Open Letter of Apology to Lyme Disease Patients

May 2014

Dear Lyme Patients,

On behalf of all of the early and current Lyme disease experts who have contributed and continue to contribute misinformation to our knowledge and understanding of Lyme Disease: I apologize for all the years and decades of suffering and deaths that we have caused, not only by our arrogance, but also by our inability to take responsibility and correct any of our mistakes over the past 37 years.

In 1975 when “Lyme Arthritis” was first described in the medical literature we were all excited to investigate and publish what we could about this mysterious new disease. As would be expected we got some things wrong. But what is unforgivable is that we got almost everything that was important about a newly discovered disease wrong, and over the next 37 years we did nothing to correct our mistakes.

In fact, we even tried to cover our glaring mistakes up with belligerence and mocking criticism of patients rather than support human pathology to better understand the disease process. We refused to do well designed treatment studies to help the persistent victims of our mistakes.

Where did we go wrong?

Where did we get off on the wrong track?

Right from the get-go and for many years we told Lyme patients in America that Lyme was primarily an arthritic disease. When we learned otherwise, we did report some neurological involvements in scattered papers, but we tried to minimize this aspect by accentuating the peripheral nervous system involvement and not BRAIN involvement.

We informed the public that severe neurological involvement was rare and usually self-limiting, and the biggest lie that almost all patients with persistent symptoms would mysteriously get better months after they have been treated with a just a few weeks of doxycycline.

We told patients that whatever symptoms and problems they had after antibiotic treatment it was probably psychological or immunological but there was no factual basis in our statements that was backed by microbiology.

Without any substantial pathology research to support our conclusions, we told the public well into the 1990s that there was no evidence that Lyme disease entered the human brain. Of course this was contrary to what we already knew about Borrelia bacteria based on our over 60+ years of experience with Tick Borne Relapsing Fevers. We knew that when rats were infected with Old World Relapsing Fever Borrelia duttonii, that it entered the brain quickly and even caused death by encephalitis. Rats infected with TBRF Borrelia turicatae; even after repeated penicillin injections directly into the rat’s brain, we could not cure the rats, or eradicate the persistent live infection. (Science Feb. 1945).

Interestingly many of the early Lyme experts were not only working on Relapsing Fevers, but were even EIS agents (CDC Epidemic Intelligence Service). This means American CDC agents knew with absolute certainty that Borrelia bacteria as a species was a lethal and persistent pathogen, that was transmitted by ticks and Borrelia was known to have the ability to change or adapt quickly to hosts thus causing relapses.

EIS = Epidemic Intelligent Service of the CDC. There are over 3,500 EIS agents in the US and more World-Wide paid $50,000 – 75,000 a year and many of them are just consultants who all seem to repeat the party line on Lyme disease. Many EIS agents before they were EIS agents spoke openly about persistent infection, intracellular penetration, pathology supporting CNS survival and penetration into the brain, antibiotic treatment failures, and the ability of Lyme disease to mimic other neurological diseases like MS, ALS, Parkinson's and dementia.

The EIS will begin accepting applications in May of each year. Applications include submission of an online application, four letters of recommendation, transcripts from degree granting institutions, and a U.S. clinical license, if applicable.

We the self-proclaimed Lyme disease experts, also maintained from the very beginning without any real data that the Lyme spirochete was not intracellular. Of course this was just sheer ignorance on our part since the dyes used to stain for Borrelia were all extracellular and could not even enter inside human cells. But when evidence started to support intracellular invasion by Borrelia in human tissues as early as 1989, we maintained for another decade that this was nonsense, Of course admitting any of this would mean our already established treatment protocols of a few weeks of antibiotics would be worthless.

I especially apologize for ignoring the role of intracellular infection because intracellular infection is one of the most important microbiological pieces of knowledge that directly affects the effectiveness of treatment. I apologize for the thousands of patients who were treated and later relapsed and then told that there was no such thing as persistent infection post antibiotic treatments.

Since we dictated world-wide the acceptable treatment protocols for Lyme disease; we could not back down from our published treatment guidelines. That would be like saying we were wrong.

I also apologize for acting like a belligerent kid. Since our leadership can't accept being wrong when faced with scientific facts that prove us wrong, we try and change the playground rules. Hey it's our ball so if we want to throw tantrums and make no sense there is nothing you can do because in the medical community we own all the balls on the playground and it takes balls to say the stuff we say and expect scientists to accept our BS. Of course when grown-ups do this it is called sociopathic behavior.

