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National Patient Support Group Listings

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L.E.A.P.
Arizona
IDSA Review Panel Lines
Final Report on Lyme Guidelines

The Infectious Diseases Society of America (IDSA) Lyme Disease Review Panel issued its Final Report on Lyme disease. This was the result of an April 30, 2008 Agreement made between the IDSA and Connecticut Attorney General Richard Blumenthal. The Agreement was the result of an antitrust investigation initiated by the Connecticut AG in 2006. AG Blumenthal stated the following in his May 1, 2008 Press Release:

“The IDSA’s 2006 Lyme disease guideline panel undercut its credibility by allowing individuals with financial interests -- in drug tests -- to participate in Lyme disease diagnostic tests, patents and consulting arrangements with insurance companies, to avoid and exclude divergent medical evidence and opinions. In today’s healthcare system, clinical practice guidelines have tremendous influence on the marketing of Lyme disease products, insurance reimbursement and treatment decisions. As a result, medical societies that publish such guidelines have a legal and moral duty to use exacting safeguards and scientific standards.”

The Action Plan of the Agreement called for an independent panel to review medical research, along with test guidelines, which were held on July 30, 2009 in Washington, D.C. The IDSA made a number of recommendations for revision, voted that those revisions not be applied to the current Guidelines. Lyme disease patients and Lyme-treating physicians question why the Panel did, indeed, make recommendations for revisions, but voted that those revisions not be applied to the current Guidelines. Lyme disease patients and Lyme-treating physicians were not consulted about the recommendations, however, will not be included in the Guidelines right now and Garcia contends that the delays in revising the Guidelines constitutes medical neglect.

The truth about the IDSA Guidelines is that they accommodate some of the Guidelines: Recommendations for revision with the CDC in the development of a Lyme disease vaccine. It would take years and years for vaccine clinical trials to be conducted if those developing the vaccines acknowledged that Lyme disease is treatable, not fatal. Antitrust Cases in the past have shown that vaccine recipients have not been treated properly, or that vaccine recipients’ cases are being disregarded.

From left to right: Commanders John W. Sanders, M.D., Gerald Medoff, M.D., Manuel H. More, M.P.H., Ph.D., Dr. Paul Lantos, Dr. Carol Baker, Jeffrey Parmetted, M.D., Paul Hurwitz, M.D., retired, David M. Mushatt, M.D., M.P.H., T.M., William A. Charini, M.D.

Publication Alert

Investigating Lyme Disease & Chronic Illnesses in the USA

July 2010

Infectious Diseases Society of America

Guidelines for FREE

at the PHA Website!

Waking Up the Nation,
Burrascano’s Lyme
Vol. 5, Issue 7

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This Disease Called Lyme

by Ashley van Tol

When I tell someone about my illness, I call it Lyme disease. However, borrelia burgdorferi is only one small part of that illness. My definition of Lyme disease is something much bigger. Lyme, in itself, was the catalyst that opened the door and invited the rest of my disease to come out to play.

For me Lyme is the large branching tree of every branch: borrelia burgdorferi, bartonella, erlichia, babesia, HHV6, CMV, EBV, parasites, amebias, thyroid imbalance, hormonal imbalance, candida, heavy metals, food sensitivities, the list goes on. I don’t differentiate, I call it Lyme. The reality is though, it is not all Lyme. Lyme is really only borrelia burgdorferi.

I often wonder how much confusion this causes. Many people write online about how angry they are that their doctor has told them they are now suffering from X not Lyme. They are angry because they are still sick. Of course they are still sick. They most likely had more than just Lyme, borrelia burgdorferi, to start with.

When the laundry list of diseases is as long as most of ours are, getting rid of one infection, even if it is borrelia burgdorferi, is not going to make us well. It is only one step in this long process.

Even the IDSA says that one of the reasons that some of us remain symptomatic is that we had Lyme disease and another infection simultaneously and were only treated for Lyme disease. Each co-infection is, in fact, a different infection. Putting aside all the monetary interests involved with the IDSA and Lyme disease, are they in part arguing semantics? Or are we, for that matter? While I believe the IDSA guidelines to be flawed and most definitely not in the interest of the ill, I have to admit that Lyme would not be nearly as hard to treat if it was only borrelia burgdorferi.

