

President's Blog



LDA LymeLiteracy

Pat Smith, President, Lyme Disease Association, Inc.

Slam Dunk for WNBA—Slam for Delle Donne & Lyme Patients



In partnership with the Lyme Disease Association, at the 2014 LymeAid 4 Kids night: All-Star and Delaware 87ers goodwill ambassador, Elena Delle Donne

From LDA President Pat Smith's Blog:

What has happened to one of the best Women's National Basketball Association (WNBA) players is no surprise to the Lyme Disease Association or hundreds of thousands of chronic Lyme patients. Elena Delle Donne, of the Mystics, has been denied by the WNBA league's panel of physicians as having a health exemption due to being at high risk for COVID 19, thus unable to be paid for exemption status if she does not play the upcoming season. She had a letter from her personal physician who confirmed her high risk status as she has

suffered from Lyme for many years, and the team doctor deferred to that physician's appraisal.

Apparently, the league's physician panel decision was based on the CDC's *list of people of any age with **certain underlying medical conditions** are at increased risk for severe illness from COVID-19*. The **CDC medical conditions list** does not include Lyme. The omission is not surprising when you consider that our government has denied treatment to 20%+ of Lyme patients because it does not acknowledge their condition. This position of the government on chronic Lyme has persisted for decades—Lyme disease as we know it has been around 46 years.

Chronic Lyme can lead in many cases to complete debilitation and even death, so why wouldn't the government classify someone with chronic Lyme as high risk? A high risk admission would provide validity to the claims backed by hundreds of peer reviewed articles published on research in credible institutions that indicate chronic, persistent, Lyme **might be real**.

The recent discovery of "persisters" and biofilms associated with Lyme disease threaten the house of cards built by the deniers. The patients they have denigrated, mocked, and dismissed over decades might really be sick? These chronic patients might actually need more antibiotics than the ~3 weeks now provided under the IDSA guidelines—guidelines clandestinely, or not so, supported by federal health officials? Guidelines that these officials have tried to remove references to on their websites by removing the name and keeping the contents? As the saying goes, "If it looks like a duck, swims like a duck, and quacks like a duck, then it probably is a duck." From what I hear, the Lyme community votes for the duck. The government continues to endorse IDSA guidelines for diagnosis and treatment.

The government will not however, reference the International Lyme & Associated Diseases Society (ILADS) Lyme Treatment

Guidelines, those used by Lyme literate physicians, who use clinical judgment to treat longer-term for Lyme disease if they feel it is necessary.

In fact, a recent NIH FOIA came to my attention which documents a discussion in 2008 between a then NIH official and an HHS employee as to possible removal of the ILADS guidelines from the government's then active National Guidelines Clearing House under HHS's Agency for Healthcare Research and Quality (AHRQ).

The chronic Lyme deniers carefully choose their handpicked biased science often published in their own journals and loudly tout the over generalized Lyme treatment trial conclusions—all are sacrosanct. Their message is clear: No more research is necessary, and no one should question that, especially patients, advocates, and Lyme literate physicians.

Meanwhile, patients cannot get a timely diagnosis, an appropriate treatment, and as Delle Donne found out, a high risk designation. All this denial, yet CDC estimates from studies that there are 300,000+ Lyme disease cases annually in the US alone, and government admits some 15-20% continue to have symptoms. But is it Chronic Lyme? NO. Persistent Lyme? NO. What is it then we ask, 46 years later. Listen to the sounds... of silence.

NOTE: Although LDA President Pat Smith is an HHS TBD Working Group Member, this Blog does not express the opinions of HHS or the HHS Tick-Borne Disease Working Group.

For more information:

Deadspin Article: 'She's Being Discriminated Against': League Says Two-Time MVP's Health Issues Not Serious Enough For Opt-Out

LDA Post 2015: Delaware 87ers, LymeAid 4 Kids Partner For Second Season

– Sevens, Delle Donne and University of Delaware College of Health Sciences to host LymeAid 4 Kids night

LDA Post 2014: WNBA Rookie of the Year Partners with LDA's LymeAid 4 Kids: on CBS TV Sports Network