

Waking Up the Nation,
One Reader at a Time...

PUBLIC HEALTH ALERT

Misleading Language Perpetuates Lyme Dilemma



by Tina J. Garcia

Since I became involved in Lyme disease (Borreliosis) patient advocacy in 2005, I have read numerous, consistently misleading references set forth in articles, quotes and on the CDC website. It is apparent to me that such language is used craftily to minimize the numbers of patients suffering from *Borrelia burgdorferi* (Lyme disease) infection. The language also serves to mitigate the degree of damage caused by this virulent, debilitating, Level II biowarfare agent.

Some of the words I am referring to are "some", "a few" and "Post Lyme Syndrome." One will notice these words used repeatedly by members of the Lyme

Medical Cartel, the Infectious Diseases Society of America (IDSA) and the Centers for Disease Control and Prevention (CDC).

In a recent article published in *Nature News* entitled *Antibodies linked to long-term Lyme symptoms*, this crafty language appears to have been utilized by the author, Amy Maxmen, to skew the reader's perceptions of Borreliosis, an infectious disease that has already been scientifically proven to persist in the body following antibiotic treatment. In quotes are some examples from Ms. Maxmen's article, underlined and in bold to delineate the language in question that is effectively used to alter a reader's understanding of the nature of this infectious disease.

Ms. Maxmen's article may currently be found at this link: www.nature.com/news/2011/110805/full/news.2011.463.html

Quote: "Now Armin Alaedini at Weill Cornell Medical College in New York and his colleagues have found that patients diagnosed with post-Lyme disease syndrome have antibodies that suggest they carried the infection for an unusually long time. The finding, published in *Clinical Immunology*¹, might help the

syndrome to be better understood, diagnosed and treated."

Comment: According to Ms. Maxmen, Dr. Alaedini referred to patients with continued Lyme symptoms and suffering when he stated that the results of his research could mean that patients naturally have a different antibody response to the infection than most people. He said it could also mean the patients weren't treated properly or that they were reinfected and never treated a second time. *The results of the study suggest that those with chronic symptoms actually experience prolonged infection.* The cause is the bacteria's ability to evade the immune system by changing an aspect of its surface protein. This is known as antigenic variation, and the immune system responds by creating new antibodies to attack the modified bacteria. The immune system is in an ongoing battle that results in persistent inflammation along with the persistent infection.

Years ago, Lyme disease researcher and Biowarfare Lab Director, Dr. Alan Barbour, published research on the antigenic variation of *Borrelia burgdorferi*. Lyme disease is similar to relapsing fever, another tick-borne disease. This is estab-

lished science that infectious disease physicians should be utilizing readily. However, this medical information is not readily disseminated in the information available to mainline physicians, who could take such important scientific research into consideration when diagnosing and treating patients.

So, if existing and new research has established that Lyme disease is a persistent infection, why do the Lyme Medical Cartel and journalists still refer to it as Post Lyme Syndrome? They infer that the Lyme bacterium has been eliminated by antibiotic treatment, yet that is not the case. Following treatment the bacteria still reside in the host and change aspects of their surface proteins to confuse the immune system. No wonder Lyme patients who have disseminated and embedded infection need repeated courses of antibiotics to maintain function! To complicate matters, many with Lyme also contracted other co-infections from the same tick bite, and those infections must be treated at the same time. Antibiotics increase fungal infection in the body, so that complicates the picture even further. Yet, the Lyme Medical Cartel, and even Ms. Maxmen, trivialize this dire

PUBLIC HEALTH ALERT

medical scenario by inferring that the underlying cause of symptoms may be chronic fatigue or depression. Truthfully, the majority of Lyme patients do have chronic fatigue and depression, but these are from the invasion of the muscles, nerves and brain by the pathogen that causes it, not the other way around.

Quote: "Some patients with Lyme disease still show symptoms long after their treatment has finished. Now proteins have been discovered that set these people apart from those who are easily cured."

Comment: "Some" is a misleading word, as the numbers of people who have been treated successfully for acute Lyme disease should not be grouped together with those who have gone undiagnosed and untreated for months to years. The latter group is a group of individuals who have disseminated and embedded infection in their tissues and organs due to lack of timely diagnosis and treatment, and these patients are the group that is the subject of the research referenced by Ms. Maxmen. Comparing these two groups - acute and chronic - is similar to comparing apples and oranges, and it is imperative that this distinction be made when referencing research studies and case histories. Patients who have long-term symptoms and who are the subjects of this study are actually the majority of or a whole group of people who have gone undiagnosed and untreated for prolonged periods of time. In other words, Ms. Maxmen smudges the line between those who suffer with chronic Lyme infection and those who resolved acute infection.