I suppose I would even go so far as to say that if you saw the right doctor, and if you were diagnosed right away, and if you only had borrelia burgdorferi, then Lyme would be easy to diagnose and easy to treat with a short course of antibiotics. That is a far too many ifs for me. It may be the exception, but it is most definitely not the rule. I don’t believe that the majority of us are talking about when we say Lyme. We have it, yes, but it is only the trunk, not the whole tree of our illness.

If you had noticed the small sapling growing, unwanted, in your garden early on, you may have been able to simply pluck it out by hand. Now though, with the size of the tree and the span of it’s branches, you are very likely going to need a tree trimmer and a bulldozer to get to the root of the problem.

Texas Lyme Disease Association
www.txlda.org

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A 37x58 transmission and dopamine enhances long-term synaptic to the effects of many drugs.²

pressing it, completely contrary to the immune system rather than suppression, stimulating the immune system while relieving the symptoms caused by the bee venom, because it's all a personal choice. That is offered many different possibilities, less is more, so I started looking for something I could live with, something I could tolerate. I did that. So I decided to look into something more natural. I found several places in New Zealand where one can make a honey with the help of a bee venom. The honey is taken from the manuka tree which is indigenous to New Zealand. This honey has its own special properties. One teaspoon of the honey has one bee sting in it, and that is something I could live with, I will say. You can say from personal use, for me, the manuka honey with bee venom does work really well. I am mentally sharper and I can think clearly now. I can be playful. I do realize that I could become allergic to the venom at any point, so I keep track of how and when I use it. I do know several people who use bee venom creams and apply it to their arthritic joints, and they say it works wonders! I have yet to use the cream, but I am betting it works great too.

After several months of using the honey, I had questions about the study I read some months before, so I con- tacted Lori Lubke. She generously granted me an interview and it is as follows:

Q. How long have you worked for the NIH?
A. 27 years this April [1982 to present]

Q. What made you go into research?
A. I was pursuing a pre-med course of study first at the University of Arizona in Tucson, and then at Washington University in Saint Louis, Mo. Both universities have an excellent support system for minority students. I am one 1997: I was assigned to a microscopy lab under the direc-
tion of Dr. Claude Garon, an electron microscopist from the Bethesda NIH campus. I completed two summer internships in that laboratory, and subsequently applied for a full-time microbiologist position in Dr. Garon’s department, where I stayed for 20 years. When Dr. Garon retired, some of us in the microscopy lab department were given the option to trans- fer to a new laboratory at RML and I was ready for a change, and I was introduced to the color- ful world of histology and electron-microscopy analyz- ing of infected animal tissue samples.

Q. What are your scientific cre- dentials, i.e. degrees, etc.?
A. I have my Bachelor of Science degree in zoology and a minor in psychology.

Q. What department do you work in now, and what depart- ment did you work in when you did the Melittin/Lyme Borrelia study?
A. I currently work in the Laboratory of Persistent Viral Diseases [LPVD], specifically in the Histopathology lab, [National Institute of Health [NIH], Rocky Mountain Laboratories [RML], Hamilton, Montana]. At the time of the project, I worked in the Electron Microscopy section of the Laboratory of Bacterial Pathogenesis, RML/NIAID/NH.

Q. Did you always want to be a scientist?
A. When I went to college, I knew more of what I didn’t want to do than exactly what I did want to do. However, I knew that I had drawn to a career in animal and human biology. I was fortunate enough to be asked to complete two back to back summer internships in any given research project as an ever-evolving story about a disease and its main characters - often a bacterium or virus or mystical protein such as a prion, and their roles in the cellular world, inside their host tis- sue of choice. The length of time it takes to unravel the complete story of a disease at the molecular level can take years, and progress can be much more meaningful, if one takes the time to express, or reflect. In general, the current story is un- tangible.

Interviewer: Take us back to 1997.

Q. How did you come about doing the Lyme Borrelia study?
A. Our laboratory was one of several combined units on the Rocky Mountain Laboratories campus studying the bacterial pathology of Borrelia burgdorferi, that causes Lyme Disease. In fact, the bacterial agent was discovered by Dr. Willy Burgdorfer in the early 1980s. Lyme ticks by the way are endemic to our area in western Montana. We were challenged in the microscopy lab with literally ‘focusing’ - often a bacterium or virus or mystical protein such as a prion, and their roles in the cellular world, inside their host tissue of choice. The length of time it takes to unravel the complete story of a disease at the molecular level can take years, and progress can be much more meaningful, if one takes the time to express, or reflect. In general, the current story is un-tangible.

