



## Opinion

# The Perils of Invisible Disease and Lyme Related Issues

David R Thomas\*

*Lyme and Tick-borne disease advocate, 410 ½ South Lehigh Ave. Sayre, Pa. 18840, USA*

## Opinion

The perils of invisible disease and lyme related issues, has brought me full circle in life. I have found that what is perceived as professional medicine has become distorted in the many minds that control medicine. This means that when a Doctor is taught one thing that his professors believe to be tried and true knowledge of a disease, the Doctor will likely not sway from those teachings. These are the controllers of medicine. The Doctors are, for the most part, not trouble-shooters and problem-solvers as they are book learners. They may want you to think they are king of the patients' world. However, in the world of silent diseases such as tick-borne issues, they are often the patients' dimming hope and demise.

Doctors do not go to school to learn to be doctors today. It seems to me that most go for the money and they figure that all they have to do is memorize books of teachings - which are outdated. Then they deliver the outdated information to the patient. This is all smoke and mirrors. The Doctor is often left with frustration, and a big fat paycheck, that is really hindering the health of the country rather than improving the health of the country. We need to take the control of pharmacy and drug producers away from pharmacy-controlled Doctors, politicians and insurance companies. I feel all medical leaders are pharmacy bought and paid. They are in control of a profit machine that is, in truth, destroying world health programs and benefiting from the great profit machine. This is the great bottom line.

This brings me to outdated medical practices. My research has found that outdated medicine has hindered the medical and patient communities concerned with Lyme and co-infections. In the 'non-Lyme literate' world, nine out of 10 general practitioners don't recognize our disease, but they can name the many symptoms caused by our disease. There is a pill for most symptoms related to tick-borne related health issues.

**\*Corresponding author:** David R Thomas, Lyme and Tick-borne disease advocate, 410 ½ South Lehigh Ave. Sayre, Pa. 18840, USA, Tel: +1 5708821230; Email: [darith1@hotmail.com](mailto:darith1@hotmail.com)

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(My Abstract leads into my paper)

For patients, this is frustrating. We know that there is something within us that the medical community is not dialing in on or is just not seeing. At this point, we patients are labeled as complainers or hypochondriacs looking for attention. The medicines that are used are often not effective, or are very effective in subduing symptoms that only return to come back later and resulting in another round of medicines.

Many patients become addicted to opiates, or just plain need those pain killers to get through the day. Many of the medicines that pharmaceutical companies make today often do very little in the fight against tick related issues. The drugs often prescribed for tick-borne diseases patients are used incorrectly, even if they are of great use for other illnesses. There was a time when trouble-shooting in a Doctor's office was commonplace, and Doctors were free to diagnose and treat according to their experience and judgment. Today, you need to be a courageous Lyme sufferer-fighter to be trouble-shooter, as some patients and Doctors have had to become. These warriors are often forced into this role when they decide to diagnose and treat tick-borne disease related issues, or the sandbox war-related Sand flea-delivered Lyme, or even Mosquitoes delivered Lyme.

Our medical system has found itself comfortable and profitable in a disease system - more than in a true diagnosis and treat system. Our profitable disease system will have to change as Lyme and associated diseases mimic over 300 different illnesses and diseases.

We in the invisible disease community take hard emotional hits when friends find us unbelievable because, according to their outdated book learning, the doctors say we are not sick. This creates a very hard lonely world that only the sufferer can understand ... unless they know other invisible disease sufferers. We are isolated by our medical advisers and health professionals. However, this is changing as more medical professionals, politicians and power brokers find themselves fighting our fight when they are infected with Lyme and co-infections.

This brings me to the next issues of designing new cures, reinventing old cures and new sciences. These will be our next generation medicines and even includes natural supplements that have been proven helpful in the tick-borne related disease fight. We are discovering many forgotten natural therapies. Over the years, I feel these natural tools were deliberately marketed out of the knowledge base of medicine by the great American marketing machine. Natural healing tools were displaced in favor of the Great Lab designer drugs of today; this includes antibiotics such as penicillin.

I am seeing great strides in understanding natural remedies for various diseases. I also understand through my own experiences that designer medications are not as always as helpful as natural remedies. When I was on the farm as a young man, we treated a cow with 'fouls of the foot'. I believe the dose then was no more than 10-ml injection of penicillin. Today, that same cow would likely get a 30-ml injection of some antibiotics other than penicillin.

We now better understand why we are needing so much more medicine to control diseases. We better understand the biofilm that bacteria and/or antibiotics tend to produce as a defense mechanism. These new scientific understanding about biofilms will help many other disease sufferers in the future. I hope scientific discoveries around biofilm are not thwarted by Big money interests that will lose profits because of this valuable knowledge.