Quote: "People who experience the symptoms of Lyme disease, which include fatigue, soreness and memory or concentration loss, after treatment for the disorder are sometimes diagnosed as having chronic Lyme disease or post-Lyme disease syndrome."

Comments: As a patient who has suffered from this Level II debilitating biowarfare agent infection for more than twelve years, my experience with Lyme Borreliosis has not been one of "soreness." The correct term for the sensations I have felt for so many years, and continue to feel, would be "excruciating pain." It appears that the word "soreness" is used in Maxmen's article to minimize the suffering experienced by Lyme patients.

The word "disorder" is a step down on the ladder from the higher-rung word "disease." Therefore, referring to Borreliosis as a disorder also serves to mitigate the seriousness of the infection.

"Sometimes diagnosed" is inaccurate, also, as it paints a picture of only a few patients from a larger group that are diagnosed with chronic Lyme disease, when in actuality, patients who primarily present to physicians specializing in chronic, infectious Lyme disease are in the chronic, tertiary stage of infection, as in neurosyphilis.

The term "post Lyme disease syndrome" also infers that patients with disseminated and embedded infection are infection-free the moment antibiotic therapy is discontinued. That is an absurd conclusion that has no biologic plausibility and is not based upon scientific fact. It is merely an opinion that has been circulated in media articles and med-

ical journals. Unfortunately, it has become a buzz word that is accepted by the media and medical journals as having been proven scientifically, when it is really a personal agenda-promoting term disseminated by the Lyme Medical Cartel.

The truth is that patients are not diagnosed with "post-Lyme disease syndrome" by physicians who actually treat patients with disseminated and embedded Lyme disease. The only physicians who MISdiagnose "Post Lyme Syndrome" are members of the Lyme Medical Cartel, who refuse to provide effective antibiotic therapy to those who suffer from disseminated and embedded Lyme infection.

What would society say if physicians refused to provide additional treatment to cancer patients who relapsed, and instead, diagnosed them instead with "Post Cancer Syndrome?"

Quote: "But these diagnoses are difficult to make, because the individuals no longer seem to harbour the bacteria that cause Lyme disease. And the symptoms could instead be indicative of chronic fatigue syndrome or depression."

Comment: The diagnosis of Borreliosis is not difficult to make by patients and physicians who are familiar with the manifestations of the infection. In fact, it is so simple to diagnose that, once patients are aware of the symptoms, the majority suspect the diagnosis themselves. This suspected self-diagnosis is what leads them to experienced Lyme-treating physicians after being tragically neglected by previous doctors who either (1) hadn't taken

the time to learn about the disease or (2) chose not to get involved with treating Lyme out of valid concern they may be brought before state medical boards for daring to treat patients with chronic Lyme.

"No longer seem to harbour the bacteria" is a baseless statement. Realistically, physicians who treat patients who have disseminated and embedded Bb infection due to lack of diagnosis and treatment for prolonged periods, monitor Bb titer levels and CD57 levels. When infection persists, further treatment is provided. Past published research has amply demonstrated persistence of the spirochete post antibiotic treatment, along with the variant forms of cyst, bleb, granule, etc., as is the case in neurosyphilis. The commonly-referenced National Institutes of Health (NIH) study, known as the Klempner study named after Biowarfare Lab Director Dr. Mark Klempner, was statistically analyzed by Allison Delong at the Center for Statistical Sciences at Brown University. Ms. Delong found the NIH / Klempner study to be seriously flawed. What a surprise!

In its quest to preserve its financial monopoly on Lyme disease research, test kits and other products and vaccine development, the Lyme Medical Cartel insults the patients they claim to serve by completely ignoring the wealth of information that patient case histories could provide in the development of an effective treatment protocol. NIH, CDC and IDSA continue to insist that the treatment protocol they espouse works for patients, despite the fact that patients have testi-

fied that it fails miserably. NIH, CDC and IDSA are well aware of the cries of pain and suffering and pleas for help from individual patients and entire families suffering with Lyme infection, laboratory test results that show persistent infection and testimony from physicians and scientists who work in the trenches of Lyme disease treatment and research. Yet, in all their power and glory, these agencies and individuals continue to blatantly ignore published scientific research and massive patient suffering with the goal of promoting their personal, lucrative, financial agenda. Case histories have demonstrated continued improvement with prolonged courses of antibiotic. Even so, Borreliosis patients desperately need a more comprehensive treatment protocol, but the development of an effective treatment has not conscientiously been pursued by NIH and CDC.