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inhibitor? No other components
others to take the findings fur-
ular and biological basis of the
therapeutic measures - our mis-
the study did not proceed to
modes of attack going on at
host chemicals and immune
the body reacting and calling in
spirochetes. Inflammation at a
chance to find and bind to the
molecules before they have a
chemicals at a given skin site
change their form and surface
dence that the spirochetes
of interest where symptoms and
fluid/cerebral spinal fluid - sites
short time, and then it is very
the tick bite area for a relatively
imagine that is the thinking
A. I really have no idea. I
rect amount?
A. Yes - Mellitin molecules
something to that effect?
A. To be honest, I did not per-
Q. Did you take photos of the
A. Yes, in the paper cited, see
Q. Do you have any recommen-
ditions?
A. Perhaps to make bee stings
less painful? But as the saying
goes, no pain no gain! Also, use
the correct term: Lyme Disease,
not Lymes Disease. It always
'bugs' me when I hear people
say that!

It "bugs" many of us too, Ms. Lubke! You would be
surprised just how many people do say that. I would like
to publicly thank you for publish-
ing such findings and granting
me an interview. I was hoping
that by highlighting your study,
showing that mellitin does
work to eradicate the spiro-
chete, some of the other
researchers out there would take
interest and do some more studies
using mellitin. As just about everyone
knows, natural is always better.

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Honeybee, p. 46; Queen City
Publications, 1993
¹ Lubke LL, Telephone inter-
view, March 2009

Q. Do you have any recommend-
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less painful? But as the saying
goes, no pain no gain! Also, use
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not Lymes Disease. It always
'bugs' me when I hear people
say that!

It "bugs" many of us too, Ms. Lubke! You would be
surprised just how many people do say that. I would like
to publicly thank you for publish-
ing such findings and granting
me an interview. I was hoping
that by highlighting your study,
showing that mellitin does
work to eradicate the spiro-
chete, some of the other
researchers out there would take
interest and do some more studies
using mellitin. As just about everyone
knows, natural is always better.

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Neurasthenia: An Old Name for Chronic Lyme disease

by M.M. Drymon

Lyme disease appears to be an ancient and ubiquitous affliction that humans have been coping with for eons. It can be argued that, using the tools available to a society within a historical culture or social paradigm, people labeled and understood neurasthenia as a form of a variety of ailments. These may have included the sicknesses associated with witches and witchcraft during the Early Modern Era, neurasthenia, the summer sickness, the currently popular fibromyalgia, and neurasthenia-an ill-defined disease that was often diagnosed in the late 19th and early 20th centuries.

The core symptoms of neurasthenia were excessive physical and mental fatigue and muscle weakness. Common features included insomnia, depression, fears and irritability, headache, sweating, paresthesias, tinnitus, vertigo, photophobia, easy exhaustion at the slightest effort, inability to sweat, constipation, frequent colds, and neurasthenia- an ill defined disease in the past. How did people with neurasthenia fare in the past? The answer is none too well. They were sometimes subjected to ridicule and their fabulous theories, pauper charity drug promotion campaigns, derision, and the occasion boast of electric shock therapy. So many labor in this guised period that they were common in every corner of the world as an American trope consider Edith Wharton's cranky wife characters in many novels and Fanny Foreve, with vague symptoms chasing after innumerable doctors, looking for help. Seem to be an ancient and ubiquitous disease that humans have been coping with for eons.
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Military Lyme Disease Support

Military Lyme Disease Support is an online source of information and emotional support. This site is for Military Members, Veterans, and their family members who suffer from Lyme and other vector-borne diseases. Members are stationed in the United States and abroad.

http://health.groups.yahoo.com/group/MilitaryLyme/

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Dallas - Fort Worth Lyme Support Group
Monthly Meetings:
2nd Saturday each month 2-4 p.m.

Harris Methodist Hospital- HEB
1600 Hospital Parkway
Bedford, TX 76022-6913
We meet in the left wing when facing the front of the building.

Contact our group leaders for more information:
Rick Houle, email: Pedler3710@aol.com
Home: 972.263.6158 or Cell: 214.957.7107
John Quinn
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I don't walk fast. I just plod along lost in another world. I feel great too. Well, you know, as great as a Lymie can feel. My energy is definitely getting better.