Now we go to how to deliver medicine, and this requires politics and education to educate the medical community in how to treat the problems of tick-borne disease related issues. We Lyme sufferers have had to figure many of these issues out for ourselves; this can make us look like witch doctors instead of patients. People tend to shy away and listen to the gods in white coats that are expected to know all the answers. This is, in part, some of our own doing. We have fallen into the trap that the best guide to good health is our doctor. This all puts the sufferers in some very lonely, shut out, relationships with friends, family, non-Lyme Literate communities.

If we are not supporting the great medical machine in our country, we Lyme sufferers will likely be condemned to die of slow agonizing painful death and many other ailments that may be caused by Lyme infection –including Alzheimer’s, MS, just to name a couple. For example, when you go to a pharmacy and order needed medicines for tick-borne related issues, the pharmacists do not understand the complexity in solving the Lyme problem.

Profiting from medicine has become a very big problem. For our survival, we in the invisible diseases world often require many drugs. This puts a very big strain on the finances of the family. Why wouldn’t a country that knows the Lyme diagnostic tests are faulty want to go one step further and develop and use a more sensitive diagnostic test for Lyme? I feel that profit may have thwarted any funding or progression in the sciences of tick-borne related issues.

I heard or read once from the Lyme Action Network, the 501c3 that is based in NYS, or you might read about this in the book “Cure Unknown – Inside the Lyme Epidemic, the 2013 revised edition, by Pamela Weintraub” that this was addressed in a high-profile meeting at Dearborn Conference around 1996; this was voted on and decided that Lyme was not lucrative enough to take on. I guess there is enough evidence of that.

I am trying to understand how a medical community has found it so easy to discard the Lyme sufferer as having the many imaginative ailments we are all accused of having.

This kind of quackery is practiced by licensed practitioners when they mislead their patients and the public by saying they are up to date on the Lyme issues. In fact, they usually refer to ‘expert opinion’ that has not been validated and outdated publications. Meanwhile, licensed Lyme literate doctors (or LLMD) – backed by decades of successful clinical practice treating Lyme sufferers, and many publications behind them, are under the threat of Center for Disease Control and Prevention (CDC) and the Infections Diseases Societies of America (IDSA) malpractice accusations.

We in the Lyme community cannot afford most of the medical advice without financial help. But the Pharmaceutical industry is flourishing because of the high demand for these special drugs needed for tick-borne related issues. Then there are the natural treatments that are

not covered by insurance. These supplements are often too costly for Lyme sufferers because poor health has led to job loss.

Even accessing medicine is a challenge for many Lyme and tick-borne disease patients. This is because of CDC/IDSA pressure to not treat Lyme sufferers over a 21-day treatment protocol. The guidelines that promote this strict protocol have been taken down from the federal National Guidelines Clearinghouse (NGC) because they fail to meet the 2011 internationally accepted guidelines set by the Institute of Medicine (IOM) and are recognized by Health and Human Services (HHS) and the World Health Organization (WHO).

There are Lyme treatment guidelines that meet these 2011 IOM standards and they are posted on the NGC –they are by the International Lyme and Associated Diseases Society (ILADS). It is very frustrating that the CDC continues to promote the outdated and delisted guidelines and ignores the updated guidelines. This will have to be addressed before there is great improvement in the Lyme world which is all of us.

I have found that so many invisible disease sufferers find themselves ridiculed, shunned from family, society, community and sometimes from the very support system that should have been there when one gets sick. We, in the Lyme world, find there is not the understanding needed for our very survival. This comes from the lack of knowledge in the general medical community – necessary knowledge that is required to help diagnose and heal these sufferers.

I have found that if a person is diagnosed with known and provable Cancer they can walk out the Hospital door with the Hospital behind them, family support and financial backing (that has become more of an industry and profit machine than a professional responsible health system). This is the USA that I talk of.

The Lyme issue and associated diseases can replicate many different diseases and mystifies 98% of my country’s medical communities. We are on the cusp of making great strides in Invisible diseases through new discoveries of this Lyme research.

You have heard me bounce in and out, and back and forth, about how I feel the USA is failing people regarding tick-borne related diseases. The wider world may be waiting for the USA to get it right and I hope we are making strides toward this goal. For now, the invisible disease sufferer mostly relies on support groups to share their experience and get possible knowledge for their own journey through the darkness of Lyme. In closing, I say again, “The Lyme epidemic will not be appreciated until long after it is eradicated.”

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