

**My name is Patricia Watters and I am in support of SB 916 without amendments.**

I am the legal guardian for my granddaughter, Summer Garza, who, with proper testing through IgeneX Laboratories, was diagnosed with lyme disease in 2008, when she was 14 years old and a freshman in high school. By the time Summer received a positive diagnosis for lyme, and began the proper treatment as prescribed by the International Lyme and Associated Diseases Society (ILADS), the following had taken place:

In 1997, Summer was bitten by a brown recluse spider, and in 2000 she was bitten by a blacklegged tick. Both insects are lyme carriers. Summer was living in Oklahoma at the time.

Summer's symptoms began in 2003, after her family moved to Oregon, when at age 11 she began to complain of headaches. By age 13 the headaches became ongoing and severe. She also became very sensitive to bright light. Over the next year she began to have ongoing muscle aches and pains, severe, sharp pains in her wrists, weak knees so that her legs would give out, often collapsing on the floor. Next came tingling sensations in both hands and forearms, and numbness at times. Pain in her body increased. Next came vertigo and dizziness, with accompanying upset stomach. At times her speech was garbled, and she would have difficulty stringing words together. She also had daily vertigo, difficulty sleeping, and she began to have "brain fog" and trouble concentrating.

By age 14, in addition to the symptoms above, her headache worsened. She described it *"like a steel ball expanding in my head, about to explode."* Severe shooting pains started, and they would come at random times. Then came periods of fainting, the spells becoming more frequent. All symptoms worsened, and by now she was having hallucinations on occasion, was severely depressed, and had the feeling of "going crazy."

During this time, Summer's primary-care physician, who had been caring for her since age 11, was baffled by all of her symptoms. Meanwhile, I was on the internet trying to learn what could be the cause. I knew these symptoms were not psychosomatic. When I suggested to Summer's doctor that I believed she had lyme disease, he studied the now very long list of symptoms, and compared them with lyme symptoms, and gave a clinical diagnosis of lyme. Following Infectious Disease Society Association guidelines (IDSA), he ordered the Western Blot test, which came back negative, as is the usual case when a patient has had lyme disease over a period of time because the immune system is no longer fighting the illness.

In spite of the negative result on the Western Blot, Summer's primary-care physician was convinced that she had lyme disease and gave us a referral to a pediatric neurologist, who refused to recognize the possibility of lyme because the Western Blot came out negative, and instead, prescribed drugs for headache and mental fogginess, and referred her to a bi-weekly pain coping clinic. When her symptoms became increasingly worse, she was referred to physical therapists, a rheumatologist, who referred her back to a physiologist, who referred her to an infectious disease specialist who stated that there was no lyme in Oregon and that the Western Blot test was negative, and referred her to an anesthesiologist for pain control, who again referred her to a rheumatologist. In January 2008, Summer ended up in the psych ward at Emanuel Hospital for suicidal thoughts. The psychiatrist also denied lyme disease because the Western Blot test had proved negative. At this point, Summer was unable to attend school because her symptoms were so severe.

I knew then that, in the State of Oregon, Summer would never receive the medical care she needed, so I took her to Seattle, Washington, to a medical doctor specializing in lyme disease who, following ILADS guidelines, ordered a test through IgeneX laboratory, which proved positive for neuroborreliosis-Lyme Disease. Summer was put on a regimen of antibiotics, and by the following September was able to return to school. Today, because her doctor followed ILADS guidelines, Summer is completely symptom free and about to graduate from Portland State University.

## CHRONOLOGY OF LYME SYMPTOMS AND TREATMENT 2003-2009

### 1997: 5 years old

- Bitten by a Brown Recluse spider

### 2000: 8 years old

- Bitten by a tick when living in Oklahoma; believed to be a Blacklegged tick

### 2003: Symptoms beginning at around age 11:

- Shortness of breath (*diagnosed with asthma and put on asthma steroids*)
- Headaches of short duration with long periods in between.