The biggest blunder that I apologize for is the fact that we told you that the only tick that could transmit Lyme Disease was the nonexistent Ixodes dammini tick. We told you that only this tick and no other tick could transmit Lyme disease. Never mind that Tick Borne Relapsing Fevers were transmitted by dozens of tick species throughout the Northern Hemisphere, and that TBRFs are very closely related to Lyme disease.

The reason identifying the Ixodes dammini tick as the only vector was such a big blunder that led to undo patient suffering, was that we were told with absolute terms that this tick was only found in the Northeast USA. More specifically near Nantucket Island and Old Lyme CT. For this reason, all the Lyme-Like illnesses we were seeing throughout the Midwest were being ignored and treatment was being denied.

“We don’t have Lyme disease here!” Shouted Infectious disease doctors across the Northern Hemisphere in unison as though we told them to say this.

Then when Ixodes dammini was discovered to be the common Deer Tick (Ixodes scapularis) found throughout the US, yet we still maintained that Lyme disease was mostly a NE USA disease. This never made sense because we always knew that infected ticks were being carried by birds and rodents throughout the USA.

We now have over a dozen Lyme disease Borrelia species that affect humans, transmitted by over a half a dozen species of ticks, and not one of those species is Ixodes dammini isolated to Northeast US.

Rather than admit this mistake Wikipedia has a revisionist review of this historical account saying that the entomologist, who discovered/created the Ixodes dammini species, was actually recognized the common Deer Tick as the vector transmitting Lyme disease. There is no mention by his alma mater that he misidentified Ixodes dammini as Ixodes scapularis, and then told us Lyme was strictly regional.

This is one of the biggest medical blunders of the 20th century and for 38 years we never received an apology or publicized the mistake. To add salt to this wound, those who are embarrassed by this mistake have insisted that I. dammini interbred with local tick species and became genetically merged. Or maybe it was just another mistake associated with our medical experts at that time?

We now admit that Lyme disease is transmitted by at least six species of ticks and we will probably see more species emerge just as we have for Tick Born Relapsing Fevers for over a century! Even the CDC had on their web site for 48 hours declared that the common Brown Dog Tick (Rhipicephalus sanguineus) transmitted Borrelia burgdorferi in about 1% of Lyme cases.

So much for general statements about length of tick attachments having to be 36-48 hours, this tick can transmit much more quickly. Mmmm maybe that’s why the CDC took it off their web site so quickly?

In 1989 when we learned Lyme disease not only penetrated blood vessels easily, but was also an intracellular disease; (Ying Ma) that was when we denied Lyme disease was ever transplacentally transmitted from mother to fetus. This was despite two positive fetal autopsies done in 1987 and seven more in 1989. And we maintained that there was no transplacental transfer during pregnancy right up until 2007. One of the greatest “Lyme Experts”; Dr. Gary Wormser made this crystal clear in the film Under Our Skin.

Since we never apologized for that unforgivable belligerence, I apologize now to any woman whose baby died as a result of our inability to inform patients to the truth so that they could protect themselves. We apologize for telling doctors that since transplacental transfer cannot occur that treating with antibiotics would be unnecessary. Oops! Sorry we didn’t believe the 9 fetal autopsies that proved we were all wrong!

Despite the fact that since the turn of the century we knew that Tick Borne Relapsing Fever caused by Borrelia spirochetes was caused by dozens of related species of Borrelia bacteria: We told you that only one species of Borrelia caused Lyme disease and it was brand knew and strictly regional. Of course we should have listened to microbiologists that told us that Borrelia bacteria are some of the most genetically variable bacteria in the world and that new pathogenic Borrelia species are constantly evolving.

Now we have eleven Borrelia species that cause human Lyme disease, and 22 Borrelia species that cause the closely related Tick Born Relapsing Fevers. Sorry we told you in absolute terms with no equivocation or hesitation based on almost no field research that only Borrelia burgdorferi caused Lyme disease and Lyme-like symptoms! I also apologize for trying to muddy the waters by telling you that the emerging species are not Lyme disease but are Lyme-Like diseases that aren’t picked up by our current serology testing for Lyme disease.