It is obvious that these agencies don't want patients to receive treatment. This scenario is highly reminiscent of the Tuskegee Study of Syphilis (syphilis is a cousin to Lyme disease). The Lyme disease "study" has been ongoing for more than 35 years; the Tuskegee Study lasted 40 years, and was only discontinued when the inhumane abuses of the study were brought to public attention. The Lyme patient community is in desperate need of a media source willing to disclose the abuses we are enduring also.

Lyme-treating physicians do all they can to help their patients by trying various combinations of antibiotics, biofilm busters and immune-boosting supplements, but do so at the risk of being brought

before state medical boards and losing their licenses for doing so.

In the meantime, the Lyme Medical Cartel retains its stronghold on research funding and excels at coaching the mainstream media on the use of key words like "some", "a few" and "Post Lyme Disease Syndrome." These misleading terms help to further disseminate the Cartel's medical disinformation campaign that keeps mainline physicians in the dark about the seriousness of this zoological epidemic.

While on the subject of zoological diseases, I'd like to point out the way in which Lyme disease is referenced by CDC and state health departments. It is referred to as an emerging infectious disease. I've got news - it's not emerging, it's already emerged! And it emerged more than 35 years ago from somewhere, either deliberately or by accident. The fact that *Borrelia burgdorferi* is classified by the American Biological Safety Association in its Risk Group Classification for Infectious Agents as a Level II bioagent, cases are being diagnosed globally, the disease causes Level II debilitating biowarfare symptoms, along with the knowledge that the possibility exists the pathogen emerged from Plum Island biowarfare lab, why isn't the Department of Homeland Security involved? Why are the CDC-run Lyme Medical Cartel and puppet state health departments downplaying the seriousness of this epidemic? With the similarities to the Tuskegee Study of Syphilis and the similar length of time it has been allowed to be ignored, why isn't the United States Public Health Service

involved?

Could it be that these agencies actually are involved, but their involvement has been underestimated?

Quote: "This is the first study I've seen that shows some immunologic difference between someone who resolves their Lyme and someone who develops post-Lyme disease syndrome," says Linda Bockenstedt, a rheumatologist and immunologist at Yale School of Medicine in New Haven, Connecticut. The presence of varied antibodies hints that the chronic symptoms could be caused by an ongoing inflammatory response caused by antibodies mistakenly reacting to the body's own proteins, Bockenstedt suggests.

"The big question to me is whether this can lead to an autoimmune phenomenon," says Bockenstedt. "But if that were the case, I'd expect the disease to worsen without immune-modulating treatment, and it doesn't."

Comment: Dr. Bockenstedt is mixing apples and oranges when she refers to "someone who resolves their Lyme and someone who develops post-Lyme disease syndrome". Those who resolve their Lyme are those who had acute infection and received enough antibiotic therapy to resolve it. Those who have persistent symptoms are those who, once again, have not received diagnosis or treatment for extended periods of time. These patients have disseminated and embedded infections. Due to the fact that Bb can sequester itself in many tissues and organs of the body and is especially known to invade brain/neural cells, there is no way to confirm

patients are infection-free post antibiotic therapy. Needless to say, blood tests are useless to determine this, as the bacteria don't reside in the blood as much as they reside in the tissues.

Therefore, Dr. Bockenstedt (and others who promote the mere opinion that Post Lyme Syndrome is an actual disorder separate from persistent infection) are promoting an assumption and speaking about it as though it is a scientific fact. In their audacity, they would have the medical community believe that every patient who suffers from disseminated and embedded infection (who had remained undiagnosed and untreated for long periods of time) is infection-free at the conclusion of tertiary-stage antibiotic therapy, no matter the length of time the therapy was administered -- short or long term. Such erroneous assumptions have no merit, as brain tissues cannot be tested in patients, until they unfortunately succumb to the devastating effects of Lyme disease. Please bear in mind that debilitating Level II bioweapons, such as Lyme disease, are highly valued for their effectiveness and ability to incapacitate people and cause diagnostic confusion. The horrible symptoms of embedded infection render people incapacitated for years and eventually, of course, do result in death.

