Grzeskowiak's website. She spent years suffering with CD before being diagnosed and has the unique perspective of being both a patient and an expert on education on CD. She can also be reached at: 514-602-1065

www.celica.org This is the Gluten Disease Foundation in Studio City, California. The phone number is: 818-990-2379

www.gluten.net This is the Gluten Intolerance Group in Auburn Washington. There number is: 253-833-6655

www.DOIHaveCelica.org The National Foundation for Celica Awareness in Ambler Pennsylvania. There number is: 215-325-1306

www.desertessencorganics.com Nadine recommended this site as a place to find shampoos, ect that are gluten-free.

On March 14, 2011, Nadine spoke at the Washington Sarcoidosis support group. You can see pictures from this meeting by going to:

www.pugetsoundblogs.com/copd-and-other-stuff/tag/lung-disease

The same week we had our support meeting, Dr OZ had a program on gluten intolerance in America. To view the program go to:

www.doctoroz.com

Select video, then diet from the menu, there will be 3 part program video on gluten-free diet. The site also has articles and recipes.

Network for the Good

Last August, I came across at web site that gave free classes to Non-Profits on a wide range of subjects. **Network for the Good** also offered a way that people could donate to Sarcoidosis Networking Association by using credit cards. This had be something that people have been requesting for several years.

We have filled out all the paper work and are now ready to accept donation thru Network for the Good. Go to **www.networkforthegood.com** and under donations enter our name, fill out the paper work and within 30 days, we receive a check . It is simple, quick and convenient.

Study: Your shower can be a dangerous place

11:14 AM PDT on Tuesday, September 15, 2009

Associated Press

WASHINGTON, D.C. - In what may be the scariest shower news since Alfred Hitchcock's "Psycho," a study says showerheads can harbor tiny bacteria that come spraying into your face when you wash.

People with normal immune systems have little to fear, but these microbes could be a concern for folks with cystic fibrosis or AIDS, people who are undergoing cancer treatment or those who have had a recent organ transplant.

Researchers at the University of Colorado tested 45 showers in five states as part of a larger study of the microbiology of air and water in homes, schools and public buildings. They report their shower findings in Tuesday's edition of Proceedings of the National Academy of Sciences.

In general, is it dangerous to take showers? "Probably not, if your immune system is not compromised in some way," lead author Norman R. Pace says. "But it's like anything else — there is a risk associated with it."

The researchers offer suggestions for the wary, such as getting all-metal showerheads, which microbes have a harder time clinging to. Still, showerheads are full of nooks and crannies, making them hard to clean, the researchers note, and the microbes come back even after treatment with bleach.

People who have filtered showerheads could replace the filter weekly, added co-author Laura K. Baumgartner. And, she said, baths don't splash microbes into the air as much as showers, which blast them into easily inhaled aerosol form.

It doesn't seem as frightening as the famous murder-in-the-shower scene in Hitchcock's classic 1960 movie. But it's something to be reckoned with all the same. The bugs in question are Mycobacterium avium, which have been linked to lung disease in some people.

Indeed, studies by the National Jewish Hospital in Denver suggest increases in pulmonary infections in the United States in recent decades from species like M. avium may be linked to people taking more showers and fewer baths, according to Pace.

Symptoms of infection can include tiredness, a persistent, dry cough, shortness of breath, weakness and "generally feeling bad," he said.

Showerheads were sampled at houses, apartment buildings and public places in New York, Illinois, Colorado, Tennessee and North Dakota.

The researchers sampled water flowing from the showerheads, then removed them, swabbed the interiors of the devices and separately sampled water flowing from the pipes without the showerheads.

By studying the DNA of the samples they were able to determine which bacteria were present. They found that the bacteria tended to build up in the showerhead, where they were much more common than in the incoming feed water.

Most of the water samples came from municipal water systems in cities such as New York and Denver, but the team also looked at showerheads in four rural homes supplied by private wells. No M. avium were found in those showerheads, though some other bacteria were.

In previous work, the same research team has found M. avium in soap scum on vinyl shower curtains and above the water surface of warm therapy pools.

And stay tuned. Other studies under way by Pace's team include analyses of air in New York subways, hospital waiting rooms, office buildings and homeless shelters.

The research was funded by the Alfred P. Sloan Foundation and the National Institute of Occupational Safety and Health.

Virginia Tech microbiologist Joseph O. Falkinham welcomed the findings, saying M. avium can be a danger because in a shower "the organism is aerosolized where you can inhale it."

In addition to people with weakened immune systems, Falkinham also cited studies showing increased M. avium infections in slender, elderly people who have a single gene for cystic fibrosis, but not the disease itself.

Two copies of the gene are needed to get cystic fibrosis, but having just one copy may result in increased vulnerability to M. avium infection as people age, said Falkinham, who was not part of Pace's research team.

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You don't get to choose how you're going to die.
Or when.
You can only decide how you're going to live.
Now.

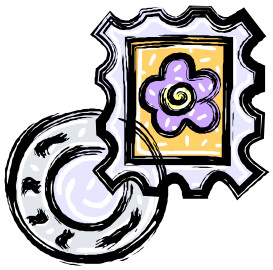
-- Joan Baez

HELP US SAVE POSTAGE COSTS?

Returned newsletters are costing SNA double fees. We pay to mail the newsletters and the post office returns all mail not deliverable and charges us an additional first class mail price of 44 cents for each piece. With the costs of everything going up and donations going down, SNA has a very limited budget.

Please mail, e-mail, or phone in your change of address. Let us know if you are going to be temporarily away so we can hold off sending you the newsletter. This will help us keep costs down and will let us mail more information packages to those who request them.

