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Jemsek Specialty Clinic Newsletter - January 2012

News From Jemsek Specialty Clinic

Welcome to the 2012 J-Letter!

Happy New Year

On behalf of the staff at the Jemsek Specialty Clinic, we'd like to wish you all a healthy and peaceful New Year! As we start our third year here in Washington, D.C., we are excited that our staff has grown to almost 25 personnel. We have a fifth provider joining us in the immediate future and hope to add a couple more within the next 18 months. Dr. Jemsek constantly strives to upgrade service to meet the expectations of his staff and his patients.

This issue of the J-Letter includes an in-depth personal look at patient Laurie Gottlieb's battle with Lyme disease; news about our newly available service for pediatric patients; an exciting update on Jordan Jemsek; and highlights of Dr. Jemsek's participation at the ILADS conference. We welcome your questions and feedback!

Patient Spotlight

Laurie Gottlieb's Lyme Disease Marathon

Laurie Gottlieb was at the prime of her life in 2005. She had a four-year-old daughter and a brand new baby girl. She also had multiple tick-borne infections - but didn't know it.

"I got really sick that year," recalls Laurie. "Unfortunately, my baby girl only knows me as sick. I was not just tired - I was sickening tired."

Her doctors chalked it up to various causes. She had just had a baby. She had thyroid issues. She had Crohn's disease.

"I would go to bed at night with the most horrific spine pain," she remembers. "It was so horrible that I would cry myself to sleep."

Her doctors attributed the joint pain in her hands, knees, and spine to her Crohn's. They sent her to a rheumatologist and pain specialist. They gave her steroid injections - and the pain got worse.

"I walked around with pain patches everywhere," she says. "One day, I woke up with numbness in my groin area. I thought I was having neuropathy from the pain patches. I called the drug company and took them off. The drug company indicated that they had no record of this ever happening."

Her gastroenterologist and urologist believed that an inflamed intestine was pushing on her bladder and causing numbness by pushing on a nerve. She was given immunosuppressive medication intravenously.

Then, she began to have numbness everywhere. She was sent to a neurologist.

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Treating Our Youngest Patients

After years of requests from [Dr. Jemsek](#)'s adult patients and other parents, Jemsek Specialty Clinic broadened its practice earlier this year to include treatment of pediatric patients. The Clinic welcomed Tara Fox, CPNP, to our staff in January 2011, to provide specialized pediatric care.

Since Dr. Jemsek was not trained in pediatrics, he used to accept teenaged patients only by having their parents and pediatrician sign a pediatric collaborative agreement. But the requests kept coming.

"People kept pushing and begging me to see younger patients, because there was such a great need," explains Dr. Jemsek. "I'm so pleased to now have a pediatric specialist on our staff so that we can truly serve patients from birth. Having Tara on board allows us to treat the whole family."

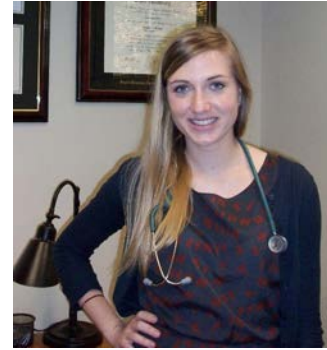
Welcome, Tara!

A Mississippi native who had lived most of her life in Tennessee, Tara had already moved to Washington, D.C. when she was alerted to our search for a certified pediatric nurse practitioner.

She barely had time to settle in at the clinic when we sent her for specialized training with Dr. Charles Ray Jones, a pediatric specialist in Lyme disease in New Haven, Connecticut.

Tara now sees an average of three to five patients each day, all of whom are under the age of 25.

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Jordan Jemsek Back in School



On a personal note, Dr. Jemsek is thrilled to report that his daughter, Jordan, who had her bone marrow transplant in March 2011, is in complete remission and her bone marrow is free of the leukemia. She is stable and will return to D.C. in March for a one-year follow-up visit.

Doctors were pleased with her progress and condition during her September follow-up visit. So much so that she got to go back to school full-time, joining her friends in first grade. Jordan has loved returning to school, but in her own words, wished it was "less serious because she needs more time to let the fun out!"