I apologize for the fact that all of our serology antibody testing is based on just one species of Borrelia and to make all of those serology tests we use a laboratory strain not even found in nature and consequently not a good representation of what we are seeing in the real world. In other words; our Lyme tests have a built in flaw that for economic reasons we accept and lie about.

But we don’t care. I am absolutely not apologizing for making money by using B-31 in our Lyme tests and patents. Because we are the patent holders on so many Lyme tests and vaccines, you can see how that make lots and lots of money. Yes, we obtained these patents by spending your taxpayer dollars to do the research. Many of our patents are also used in Veterinary Lyme test kits, making us more money by using free tax-payer dollars.

But no apologies: Business is business and Lyme tests and patents held by doctors, CDC workers, and Universities is just business so don’t take it so darn personally everyone likes making money and corporations must be protected!

Yes, we told all of America in absolute terms that only one species of Borrelia caused Lyme disease, but did you know we also got the reservoir-hosts wrong. Lyme disease just doesn’t just appear inside the ticks by magic. The uninfected ticks have to feed on infected reservoir-hosts to become infected.

We told you for years that only the white footed mouse and possibly a few other rodents carry the infection in their blood, but we failed to tell you for 35 years that the common chipmunk was a big carrier, that the shrew may be more important Lyme reservoir near human habitats than mice, and that the common Robin and other ground feeding birds not only carry the bacteria in their blood and infect ticks. The birds then carry those infected ticks across the country!

Whew! I really apologize for chastising and belittling Dr. Edwin Masters in Missouri for trying to tell us all of this in the early 1990s. Boy we really persecuted him for nothing. Turns out he was right about just about everything including the emergence of a new pathogenic Borrelia Lyme-like species that is invisible on our B-31 based Lyme serology tests. We denied this was true for years and we even seized his patient records and frozen blood samples that we destroyed instead of using for research.

Then after Ed Masters died, we admitted he was right and named the new disease after him. Never mind that his patients had in their own freezers identical blood samples of the ones we confiscated and destroyed, and then threatened to sue us. So we decided Dr. Masters should be left alone at least until he died. Then we started up again on making Borrelia lonestarri sound like a completely unrelated disease and the bull’s-eye skin rashes seen in those patients under no circumstances should be called Lyme rashes or be confused with Lyme disease! (Of course we can’t see the difference either!)

Yes, we admitted that we were wrong when it appeared we violated a few federal laws including HIPA and that Dr. Master’s patients had the evidence to make it to court. Ed

Masters had amazing grace, zeal, compassion and humor. Too bad he died before he could see how wrong we were about almost everything and how right he was about almost everything!

Imagine just a plain old country doctor who cared about his patients out smarting us and by documenting his patient concern with over 350 photos of Bull's-Eye rashes caused by Borrelia bacteria transmitted by a tick we said could not transmit Lyme disease. Well to be honest we'll never call it Lyme disease. Maybe we'll just make a new category for it to save ourselves humbling embarrassment. We'll call it Not-Lyme!

Oh by the way, we aren't done persecuting Dr. Edwin Masters, we are going to use his patient photographs of those 350 beautiful Bull's-Eye EM rashes and use them as an example that Lyme disease cannot be diagnosed by the rash because all these rashes are MASTER'S disease and not Lyme. Never-mind that these EM rashes by CDC standards are diagnostic of Borreliosis which is what we should be calling Lyme disease in the first place.

Lyme really is closely related to Relapsing Fever. In fact, in a paper by Alan Barbour it appears that Lyme disease (Borrelia burgdorferi) is genetically closer to Tick-Borne Relapsing Fever than Borrelia duttonii???? Odd since Borrelia duttonii is an "Old World" Relapsing Fever from North Africa. Wow all this science stuff even confuses me it's hard to keep our stories straight!

I apologize for our so called science that often appears to support the wishes of insurance companies and HMOs, or tries to save face for our leaders. Like when we tried to discredit the Monkey Autopsy Study by Embers and Barthold. Frankly just between you and me we try and suppress all pathology because it usually proves us wrong. And if we can't get a pathologist or microbiologist to play ball with us, we either make them an EIS officer or threaten their credibility.

Did you know that many medical journals have special supplements?

Did you know that some supplements can be sponsored by contributors and accept donations from the sponsors, and that the articles in them don't go through the same peer review process as real medical research? Even though there are medical articles in these "special-reports" that look like regular medical articles but aren't given the same scrutiny as other submissions. Often supplements are on special topics that favor the wishes of the sponsors.