It is not scientifically appropriate for Dr. Bockenstedt or others to state conclusively that patients with disseminated and embedded, tertiary stage, spirochetal, *Borrelia* infections (who were not diagnosed and treatment for prolonged months and years) to be infection-free. Medicine cannot make that

SPECIAL REPORT

determination presently, and therefore, the clinical aspect observed by the treating physician, along with the patient's response to antibiotic therapy and the patient's feedback regarding their symptoms are the most reliable evaluative tools to determine the need for additional treatment.

As Dr. Bockenstedt has extensive experience with Lyme disease research, having worked with Dr. Allen Steere, the epidemiological Godfather of Lyme disease, I think she must be aware of Biowarfare Lab Director Alan Barbour's work on the antigenic variation of *Borrelia burgdorferi*. I agree with Dr. Bockenstedt that there is definitely an inflammatory component to persistent symptoms, but I ask this very pertinent question -- does the cause of persistent symptoms need to be attributed to just one aspect of the disease complex? I think not.

The continued attempts to attribute the interaction of the complex factors of this disease to only one cause is one of the reasons Lyme disease patients have suffered without an adequate treatment protocol for decades - more than 35 years! This is a medical travesty that should be immediately addressed by NIH and CDC. I appreciate this research by Armin Alaedini and view it as a step forward toward the development of an adequate treatment protocol; that is, if the NIH and CDC are willing to concede that the IDSA treatment guidelines have, for too many years, ignored the published research on antigenic variation and persistence of infection.

As a patient who has suffered since 1998 -- more

than 12 years -- with persistent Lyme disease infection, along with persistent inflammation, I bear witness that there are a multitude of factors involved with this horrible, debilitating biowarfare agent - infection, antigenic variation, inflammation, coinfections and genetic aspects, all of which determine the wide array of symptomatology. Borreliosis is the New Great Imitator that manifests in a myriad of symptoms and conditions, including MS, ALS, Alzheimer's, Parkinson's, rheumatoid arthritis, lupus, autism, chronic fatigue and fibromyalgia. In addition, physicians have observed that Bb infection can cause more than 300 different conditions throughout the body including lymphadenopathy, thyroid disorders, hypertension, scleroderma and RSD.

Of utmost importance, the long-term suppression of the immune system and accumulation of pathogens in and stagnation of lymph and nodes, due to continual activation (inflammation) in response to Bb antigenic variation, allows the proliferation of common, dormant, normally-manageable viruses, such as Epstein-Barr, cytomegalovirus and Human Herpes 6 (roseola) to proliferate to extremely high levels. Such a condition becomes fertile ground for the development of lymphoma and myeloproliferative cancers.

Unfortunately, I have reached this point at which my body has become a fertile ground for cancer due to extremely high levels of these viruses, especially HHV6. The extreme stress placed upon my immune system has allowed these viruses to replicate to unacceptable levels,

causing spinal pain, sciatica and seizures.

I carry resentment for the Lyme Medical Cartel, because this dishonest group of individuals is responsible for the fact that I did not receive appropriate diagnosis and treatment during the early stage of disease. Of course, my case is not isolated; thousands of other Lyme patients have experienced the same deliberate medical neglect. Members of the Lyme Medical Cartel, in my opinion, should be held legally responsible for the devastation of lives they have caused. I would like to see them forced to pay financially for patients' treatment costs that are not covered by insurance. I would also like to see them imprisoned for their Lyme Crimes, as through their greed they have sentenced Lyme patients to LIFE IN PRISON FOR THE CHRONICALLY ILL.

I also resent the tip-toeing and walking on eggshells encouraged within the Lyme community. It is ludicrous to believe that we can talk the prison guards into releasing us. Such efforts, although perhaps well-intentioned, have stymied the patient community into a sense of intimidation and fear of speaking out. This fear has rendered the community impotent when it comes to activism.

Rallies should be held each year with as many of us attending as possible. In May of 2012, I will do everything possible to attend the MayDay Rally in Washington, DC. I urge the Lyme community to slough off the old advocacy skin and forsake the old and ineffective fear tactic that renders us afraid to speak out for fear of how we might appear

to those who hold us hostage. The squeaky wheel gets the grease, folks, and we should have been squeaking loudly a long time ago. This must be done peacefully, of course, but banging on pots and pans with metal spoons and using a bullhorn can make a lot of noise, that hopefully, will shine a spotlight on the perpetrators of the Lyme Crimes, make them squirm and bring their wicked deeds to public attention. *pha*