### 2003-2005: Symptoms beginning age 11-13 (in addition to prior symptoms):

- Gradually the headaches became of longer duration and the periods between shorter.
- By 2004 the headache became ongoing with the "scale of intensity" shifting upward over time from a # 3 AM/ #6-8 PM, until by 2005 the headache was severe and ongoing.
- Tendonitis in both wrists
- Sensitivity to bright light
- Menstrual irregularity and stomach pains

### 2006: Symptoms presenting approximately age 13-14 (in addition to prior symptoms):

- Muscle aches/pain (neck, shoulders, back, arms)
- Severe/sharp pain in wrists; tendonitis
- Weak knees so legs give out, often collapsing to the floor
- Tingling sensations in both hands and forearms; numbness in hands at times
- Stiff, very sore neck and shoulders with knots (ongoing; creaking sound in neck)
- Dizziness/vertigo (daily)
- Insomnia (becoming an increasingly more major problem)
- Occasional garbled speech and difficulty in stringing words together
- "Brain fog" and difficulty concentrating and staying focused
- Almost constant nausea but no vomiting
- Sharp or aching pain in eyes (several times a week)
- Uncontrolled shaking of hand lasting several minutes
- Chills that come at odd times (when it's not cold)

### 2007: Symptoms presenting around age 14 (in addition to all of the above):

- Headache worsening ("like a steel ball expanding and my head is about to explode")
- Sensation of "pinched nerve" with pain running down arm and wrist
- Periodic sharp pain in center of chest becoming more frequent
- Soreness in ribcage area
- Severe, shooting pains occurring randomly in body many times/day and lasting 5-15 min
- Fainting (several episodes during the past three months) with spells becoming more frequent
- Carpal tunnel in both wrists causing severe pain in hands and arms; often unable to write
- Knees buckling frequently (ongoing)
- Feeling of "going crazy" at times; Depression (started taking Cymbalta for depression 8-20-07)
- "Flashes" in front of eyes (9-11-07)
- Severe pain in throat; lost voice temporarily (starting 9-13-07)
- Persistent unexplained cough at times
- Depression with suicidal thoughts becoming more frequent
- Fainting more often (two times at school on 9-18-07) and several times in the days following
- Severe menstrual cramps (irregular cycle)
- Pains in stomach and chest (beginning about 9-18-07)
- Asthma worsening (hospital visit 9-26-07)
- Vomiting occasionally (three times at school on 9-26-07)
- Sub-normal temperature (96.8-97.9)
- Extreme pain in neck; does not respond to pain medications
- "Hot flashes" alternating with chills
- Depression worsening; suicidal thoughts (possibly attributed to taking Cymbalta???) 11-16-07

### Jan 2008: Could no longer attend school; new symptoms included the following"

- Hallucinations (visual & auditory)
- CD57+NK Test count at 46 (normal range 200-360)
- Western Blot (IGeneX) positive for IgG (3 bands)
- Numbness starting in hand and moving up arm (2/08)
- Extreme fatigue, all-over muscle pain, headache unbearable
- Taken off Cymbalta but suffered withdrawals of heightened suicidal thoughts
- Depression worsening; hospitalized 1-8-08 to 1-19-08

**Feb 2008: Consulted Dr. Ross in Seattle Washington (no lyme doctors in Oregon)**

- Prescribed; Doxycycline 400mg/day for 3 weeks in preparation for Igenex blood test.
- Test was positive for neuroborreliosis-Lyme Disease

**March 2008 –June 2009: Began aggressive antibiotic protocol under Dr. Ross (LLMD in Seattle)**

- Probable Herx (all symptoms gradually worsening); Pain all over increasing; headache much worse; severe neck, back and shoulder pain; Dizziness and blackouts: worsening and becoming more frequent; Carpal Tunnel and Tendonitis in arms and wrists worse; Depression worsening (emotional; crawling into bed and sleeping for several hours during the day)
- Benadryl added to evening medications (antibiotics and Celexa)
- shooting neurological pains gone, no fainting or lightheadedness, all-over pain and headache greatly diminished (except when herxing from antibiotics);
- depression still a problem, though more able to cope

**Sept 2009: Returned to School to repeat 10th grade**

**Sept – June 2009 Continued Improvement**

- Asthma no longer evident; non-steroid Singulair continued as a precaution (asthma is often a result of untreated Lyme, and the steroids for asthma escalate the growth of the bacteria)
- Continuing to respond positively to antibiotics;
- End of school year excellent grades (all A's except math); very active; choir after school; ballroom dancing 3 days/week; Portland Youth Philharmonic weekly rehearsal and flute lessons;
- Brain fog and other symptoms gone;
- herxing from antibiotics exhibited as extreme fatigue and bad headache