Once upon a time there were two back-to-back articles touting the benefits of using the least expensive antibiotic oral doxycycline over the most expensive antibiotic ceftriaxone IV published coincidentally in medical journal supplement.

Although the Lyme patients in these studies only had "Lyme Bull's-eye Rashes" as their only symptom, and followed up after treatment for only two weeks, and that they used Lyme serology tests to determine cure (this cannot be done) they concluded that in early Lyme disease that oral doxycycline was just as effective as IV ceftriaxone. And then cited that keeping patient costs down was good for the patient, so all doctors should use doxycycline and not Rocephin. Mmmm who really benefited from those two studies? Who sponsored them? How long was the follow-up and what criteria was used for determining cure and relapse? Luckily they didn't have to pass peer review standards like other studies! (Here is a hint: the studies were funded by insurance providers.)

Then almost immediately after the studies were published a Minnesota physician sent out a medical letter to physicians in Minnesota and Wisconsin urging all doctors to treat Lyme patients as though they actually had Ehrlichiosis (HGE), and not use amoxicillin or similar drugs, but to use doxycycline because this would cure Lyme disease and Ehrlichiosis at the same time.

This sounds reasonable and sound like a financial bargain, but what if patients with Lyme disease only looked like they got better in two weeks and then many months after treatment they actually relapsed? Oops the medical institutions met their obligation to treat so all further treatment is denied.

If you want years of ceftriaxone pay for it yourselves. After all we did the two-week study and proved conclusively in a hand full of patients that doxycycline is the way to go and as we point out it is considerably cheaper. (Except now that isn't true anymore because doxycycline increased in price, so now we see it being used less.)

But we did make the same flaw that Embers and Barthold made in the Monkey autopsy study: we didn't do blood levels, and never recommend blood levels when using two weeks of doxycycline because we already know that two-weeks of doxycycline cures all patients, in all stages, and it works every time, usually!

I guess we didn't look at basic pharmacology that shows doxycycline to be a bacteriostatic drug and its use against a bacterium that is prone to going dormant may have limited use. Sorry it that it drives the bacterium into a non-metabolic state! Of course now that doxycycline isn't the cheapest drug anymore we may have to decide that other drugs work better.

I guess I better talk a bit about conflicts of financial interest and how we the experts used our power and position in ways that are in direct conflict with pure science and compromises patient safety.

You see in the late 1990s there was a race to be the first to get a Lyme disease vaccine on the market.

Now in 1989 we already knew that in some patients infected with Lyme disease; that a bacterial outer surface protein from the bacterium can lodge inside human joint tissues like the synovial tissue. Yet we allowed this same exact protein to be used in the human Lyme vaccine knowing that the antibodies made against this OspA protein might attack human joints that had this protein previously embedded in their tissues by having been exposed to Lyme disease.

Also we knew from previous mouse studies that Lyme infected mice could react badly to the vaccine just as was predicted by over 200 scientists that signed a petition against the development of this vaccine. Even eminent scientists who worked on Syphilis for 40 years had reservations about the vaccine's safety spoke out about it a full year before its approval!

I apologize that many of the Lyme experts and major medical institutions had financial ties to the vaccine and that the Lyme experts advising the CDC and the public should probably have disclosed these conflicts. Certainly in papers supporting the vaccine's effectiveness we should have told the research community of our financial ties. And when we tested the vaccine we should have had better safety concerns and demanded tissue typing. But we had to beat the European competitors to market in the USA. We knew they had a better and safer vaccine. After all America with 300 million people was a limited and marginal market base, and first to market meant greater profits! Let me repeat that: Being first in the market place with an inferior Lyme vaccine would mean greater profits than being second in the same market place especially if the other vaccine (based on endothelial cell binding proteins) was a better vaccine.

Oh but we don't have to say we're sorry: the vaccine was voluntarily withdrawn from the US market for lack of profits, gosh the third year it took in less than 5 million dollars of course maybe the three class action lawsuits scared the doctors away from prescribing it! But it was cleared by the FDA as being safe, and the class action lawsuits are nothing but a coincidence and a financial inconvenience, so I don't see the need to apologize. Once again business is business, nothing personal. But since we voluntarily withdrew the vaccine, we can relaunch it again when the public forgets about the truth and believes what our PR machine tells them.

So let me just review what we got wrong about Lyme disease?