She's also having a great time chasing her new white Havanese puppy, Kirby, around the house and yard. (The Havanese is a small-sized, hypo-allergenic breed that's great around children.)

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Dr. Jemsek Spoke at October ILADS Conference

Dr. Joseph Jemsek took to the stage during the International Lyme and Associated Diseases Society ([ILADS](#)) conference in Toronto, Canada, October 28-30, 2011.

His main presentation-Advanced Techniques in Physical Diagnosis of Lyme Borreliosis Complex-was on Saturday, October 29 during the Clinical Excellence track. Dr. Jemsek worked with a volunteer "patient" to demonstrate the art of physical examinations and his clinic's approach to the diagnosis of Lyme Borreliosis Complex.

"We strongly believe diagnosis to be a clinical process, not simply a review of test results," said Dr. Jemsek. "Conducting a thorough, detailed physical exam is vital during the clinical visit."

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Lyme Disease Marathon Cont.

Pain Everywhere

"It was the most horrible, burning, stabbing, nerve pain," says Laurie. "I went to neurologist to neurologist to neurologist, searching for an answer. I was even sent to a neurosurgeon to do a biopsy of my nerve."

After receiving a positive anticardiolipin antibody blood test, doctors took yet another new turn. They sent Laurie to the lupus center at an area hospital.

She was told that having one autoimmune disease, like Crohn's, makes you more inclined to have another. She was put on several immunosuppressive medications. But nothing worked.

"I was placed on a medication to help with the nerve pain. I only got sicker."

Laurie began having severe neurological problems in 2008 - a worsening of her neuropathy, lightheadedness, brain fog, dizziness, confusion, ringing in her ears, and horrible disabling headaches that never went away.

Her gastroenterologist said in all his years he had never had a Crohn's patient have profound neurological problems. He suspected something else. So back she went to the neurologist and rheumatologist. They treated her for migraines, but they never got better.

Discovering Lyme

"One day I happened to be watching a TV show about this girl who had Lyme disease," says Laurie. "I thought, oh my G-d! That is me. I did some research and realized I had all the symptoms of Lyme."

Her doctor at the lupus center dismissed Laurie's revelation, insisting she had an autoimmune disease - not Lyme. Thankfully, her primary care doctor had an open mind.

"He happened to be doing blood work for me, so I asked him if he could also check me for Lyme. He said 'sure'. He was also arranging a spinal tap and added Lyme testing to that order, as well."

The tests found Lyme in Laurie's blood and spinal fluid.

Fast-forward to 2010. Laurie improved a little while seeing a Lyme doctor - but her progress was slow and she was getting sick from the constant daily antibiotics.

One day, she attended a screening of *Under Our Skin* - a film about Lyme disease - at a community college. She liked it so much that she arranged to hold a screening at her daughter's school.

Help from Dr. Jemsek

Laurie met Dr. Jemsek when he happened to attend her screening - and before long she was in treatment at the Jemsek Specialty Clinic.

"Dr. Jemsek takes the whole body and really looks at it," she says. "He tested me for co-infections and discovered I not only had Lyme, I also had Bartonella and Babesia. It turns out ticks carry multiple infections - and if you don't diagnose and treat those, then your Lyme can't get better."

The daily antibiotics treatment Laurie had been on caused its own problems. Dr. Jemsek switched her to pulse antibiotic therapy. She also had to go on intravenous-only feeding from October to June of 2010.

"Taking antibiotics every day was too much for my body," she says. "Dr. Jemsek explained that I'd never ever kill every single bacteria in my body. Antibiotic pulsing helps train my body to fight the bacteria itself and allows me to rest."

With Dr. Jemsek's help, Laurie fought back from another setback a year ago. She was in the hospital for a month with Bell's palsy of the gut or gastroparesis.

Nearly Normal

"This time last year, I could barely lift my head up," recalls Laurie. "This morning, I was at my daughter's soccer game. I still have symptoms, but I'm finally functioning like a normal human being."