Currently walking is the only exercise I am getting. Although I got my Far Infrared FIR Portable Sauna a few days ago. It has been reported that a 30 minute far infrared sauna can be as advantageous to the cardiovascular system as a 4 mile run. NASA has even used far infrared for cardiac condition. I'm going to be fit before I know it.

I've got a couple of other tips/ideas for getting fit on an exercise routine. I'm not a doctor so be sure to check with yours before starting any type of exercise. Seriously, my doctor wasn't too impressed with yours before starting any type of exercise. Seriously, my doctor wasn't too impressed with yours before starting any type of exercise. Seriously, my doctor wasn't too impressed with yours before starting any type of exercise.

I and our groups failed him. He should have taken Allen to a physician or hospital right away recently at University Hospitals in Madison, Wisconsin. Allen suffered terrible intestinal distress along with Lyme disease. He died from a perforated bowel, the result of a diagnostic procedure to find the cause of his mortal pain. Allen was diagnosed just before his death with Crohn's disease. Lyme is often a contributing factor of Crohn's disease:

http://thehumansideoflyme.net/ viewstory.php?tag=547369
http://www.coolyme.com/crohns_2%27s.html

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Public Health Alert

Immune • Energy • Gut

Due to the efficacy and the science behind the products, these are my favorites - Joseph J. Bursacano Jr. M.D.

Immune System Front Line Support
Most of our patients’ immune systems are very weak. In order to provide the nutritional support for a healthy immune system, I recommend Transfer Factor Multi-Immune™. These folks have put a lot of thought into developing a product which promotes healthy natural killer cell function. The combination of transfer factor and the herbal and nutritional base make this an extremely effective product.

Mitochondrial Support
One of the most common complaints among our patients is lack of energy. I became intrigued with NT Factor Energy™ during a medical conference presentation which showed a 40% reduction in fatigue in eight weeks(1). When I tested my patients on this product, they reported a noticeable improvement in energy. The product’s success is due to its ability to deliver a stabilized and absorbable phospholipid complex to promote healthy mitochondrial membrane potential.

Probiotic Support
Prescript-Assist Pro™ is clearly a step above what has been generally available, and I highly recommend it. If you do not have enough good gut flora then you may not only develop GI upset and bad flora overgrowth, but you may also develop food allergies and other ugly stuff. There is nothing more important than a good probiotic. This product was developed to assist you if you are taking antibiotics.

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*These statements have not been evaluated by the Food and Drug Administration. These products are not intended to diagnose, treat, cure or prevent any disease.

ABOUT THE COMPANY

Nutramedix was founded in 1993 and currently has facilities in Jupiter, Florida, USA and in Shannon, Ireland supplying highly bio-active nutritional supplements to health care professionals and consumers.

From the beginning, Nutramedix has operated with a unique business model. First, the owners and management work diligently to operate a company according to Biblical principles— with honesty, integrity, value and respect for all people. Its corporate environment is one that works to serve both its customers and its employees, producing one the best customer service teams in the industry. Second, Nutramedix was founded with the goal of using a significant amount of its proceeds to support orphans, widows, Christian pastors and missionaries in economically distressed parts of the world. So as a customer, you are not just purchasing high quality nutritional supplements, you are helping us give back to people in need all around the globe.

ABOUT THE PRODUCTS

Nutramedix has made a significant investment to develop a novel, proprietary extraction and enhancement process used to manufacture its liquid extracts. The result is a highly bio-available whole plant, broad-spectrum extract that is also very cost effective. We were the first to introduce Samento, a rare chemo-type of Cat’s Claw, which has remained one of our signature products. We have since developed a full line of liquid extracts utilizing the same proprietary extraction and enhancement process.

Nutramedix also conducts extensive research to procure the very highest quality raw materials for its powdered capsule products, many of which have been designed to enhance the effectiveness of the liquid extracts. We are committed expanding our line of natural products meeting the highest expectations of health care professionals and consumers.

ABOUT THE FOUNDATION

The owners of Nutramedix have been involved in international Christian ministry since the 1980s. Prior to starting the company in 1993, our Founder and President was a missionary pilot serving tribal groups in Peru. The Kairos Foundation was created in 1995 to fund projects that address both the physical and spiritual needs of people in some of the most disadvantaged areas of the world. The foundation provides ongoing financial support for organizations operating in Africa, Asia, Eastern Europe, North America and South America.