Where? Well we were dead wrong about it being just in the Northeast US; now Lyme-Borreliosis is found throughout the Northern Hemisphere throughout the temperate latitudes. 12 species infect the US and Europe and range from Canada to Florida and from Finland to Spain and from Poland to Japan and from Japan to China.

When? Well when we found out it was related to Relapsing Fevers going back 100 years, we chose to disregard what we had learned from TBRFs. We insinuated that Lyme disease was pretty much was brand spanking new!

How? Yes, we made up a tick species that didn't exist. Then we told you just Deer Ticks transmit Lyme, then 20 years later we have 6 tick species that transmit Lyme disease, but we're not going to mention Ornithodoros hermsi ticks that transmit a Lyme-like Relapsing Fever, and can do it in just ten minutes from tick-bite to human infection. Also Borrelia hermsi can travel to the human brain and cause MS-like symptoms and that 25 % of MS patients near Lake Tahoe test positive for Borrelia hermsi and respond to antibiotics. (Bonnie Bennet's book Tick Bites and MS)

What? We told you for 20 years that Lyme is caused by Borrelia burgdorferi how many times do we have to tell you in a loud and absolute voice that ONLY Borrelia burgdorferi causes Lyme disease!

Oops, I guess we now have 12 species that cause human Lyme disease! But we are definitely not going to open the Tick-Born-Relapsing-Fever can of worms. My god that would be horrible to think that Lyme was related to such a horrible group of diseases that we knew about for 100 years and then ignored all that we knew including that some TBRFs were incurable!

Transplacental transfer from mother to baby? Yeah we got that wrong big time! Sorry! We're still denying it and still got it wrong.

Lyme infections don't involve the brain. I guess you didn't believe all the intrathecal antibody studies which proved us right. I guess because the autopsies proved us wrong.

Oops, another case where pathology trumps serology!

Lyme does not cause brain demyelination. Oh sure there are lots of correlations and observations and case histories and What? Oh it appears now our self-proclaimed experts are presenting cases of demyelination in Lyme patients that are reversible with antibiotics. Guess we got that one wrong if our own people who once denied demyelination are making a case that demyelination is reversible!

Does Lyme cause a MS-like condition? No! Any MRI expert or radiologist can tell the difference on MRI. What? Wait? Are you telling me they can't tell the difference? Oops, looks like Borrelia can cause sclerotic lesions in the brain, but we refuse to do brain autopsies to get an incidence rate of misdiagnosis of MS when they really have Lyme.

Listen there is no way we're doing a national brain autopsy study that proves we caused countless deaths and unspeakable morbidity caused by this under-treated, underdiagnosed demyelinating disease.

Why do we continue to do bad science and support a scientific position so easily disproved by pathology? I'm not saying we are told to toe the line and tell lies and commit scientific ineptitude. I'm not saying that the EIS is involved and maybe hiding something that is related to Tick Born Relapsing Fever research that began in 1945. But I am saying something is wrong and we aren't trying to fix it or help patients.

Patients want better brain pathology studies and access to antibiotics for their persistent symptoms.

How easy it would be to silence the critics by giving them what they want like we finally did with Gulf War Syndrome and soldiers wanting longer treatments with doxycycline.

It is beyond me why we don't try to help Lyme patients and continue to spend your taxpayer dollars at major medical institutions on worthless tick and deer studies or worse spend tax dollars to prove that we are right and the patients are wrong, and only think that they are sick.

So I apologize for the recent outpouring of junk science led by just a few in our organizations that is intended to reveal nothing, admit no wrong, admit no guilt, and to use scientific semantics to tell you that you aren't really sick, but the sickness you have is caused by lingering Lyme bacterial proteins. (Like the live infection in rat-brains, I guess that counts as lingering proteins!)

Sorry we told you for years that if you had lingering symptoms you needed to see a psychiatrist. (ACP training video) I guess we should have told you, that you had lingering proteins, and then send you to our overpriced psychiatrists!

I'm sorry but not sorry enough to make any changes or to speak against my fraternity of conspirators. I'm not sorry enough to take a stand against the status-quo or admit culpability or a connection to a higher power telling me what to say. After all the department of defense and insurance companies need people like me to prevent patients from knowing enough to embarrass us and cost us money, and I guess that is worth a few thousand people's lives being destroyed!

A Lyme Disease Expert 1975-2014