**June 2009: Consulted Dr. Kimiai (lyme naturopathic doctor/practitioner)**

- Mercury amalgam fillings removed on advice of doctor (follows Dr. Klinghardt's protocol)
- Doctor determined through tests that the source of the lyme disease was the brown recluse bite, not the lyme tick, but believed that could have been the basis for some of the co-infections
- Other tests revealed the presence of lead, arsenic, mercury and silver; started on chlorella
- Muscle testing revealed the presence of bartonella, babesia, mycoplasma, rickettsia and Chlamydia pneumonia;

**July 2009: Started frequency treatment using GB-4000; discontinued antibiotics**

- Remaining symptoms include headache in varying degrees from 3 to 8 in intensity)
- Some fatigue if herxing from frequency treatment (experimenting to learn what works)
- Depression still a problem, though greatly alleviated with certain frequencies
- Very active in music, dance; Musical Theater and classical studies (summer months)

**July 31, 2009 will turn 17 years old: A long battle that is being won!!!**

**FINAL NOTE:**

**March, 2015: Summer Garza is now a senior at Portland State University and doing well**

- All symptoms of lyme are gone
- No meds of any kind, no depression; great attitude, doing well in college
- Has a job that totals 15-hours a week, along with a full college schedule

## HEALTH CARE PROVIDERS FOLLOWING IDSA GUIDELINES

|                                    |  |
|------------------------------------|--|
| Dr. Ron Culver, MD<br>4/04-Present | <u>Primary care physician since 2004</u> ; treated for recurring and ongoing headache with pain medications which had no effect. Referred her to Dr. Koch, pediatric neurologist at Doernbecher's Children's Hospital.   |
| Dr. Koch, MD<br>4/06-3/07          | <u>Pediatric Neurologist Doernbechers</u> ; diagnosed chronic daily headache (no tests such as CAT scan or MRI) and put her on the following drugs: Elavil (8/06-12/06) disc; no effect on headache; Depakote (12/06-2/07) mental foginess; discontinued; Topamax (disc; severe eye reaction)<br>Koch referred her to Doernbechers Pain Clinic |
| Pain Coping Clinic<br>6/06-10/07   | <u>Biofeedback Pain Control</u> ; Doernbechers; pain coping team included weekly visits to learn ways of coping with pain  |
| Dr. Laura Rubiales<br>4/06-7/06    | <u>Accupuncture/naturopath</u> ; referred by Dr. Koch for pain control; discontinued after four months   |
| Dr. Bobby Jones<br>5/06-7/06       | <u>Chiropractor</u> ; for muscle tension and knots; referred by Dr. Rubiales   |
| Dr. Raji Matthew                   | <u>Dentist</u> ; to check for TMJ disorder of other dental causes for headache   |
| Dr. Strasser<br>3/07-5/07          | <u>Cranial Osteopathist</u> for ongoing headache   |
| Connie Heddon                      | <u>Physical Therapist</u> (4/07) for carpal tunnel; no relief  |
| Dr. Kingsbury, MD                  | <u>Rheumatologist</u> ; (10-10-07) inconclusive; referred her to a physiologist; seemed pointless; did not follow up   |
| Dr. Guzman, MD                     | <u>Infectious Disease Specialist</u> ; (10-17-07) inconclusive; referred her back to a neurologist   |
| Pain Coping Clinic                 | <u>Referred her to Dr. Koh, an anesthesiologist for pain medication</u>  |
| Dr. Jeffrey Koh, MD                | <u>Anesthesiologist</u> (11-06-07) referred her to a rheumatologist  |
| Dr. Kingsbury, MD                  | <u>Rheumatologist</u> (no help; referred back to Dr. Koh for pain relief)  |
| Dr. Crombie, MD<br>1/8/08-1/19-08  | <u>Psychiatrist</u> (Emanuel Hospital psych ward) 1/08; checked in willingly because of severe depression and ongoing suicidal thoughts; Dr. Crombie denied Lyme; diagnosed bipolar disorder<br><b>END IDSA GUIDELINES;</b>  |

## BEGINNING ILADS GUIDELINES

|                                 |   |
|---------------------------------|---|
| Dr. Marty Ross, MD<br>2/08-8/09 | <u>LLMD (Lyme Literate Medical Doctor)</u> followed ILADS Guidelines over the next 1-1/2 years; gradually symptoms disappeared  |
| 9/09-present                    | Summer able to return to high school; lyme symptoms gradually dropped off; Graduated from high school in 2011; is currently symptom free and about to graduate from Portland State University |