

LYME ALIVE MARCH 2021 NEWSLETTER

Hey there Lyme Alive Family,

I hope everyone is doing okay and hanging in there through these continued difficult times. I feel like I see some light at the end of the pandemic tunnel and have been wishing you all healing vibes throughout. For those that are interested in joining our support group, it is going to be held **this Saturday (3/13) from 2pm-4pm on Zoom**. I will post the link for that below.

I had a great first time experience lobbying congress for federal funding facilitated by the Center for Lyme Action along with 200+ members from the Lyme Community across the country. We had 6 separate line items, or specific "Asks" that we requested which involved continuing to fund the Kay Hagan Tick Act, research at the NIH, a program for veterans, their families, and the DOD, a National Public Health Framework that is to "ensure the development and implementation of a national strategy to address the 20 different vector-borne diseases, including tick-borne diseases." The last two requests for funding I feel will show a lot of promise. Federal funding was requested to enable direct research into the persistent/chronic illness due to tick-borne disease. We want Congress to be acknowledging and helping to finance the ability to treat chronic Lyme+ patients. The last one began with a very generous and the largest private donation by the Cohen Foundation. Along with their \$25 million dollar grant, the CLA is asking Congress for an additional \$5M to launch the [HHS Lyme X Innovation Accelerator](#). This program is spearheaded by Sr. Advisor to the Assistant Secretary of Health, [Dr. Kristen Honey](#), who is a Lyme survivor, was a previous co-chair on the Tick-Borne Disease Working Group. With her expertise and lived experience she is working within the Human Health Services to make some serious moves. Lyme X is designed to carry out cash prize competitions, education and awareness programs, innovation, and incentivize the public/private medical industry to create better diagnostics and more efficacious treatments. The [Cure Lyme Moonshot 2030](#) is also wrapped up in Lyme X as well.

Project Lyme coverage and lists the 6 specific appropriations: <https://projectlyme.medium.com/lyme-advocates-sound-the-alarm-on-a-growing-health-crisis-c6b89d461cfa>

More info on Lyme X <https://www.nextgov.com/emerging-tech/2021/03/hhs-aims-accelerate-technologies-combatting-lyme-disease/172482/>

Center for Lyme Action: <https://centerforlymeaction.org/>

Much of this is building off what the CLA was able to accomplish for FY2021 that got announced last December. The work for next year, FY2022, is what we're doing now and just in 2 years Lyme funding has tripled. While funding still pales in comparison to other communicable diseases with lower case rates, there are new precedents being set that we can continue to build off of in the future. I know, I know, trust me...this is such a sluggish process, but we have to start somewhere and CLA is making more progress on a congressional level than any organization out there has in decades. I'm humbled and honored to have been a part of it. So, I think what I will do is come up with a default letter for a template and send that out to you all. Change it up, write your own, whatever you feel, but in April we all need to reach out to our district representatives (my rep, Gerald Connelly actually is serving on the newly formed Lyme House Caucus) and our state Senators to support these appropriations and vote yes on more funding for Lyme and other Vector-Borne Disease.

The way I see it, if both Harvard Medical and Johns Hopkins can compare "Long Haul Covid," now dubbed Post-Acute Covid Syndrome (Sound familiar, Post Treatment LD Syndrome?), then they should start paralleling those funds as well. Two weeks ago the NIH pledged \$1.4 Billion dollars to

study PACS. I spent the day a few weeks ago asking for appropriations that total about \$120 Million for the Lyme Pandemic. By all definitions it has been a pandemic. I've had complications and persistent Lyme for at least 8 years and caught Covid a year ago last week. I treated covid fairly quickly, but not quite quick enough given my underlying issues aside from just Lyme it allowed for a fairly moderate case. Now Lyme, Bartonella, Strep, and Mycoplasma have all relapsed acutely. Lyme and Covid...I don't call them the great imitators anymore. They are the "Stealth Detonators." Even the Brazilian strain is showing that it can adapt and evade natural immune responses. It's all so very familiar and I knew it, the moment I caught it. On top of all that, even Dr. Sanjay Gupta compared "long haul covid" to Lyme last week on air, on CNN. That's the first I've heard it spoken of in any serious relation to human suffering on a national platform. He even gave a great endorsement on the cover of the new book on Lyme+ and the autoimmune pandemic called, CHRONIC. It was a great read and still highly recommended. Sanjay is definitely up to speed as he is a brilliant neurosurgeon and medical journalist.

So while the funding is heavily tipped over on the scale of similar illnesses. I do hold on to hope that the research will translate over and open doors for future epiphanies on how to treat these immunosuppressive, multi-systemic illnesses...no matter what the trigger. As someone extremely close to me has consistently reminded me, "There is still more that we/they don't know, then what we do." I think that's a pretty accurate point.

