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Title: Lyme Patient

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Committee/Subcommittee: House Committee on Foreign Affairs, Subcommittee on Africa, Global Health, and Human Rights

Re: *Testimony for Congressional Sub-Committee Hearing “Global Challenges in Diagnosing and Managing Lyme Disease – Closing Knowledge Gaps”*

First I would like to thank the Sub-Committee for accommodating me in arranging for me to testify by video conference. My wife was originally due to give birth to our first child this Friday so I was unable to make travel arrangements. Nevertheless, our son came last week and both he and Mom are doing great.

Now my becoming a new Dad brings me to a great point that underscores my entire testimony. My story has a happy ending, those that I am here representing do not have the opportunity to have a happy ending. Today I am able to appear before this sub-committee as a new father, husband, attorney, business owner, employer and advocate for the rights of Lyme Disease patients because I had the benefit of receiving medical treatment that is not currently recognized as a treatment option by the National Guidelines Clearinghouse as a treatment option for Lyme Disease sufferers—long term antibiotic treatment.

To be clear, if I hadn't received this course of treatment for my chronic Lyme disease symptoms, I would not be here today. Years of my life are now missing due to my bout with Lyme disease and my fate at one point appeared very grim, until my case was recognized as a

chronic form of Lyme disease and addressed by a physician with day to day, hands on experience in treating Lyme disease patients.

What I hope this subcommittee is able to take away from my testimony is that the net effect of the NGC's restrictive treatment guidelines is that it deprives the numerous chronic Lyme disease patients, who suffer just as I had, living normal fulfilling pain-free lives.

I offer my personal history as a real life case study, that like so many others individual cases, shows that chronic Lyme disease exists and but may be effectively treated if given the healthcare option to pursue the same long term treatment I received.

My story begins over 21 years ago, in the fall of 1990, as I was entering middle school, I became ill with flu-like symptoms and doctors were able to diagnose that I was suffering from Lyme disease however, for my course of treatment physicians made the same error so many make today when faced with the diagnosis—offered only four weeks of antibiotic treatment for my symptoms. This course of treatment proved to be catastrophic. After antibiotic treatment failed to alleviate Lyme symptoms including severe fatigue and headaches, due to the treatment guidelines in place that still remain in place, my doctors felt that the best course of treatment would consist of psychiatric and physical therapy.

Under this course of treatment, not only did my symptoms worsen, but I experienced new and different symptoms, that I simply couldn't grasp at the time. As I recall, performing everyday functions both mentally and physically became increasingly difficult and ultimately impossible. After nearly six months under this treatment my physicians threw their hands up in disbelief when my blood tests confirmed my suspicion, I was getting sicker due to the untreated Lyme disease. I was left in a position where like so many patients today, I felt, hopeless,

helpless and misunderstood. The oversight made by my initial treating physicians in offering only short-term treatment, as I said proved catastrophic, the result was four years of my life lost to battling this disease.

Over the course of a year, I was transformed, once an otherwise healthy, active, happy kid, I became unrecognizable, my Lyme symptoms worsened physically, to the extent I became bedridden, a wheelchair was my only mode of transportation by this point and my weight fell to 60 pounds. Neurologically I regressed the point where tasks like reading writing and even basic verbal communication seemed next to impossible. Whereas, in the fall of 1990 I was due to enter middle school, by fall of 1991, after diagnosis and improper medical treatment at age 13, my prospects for a normal life were as dim as ever. I had moved into a full time children's rehabilitation facility.

Shortly, thereafter new physicians discovered that the initial refusal to continue antibiotic treatment gave way for the disease to penetrate my blood brain barrier, causing hypo perfusion in my brain. While this discovery offered some insights as to my condition, Physicians at the children's hospital were simply confused and confounded by my case and could not offer me anything as far as relief of effective treatment was concerned. While living in the children's rehabilitation facility, due to the simple helplessness of my situation my family and I faced, was this it? was this my life? would I ever be able to live a normal productive life again, let alone function?

After spending virtually two years in hospitals, I was sent home to receive outpatient treatment. Additionally, through the fortitude and determination of my family, they were able to secure an appointment with a physician who himself was a patient and who treated individuals

with Lyme disease, like me on a daily basis. In retrospect, this was the turning point, the opportunity that changed my fate. This physician clearly had a deep understanding of my condition. His treatment was methodical and effective and grounded in real life results--that is Lyme patients who through his, long term antibiotic treatment were able to experience relief from Lyme symptoms.

While I had a significant way toward full recovery, with this treatment, for the first time two years, I experienced progress. My ultimate recovery was very incremental and took another full two years of my life but it was clear that only upon the care of this Lyme physician, was I able to change course and undo the devastation caused by my earlier short term treatment.

Depriving Lyme disease patients of the option for effective long term medical treatment, through biased treatment guidelines is an injustice that has gone on far too long. Whereas the self-interested members have been steadfast in their opposition to long term treatment, their corresponding arguments fail to show chronic Lyme sufferers in the light which they hope, either medical anomalies or misdiagnosed individuals. The suffering Lyme constituency has only grown to prove those against proper long term treatment wrong, time and again. It's time for those with vested interests in the current guidelines to step aside, let down their opposition, recognize the Lyme community and make way for relevant treatment guidelines that provide our suffering constituency with the same opportunity given to me, the opportunity to have effective medical treatment, the opportunity to recover.