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*News for Darien*

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## What One Darien Family Went Through When Their Son Got Lyme Disease

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At a gala fundraising event in front of about 500 guests, including celebrities — a former Fox News host (Gretchen Carlson), a singer (Marina Morgan), a novelist (Jay McInerney), a mixed martial artist (Jim Miller), U.S. Sen. Richard Blumenthal and U.S. Rep. Jim Himes — the entire crowd gradually became silent as Tara Vessels of Darien stood at the podium and spoke, her voice sometimes cracking with emotion.

Vessel, one of the event chairs at the [Global Lyme Alliance's](#) "Greenwich Gala," reminded them all why they were there. She spoke about how her son getting Lyme disease at age 12 changed his life and the lives of his parents.

"If I was a high school student suffering from Lyme disease and was writing a college essay for admissions, the title would be 'Sidelined,'" the Darien mother said. "This is what happened to our very healthy, happy, energetic, 12-year-old son, Chase, almost seven years ago."

Vessels went on to describe the family's ongoing search for treatment and the difficulties Lyme disease put in her son's path.

Other speakers at the event included Blumenthal, who mentioned that last year he had gotten additional federal funding for Lyme disease research and was trying to get more this year. Carlson also briefly recounted her experience getting Lyme disease, as did GLA director Scott Santarella.

*Here's the rest of what Vessels said (followed by excerpts of Carlson's and Santarella's comments):*

### **Tara Vessels**

It started with an enflamed knee after playing outside, and a trip to the pediatrician's office, where two doctors thought it was a possible staph infection. We rushed him to the emergency room, where two infectious disease doctors diagnosed it as a ruptured bursa sac.

If only they would have suspected Lyme, which can present in this way and is clearly very endemic in our area, and given us three weeks of antibiotics, our journey would be very different from the nightmare that we have endured over the past seven years.

Our son started getting sick monthly with the same symptoms that kept him home in bed for days. We consulted with several doctors in different states and basically chased our tails for over a year looking for a diagnosis.

We pushed for a Lyme test, which at this point we had suspected. It came back negative by CDC standards. At this point, our son was in the eighth grade and could no longer attend school on a regular basis. Further testing for Lyme and co-infections finally revealed that he was positive.

We were so relieved to have that diagnosis, but we had no idea of the exhausting journey that we were about to embark on — the mountain we would climb in search of treatment that would give him his prior life back.

We had hoped and assumed that we would get proper medical treatment, but we quickly found out that Lyme is a do-it-yourself disease. We continued to see several specialists who all contradicted each other. The medical denial of this disease was so painful as we watched our son's health deteriorate.

He went from being a good student who lost his love of reading. His once-sharp math skills were now weak as he experienced cognitive limitations. He was a good athlete. He had played hockey and lacrosse competitively since he was old enough to hold a stick. He played both sports year-round and loved being part of a team. He loved the camaraderie that it provided.

*See also:*

— [Darien Moms Speak Out to Help Fight Lyme Disease](#) (March 17)

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These past years we have had endless tests, and have desperately tried many treatments oral antibiotics, bicillin shots, IV hydrogen peroxide, IV ozone therapy, reikishi, herbal treatments. We bought an infrared sauna — which he doesn't get in — even though my husband did install speakers.

A move to California for three months for alternative treatment. Autologous stem cell in Germany, quartz stem cell in Panama, [another treatment] for the past four months, more oral antibiotics and a football field of supplements, and I would be remiss not to mention I did speak with a healer from Arizona who was perched on a red rock, and when things settle down, I think I want to circle back to that guy, because I want to apply for that job.

We were fortunate enough to have the resources to explore the different treatment options, but what about the sufferers that don't? Insurance companies cut you off, usually after 28 days in the majority of cases. And it is a tragedy that people, and especially children in the prime of their lives who are left to suffer.

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Youth should be a time of exploration and joy, but these kids are out of school, they're isolated from their peers. They lose the person they once were, and the dreams and the goals that they once had, and there is a real fear for their future.

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Even the most resilient warrior can feel like giving up. This disease completely wears you down

I was recently at a stop sign in my neighborhood behind a school bus, and I saw the kids climbing off with their backpacks and I thought, "Wow, it's the simple things you take for granted. Being able to go to school full-time would be a dream come true."

We feel fortunate that we found an open-minded and caring Lyme doctor who is working with us on different protocols as we continue to climb the mountain of healing. The hope is that the CDC Infectious Disease, insurance companies and doctors can all finally come together and help us battle this insidious disease.

The people in this room are the people that are trying to make the change.

Global Lyme Alliance is changing the landscape by working to fund the research to find the answers, and this will lead to the proper treatment so that Lyme sufferers can get back to living the lives that they deserve to live.

I feel very honored and I feel very, very privileged to be part of this organization.

This past fall as the mother of a sick child, I wasn't in a good place. The women of GLA lifted me up and gave me the strength to go home, put on my big girl pants and fight for the injustice of this disease. There is light ahead for all those who are suffering and that light is the research that will result in effective treatments, and we will not give up until we find the answers.