When we asked Laurie if we could share her amazing and painful journey in the newsletter, she immediately agreed.

"I don't want people to end up like I did," she says. "It's suspected that I have actually had this since early adulthood. If sharing my story can help prevent anyone from getting to the position I was in all these years, it will help make the whole experience worthwhile."

In recounting her long, hard journey, Laurie recalled an encounter from years ago. "I was walking my first baby one day in a baby carrier through a grassy area. It was a weird day. I saw a pack of deer approach me. Most deer run away. These didn't. I always wondered if that was the fateful day when I got the tick bite. Was that the day that changed my life forever?"

Youngest Patients Cont.

"I get their history and do a thorough physical exam," says Tara, "discussing our findings and giving them information on Lyme Borreliosis Complex - carefully, without overwhelming them."

While nursing and nurse practitioner programs teach very little about Lyme disease, Tara already had exposure to the subject because she knew people who had it, including one of her best friends.

"I remember wanting to impress Dr. Jemsek during my interview by telling him what I had learned about Lyme disease so far," recalls Tara. "But he stopped me right there and said, 'Forget everything you know! You'll learn a lot more here.'"

Tara says her training with Dr. Charles Ray Jones and her time here with Dr. Jemsek has dramatically expanded her knowledge - and made her much more aware of the disease's nuances and variations.

"Overall, the pediatric population's immune system and metabolism are different from adults, so they tend to respond better to treatment. Most do fine with oral antibiotic therapies. They tend to get better faster, overall."

What to Expect

Tara says the most important thing for her new patients to do when they first come to the clinic is give us a thorough history and a list of their medications, including any supplements. "Oh, and don't believe everything they read on the Internet!" she adds.

"I let them know we're here to help," says Tara. "We want to alleviate their symptoms and treat them effectively so they get better as quickly as possible."

Between 30 and 40 percent of the clinic's patients are in the pediatric age range, particularly teenagers and young adults. Tara enables us to offer these young people care that is specific and appropriate to their age group.

"It's sometimes hard to say exactly when they got infected," observes Tara. "Many could be congenital transmission, because we see their parents also."

Our pediatric approach typically includes pulse treatment - antibiotics taken every six to nine days - depending on each patient's individualized response. This differs from some doctors, who have their Lyme patients take antibiotics every day.

"This is still a new field," says Tara, "so different doctors use different approaches. Dr. Jemsek's pulse treatment strategy has proven very effective for our pediatric patients."

ILADS Conference Cont.

Dr. Jemsek was also a panelist during "Ask the Expert" sessions on Friday, October 28 (4:15pm-5:00pm, with Bernard Raxlen, MD) and Sunday, October 30 (10:30am-12pm, with Robert Bransfield, MD; Daniel Cameron, MD; and Steven Bock, MD).

"Physical findings are indeed discernable during clinical examinations," added Dr. Jemsek. "Technology, while often helpful, cannot be relied upon as the core of effective medical practice. A doctor's skills of observation and communication are vital tools in the diagnosis and treatment of Lyme Borreliosis Complex."

The conference was a great opportunity for Lyme disease specialists-as well as patients, friends, family members, and medical students-to share insights and learn about the latest advances. Dr. Jemsek feels that the conference was a great success and he hopes to return next year, as a presenter in a more expanded format!

Back in School Cont.

[Jordan was thrilled](#) to visit the Charlotte Motor Speedway in North Carolina recently to watch NASCAR driver Bobby Labonte make his qualifying runs for the Charlotte 500. This was her first time at the race track since last fall, although [Labonte has been in touch with Jordan](#) throughout the year by phone so he could keep track of her progress.



Another well-known friend, WBT radio personality Keith Larson, [hosted Jordan](#) at the station and came to her birthday party.

Jordan's brother, James, has also been doing great. He turned 12 years old in September and went back to school.



The content contained in this website is based on the opinion, clinical experience and clinical findings of Dr. Joseph Jemsek and the Jemsek Specialty Clinic. It may not reflect the opinion of the general medical community, as opinion within the medical community is deeply divided regarding the best approach for treating Lyme disease.