The 2020 report to Congress from the Tick-Borne Disease Working Group finally came out. I am about half way through the 180 page report which I will link below. So far the semantics and language is addressing the need to dive into researching the persistent forms of the various pathogens, particularly Lyme. Of course Eugene Shapiro gave a dissenting minority report when it came to a couple chapters. But that's good, he's the minority for a change. Out on his own limb trying to hang on to the dogma. It's wild to read what they are admitting as a group during these meetings, yet the Infectious Disease Society just a few months ago put out their new [Lyme guidelines](#) and they are more rigid than ever before. It's absolutely ridiculous, oxymoronic, and literally dangerous. Here is the 2020 report to Congress for those interested: https://www.hhs.gov/sites/default/files/tbdwg-2020-report_to-congress-final.pdf

There is only (1) two-year term left, so we need to hit them hard with in-person public comments, written comments, and you can email them at any point in time. There are still several factors in my opinion that have yet to be addressed. Or, they've been addressed, but not resolved. I figured we would see a lot more rigorous debate throughout, not just the last two meetings Shapiro actually attended.

I know a lot of people in the Lyme Community are wondering about the Covid vaccine and I am one to respect people's decisions one way, or the other. I will not sway, or promote anything one way, or the other, but what I will do is share information provided by our nation's top Lyme specialist with the hope that it provides you with some clarity on what is best for your specific and unique health situation. Personally, my doc said to hold off because of how hyper-immune I am at the moment, but that in general since over 100million have been dished out they are finding the adverse reaction percentage very low...In general. So again, please check with your own provider on that topic and check out what [Dr. Bill Rawls and Dr. Cameron spoke about in the webinar sponsored by our friends at Project Lyme](#).

Just a quick update about my work with the [L.E.A.F. Program \(Lyme Education Awareness Foundation\)](#)...We are starting to kick things into gear as the Spring season is quickly upon us. Our primary goal and initiative is saving children's lives. We know children/adolescents are at the highest risk. During the past year, people naturally spent more time outdoors, but tick bites went up 20% and illness went up 6% (Project Lyme). Virginia Tech's science department has not only identified an

antigen that could contribute to late Lyme arthritis, but has tracked tick emergence and it has risen to a whopping 6,000% since 2005. My hypothesis seems to be happening as well, as North Carolina claims the highest rates of lone star ticks and I believe that those ticks are moving up to VA and commencing with the black legged ticks. I have so many friends in their 30's that are losing their health in their prime and explain so many similar symptoms and never get full answers, or proper care. It can't just be happenstance. Bartonella is so common among kids and a hugely under reported infection as well and has its own damaging effects by itself. So with L.E.A.F. We are doing virtual tick prevention & awareness courses via Zoom for now. We will be doing our demonstrations and discussions with the youth and adults as well. If you know of anyone, or any group that might be interested in setting up a meeting of that nature then feel free to email me at lymealive4u@gmail.com. Soon we will have a podcast up and running called "That Bites: Health Huddles" which will be found on your favorite podcast app. We will be having special guests to discuss all aspects of health. There are several things in the works, such as new merchandise, Dr. Nancy Fox has her third book coming out soon, and more events to come. It has been a great joy and most definitely uplifting to be taken in with open hearts & minds and working with such amazing people within the foundation.

Again, our monthly Lyme Alive Support Group will be **THIS SATURDAY from 2pm-4pm** and will look forward to discussing some of these topics with you and of course will open up the floor for anyone who would like to share. We are stronger together. If you have any questions, or need to chat one-on-one don't hesitate to reach out.

Zoom Info for Support Meeting:

Topic: Lyme Alive March meeting

Time: This is a recurring meeting Meet anytime

Join Zoom Meeting

<https://us02web.zoom.us/j/6514675110?pwd=ZnNpZ2ZOZE8vV3NqamVvMjh2Q0xkUT09>

Meeting ID: 651 467 5110

Passcode: 535214

Extra Links of the month:

~[Link to a short, artistic video created by a member of the Colorado Tick-Borne Disease Association](#)

~[Article on Bartonella and Children](#)

~[We need more celebrities to speak up, speak out, and help the cause! Yolanda Hadid can only do so much, but an article in Vogue is a big deal!](#)

~[Monthly Suggested Book: 'Keep Sharp' by Dr. Sanjay Gupta](#)

I am wishing everyone healing vibes and happy days as the seasons change. It's definitely that time of year again and after a mild Winter, we all know the ticks are activating so please check out our Facebook page, or website at www.lymealive.weebly.com for information on prevention tips. Be safe out there and much love!

Be well,

Jake Broughton