To all the people who are affected in some way: Know that we are fighting for you, We are fighting for your future and we will not give up and we will find the answers. Thank you so much.

### **Gretchen Carlson**

Lyme disease is incredibly important to me, and that's why I volunteer my time to this organization. I'm so glad to be back this year, so thank you for having me. It's important to me because I'm a Lyme disease survivor. Five years ago I got a bullseye rash, right here on my forearm.

Unfortunately, when I went to a particular doctor, there was not the immediate diagnosis of Lyme. In fact, I had been traveling in Ecuador, and the diagnosis was ringworm. That was incredibly unfortunate for me because had I been treated at that time, I would have never, probably, gotten full-blown Lyme disease, but instead, six weeks later, I became incredibly ill.

It was actually another doctor who was doing an interview with me on my TV show at the time who said to me, "You know, you really don't look like yourself."

"I said, 'You know, I really don't feel like myself.' And I proceeded to tell him in a commercial break, 'You know, I had this rash —'

And he immediately stopped me, and he said, 'What did it look like?'

And luckily, I still had a picture of it on my phone, and he said to me, 'Gretchen, you have Lyme disease.'

"Now here's the second part of the problem. I went to get tested. And many of you in this room understand that the tests simply aren't accurate. And so my tests were inconclusive, but luckily that physician started me on the drugs that day, and within seven to 10 days, I was feeling better, and they officially said to me, 'You have lyme disease.'

"I'm one of the lucky ones, and I also like to knock on glass or wood by saying that I don't have any symptoms of the chronic disease at this point. But so many other people are affected by this in such a serious way.

And without that reliable diagnostic test [...] far too many people are not correctly diagnosed. They go on forever wondering what's wrong with them. And that's why the work of this alliance is so crucial, and especially for our kids.

I look at my kids every single day, 13 and 12, and hope that they're not going to have to go through this.

So, through research and education — that's why we're here tonight. And you're going to be blown away if you haven't been here before, by the experts in this field and what they're doing and the great strides that they're making. [...]

**Scott Santarella**

I have spent the last two decades leading organizations that help patients overcome the injustices associated with neglected, underfunded and stigmatized illnesses. And there is no bigger injustice in the infectious disease world than the injustice Lyme disease patients face every day: no definitive diagnostic test, limited

treatment options and minimal government support. Thanks to your support, GLA is changing that!

*Santarella also spoke about deciding to join the GLA two years ago as chief executive officer:*

I was immediately drawn to their tireless commitment to changing the paradigm of Lyme disease through research, awareness and education — in my experience, the three keys to success in beating disease.

## **SIDEBAR:**

### **Global Lyme Alliance on How to Lessen Your Chances of Getting Lyme Disease**

*Prevention tips from the Global Lyme Alliance [website](#):*

#### **EDUCATE YOURSELF**

The best way to prevent Lyme and other tick-borne diseases is to avoid areas where ticks live. This sounds like a simple solution but turns out to be an impractical one, especially for those of us who love the great outdoors. Here are some practical ways you can reduce your risk of being bitten by a tick.

#### **BE AWARE OF YOUR SURROUNDINGS**

- Ticks are most plentiful in areas where woodlands transition into fields, meadows or yards. In fact, many Lyme patients contract tick-borne diseases in their own yards.
- Ticks are often found in tall grass, gardens or mulch beds.
- When hiking, walk in the middle of trails.
- Leaf litter, woodpiles and rock walls are areas of high tick concentration.
- Coastal areas with beach grass also harbor ticks.

#### **DRESS DEFENSIVELY**

- Wear light-colored clothing so you can spot ticks more easily.
- Wear a long-sleeved shirt, tucked in at the waist and long pants tucked into high socks when in Lyme endemic areas.
- Wear a hat and tuck your hair in, if possible.
- Don't walk barefoot or in open sandals except on pavement. Even short grass can harbor ticks.  
Wear closed-toe shoes or boots.

#### **USE TICK REPELLENT**

- Wear tick-repellent clothing that's treated with permethrin, an insecticide that repels and kills ticks. Purchase pre-treated clothing (good for 70 washings) from a number of well-known clothing companies or you may spray your own clothing with it (good for 6 washings), follow manufacturers' directions.
- Spray footwear with permethrin to prevent ticks from crawling up your shoes.
- Apply EPA-approved repellents with ingredients such as DEET, oil of eucalyptus or picaridin to exposed skin.
- Protect your pets! Even if you're not especially outdoorsy, your pets can bring ticks into the house and on to you. Ask your veterinarian about products that minimize your pet's tick risk.

**CHECK FOR TICKS FREQUENTLY**

- Remove a tick before it has a chance to transmit disease. To learn how to identify a tick, [click here](#).
- When you come in for the day, toss your clothes into a dryer at high temperatures for 10-15 minutes. This will kill any live ticks. Putting them in the washer, however, will not.
- Shower or bathe as soon as possible to wash away any unattached ticks. Feel for bumps that might be embedded ticks. Pay particular attention to the backs of knees, groin, armpits, in and behind the ears, belly button and scalp.