If you would prefer, we can also send your copy of the newsletter by e-mail. Please let us know.



Wednesday, March 16, 2011 Mark Lassiter, Press Officer

Social Security Holds Compassionate Allowances Hearing on Autoimmune Diseases

Michael J Astrue, Commissioner of Social Security, today hosted the agency's seventh public hearing on Compassionate Allowances. Commissioner Astrue joined Robert H Carter, Deputy Director, National Institute of Arthritis and Musculoskeletal and Skin Disease, National Institutes of Health, and other Social Security officials in hearing testimony from some of the nation's leading experts on autoimmune diseases about the possible methods of identifying and implementing Compassionate Allowances for adult and children with autoimmune diseases.

"Over 29 million Americans suffer from autoimmune conditions, which particularly affect women and children, " Commissioner Astrue said. "The social and financial burdens imposed by these chronic, debilitating diseases for individuals and their families. With this hearing, we are searching for objective medical evidence and decision rules that we can use to expedite cases for those with the most severe conditions and quickly provide them with some measure of financial security."

Social Security implemented Compassionate Allowances in October 2008 to expedite the processing the of disability claims for applicants with medical conditions so severe that their condition by definition meet Social Security's standards. Currently, 88 specific diseases and conditions qualify as a Compassionate Allowance.

To learn more and to view a web cast of this hearing go to:
www.socialsecurity.gov/compassionateallowances.

"Last year, the Compassionate Allowances initiative, along with our Quick Disability Determination process, allowed us to quickly approve over 100,000 disability applications for the most severely disabled Americans," said Commissioner Astrue. "This year we expect to increase the number of fast-track cases to about 150,000. We also plan to expand our list of Compassionate Allowance

2011 17th Sarcoidosis Networking Association Health Conference

The Board of Directors of the Sarcoidosis Networking Association is pleased to announce the 17th annual Health Conference on Sarcoidosis will be held on **October 8th, 2011** at OHSU Hospital in Portland, Oregon, in the Vollum Conference room.

The Board is in the process of inviting speakers and planning the form of the conference. When we are further along in the process, we will release more information.

Please keep **Saturday, October 8th, 2011** open to attend our conference..

NOTES FROM THE DIRECTOR

Lynn F. Short, Executive Director

Thank you for your response to our Fall Fund Raiser Drive. This money makes up a major portion of our yearly budget. As our fundraiser letter stated, this money pays for the Web site's fees, the newsletter, and phone bills. I hope you enjoyed the small gifts that were included in our thank you letters this year**.**

I am sad to let you know that Gloria Hooten is no longer working in the office because of on going complications of her sarcoidosis. Also Mary Prior has resigned as newsletter editor to move to Arizona to be near her son. Both will be missed here at the office.

In January 2011, SNA gave up its outside office and moved SNA back to my home. I run the SNA from a room in my basement. Since I am the only one in the office these days, things will be going at a little slower pace. I ask your patience with this change.

On May 23rd and 24th, Kristi Anderson will be in Washington DC to attend The PIO Conference . This is an invitation only conference put on by the NIH. Each year, NIH pays for our flight, hotel and meals. We meet with other auto-immune groups to give our views on current health problems and find out what new drugs are being researched. The NIH also listens to our suggestion about on going research into sarcoidosis and other autoimmune diseases.

After the 2 day conference is over, Kristi will then visit the members of Congress to present your information and concerns.

WEBSITES FOR SARCOIDOSIS RESEARCH

www.sarcoidosisnetwork.org
www.snaregistry.org
www.sarcoidcenter.com
www.rarediease.org
www.nih.gov
www.sarcoidosisonlinesites.com
www.nationaljewish.org/medfacts/sarcoid.html
www.sharmasarcoidosis.com/pages/1/index.htm
http://groups.msn.com/sarcoidbuddies
www.sarcoidlife.org
www.nim.nih.gov/medlineplus/tutorials/sarcoidosis/htm/index/htm
www.jsof.org
www.stopsarcoidosis.org
www.thoracic.org
http://rarediseases.info.nih.gov

Registry Online

The Sarcoidosis Registry is online: www.snaregistry.org. An improved, easier to download version is now available. We have received a large number of responses to the site and are preparing a follow-up for those who have already responded, as the original questions generated a need for more information.

To contact Registry Director Kristi Anderson about the Registry,

E-mail: admin@snaregistry.org

Phone: 541-905-2092.

Thanks to all who have responded. When we work together, we do make a difference!

I find that it is not the circumstances in which we are placed, but the spirit in which we face them, that constitutes our comfort.

-- Elizabeth T. King

No two snowflakes are identical and no two individuals with Sarcoidosis appear to have identical symptoms. Therefore, snowflakes have been chosen to symbolize Sarcoidosis.

Office Hours: *10 AM to 4 PM*
Tuesday, Wednesday & Thursday
Pacific Standard Time

253-826-7737

E-mail:
sarcoidinformation@
sarcoidosisnetwork.org

SNA Website
www.sarcoidosisnetwork.org

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WHAT'S SARCOIDOSIS NETWORKING ABOUT ???

The newsletter ***SARCOIDOSIS NETWORKING*** is published by the Sarcoid Networking Association for individuals with Sarcoidosis and those interested in this disease. Its sole purpose has been to heighten awareness and form a network with each other, the medical community and the general public.

It is not intended to replace the advice and/or diagnoses by health-care professionals.

You are advised to seek proper medical attention whenever a health problem arises requiring an expert's attention.