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Re: Aeneas Heller
DOB 4/17/95, 9 4/12 years old
Greiffenbergstr 33
96052 Bamberg/Germany

On 8/12/04 I received a telephone call from 9 year old Aeneas Heller's mother, Petra Heller, informing me that her son had been taken away from her because she was accused of "mistreating him with prolonged use of unnecessary IV antibiotics for treating his Lyme disease". Obviously, Petra was upset and crying and was desperately trying to find out where her son had been taken and how she could get him back. She was concerned about Aeneas' reaction to being taken from his mother and that his Lyme disease would worsen if IV antibiotics were discontinued prematurely. She asked me to intercede on Aeneas' behalf.

I have been advising Petra Heller appropriately about treatment of her son's chronic persisting Lyme disease since 2002. Aeneas has improved since being treated with IV Rocephin and vancomycin. He has more energy. He has less joint pain. He is reading better and has fewer headaches. Petra Heller sought my advice because she wanted the best care from a professional with expertise in treating Lyme disease.

Please allow me to clarify my experience in this case. I am a physician in the practice of pediatric and adolescent medicine. I have evaluated and treated over 7000 children between one day and 18 years old with Lyme and other tick-borne diseases from every state in America and every continent abroad. No other physician has my experience in treating children with tick-borne diseases. At Columbia University there are several endowed funds to support research and education. One of these funds is called the "Charles Ray Jones Endowment Fund". The purpose of this fund is to educate medical students about Lyme disease and other tick-borne diseases. The fund was named after me to honor my dedication and pioneering work as a pediatrician devoted to helping

children with chronic Lyme disease and related disorders. Medical students from Columbia who are awarded this fellowship spend time learning about Lyme disease from me in my office at 111 Park Street, New Haven, Connecticut 06511. I am also a charter member of The International Lyme and Associated Diseases Society.

Aeneas has ample evidence supporting the clinical diagnosis of Lyme disease and has laboratory evidence indicating exposure to the *Borrelia burgdorferi* spirochete, the bacterium that causes Lyme disease. The CDC stipulates that the diagnosis of Lyme disease remains clinical and the rigid CDC surveillance criteria, including ELISA and Western Blot, should not be used to make a diagnosis of Lyme disease.

Aeneas Heller has had two significant epidemiological risks for exposure to the *Borrelia burgdorferi* spirochete, the Lyme bacterium: 1.) through gestational transmission, and 2.) from *Ixodes scapularis* tick attachments. Aeneas' mother, Petra Heller has had Lyme disease since 1985. Her Lyme disease was not treated until long after Aeneas was born. Aeneas has had 3 known *Ixodes scapularis* tick attachments: in 1995 (below his clavicle), in 1998 (on his hand), and in 2001 (on his arm).

Aeneas has clinical symptoms and responses compatible with Lyme disease: fevers, night sweats, chills; weight gain; fatigue, tiredness; sore throat; swollen glands; pelvic pain; irritable bladder; abdominal pain; diarrhea; chest wall (rib) pain; shortness of breath; bradycardia, apnea; joint pain and swelling (knees, toes); stiffness (neck, back); daily headaches since 1998 when he was 3 years old; tingling paresthesias in his fingers and toes; light sensitivity; floaters; impaired hearing; motion sickness; poor balance; tremor; confusion, difficulty thinking; difficulty with reading due to an increase in headache if he reads more than 2-4 minutes; disorientation, going to the wrong places; disturbed sleep; Jarisch-Herxheimer reactions; and improvement on antibiotics, especially IV antibiotics.

Aeneas has serological evidence of exposure to the *Borrelia burgdorferi* spirochete, the bacterium that causes Lyme disease; 7/7/00 Laboratoriumsmedizin Lyme Western Blot IgG 34 39 41. Bands 34 and 39 are genus specie specific for *Borrelia burgdorferi* and confirm the clinical diagnosis of Lyme disease.

There are nine known Borrelia burgdorferi genus specie specific KDA Western Blot antibodies (bands): 18 23 30 31 34 37 39 83 and 93. Only one of these Borrelia burgdorferi genus specie specific bands is needed to confirm that there is serological evidence of exposure to the Borrelia burgdorferi spirochete and can confirm a clinical diagnosis of Lyme disease. CDC Western Blot IgM surveillance criteria includes only two Borrelia burgdorferi genus specie specific antibodies for IgM 23 and 39 and excludes the other seven Borrelia burgdorferi genus specie specific antibodies. CDC Western Blot IgG surveillance criteria includes 18 23 30 37 39 and 93 and excludes bands 31 34 and 83. It does not make sense to exclude any Borrelia burgdorferi genus specie specific antibodies in a Lyme Western Blot IgG and to include only two of these antibodies in IgM because all the antibodies in IgG were once IgM. IgM converts to IgG in about two months unless there is a persisting infection driving a persisting IgM

reaction. This is the case with any infection including the Borrelia burgdorferi induced Lyme disease. CDC wrongfully includes five non-specific cross-reacting antibodies in its Western Blot surveillance criteria: 28 41 45 58 and 66. This leads to the possibility of false positive Lyme Western Blots. There can be no false positives if only Borrelia burgdorferi genus specie specific antibodies are considered. One can have a CDC surveillance positive IgG Lyme Western Blot with the five non-specific antibodies without having any Borrelia burgdorferi genus specie specific antibodies. This does not make sense. CDC recommends that the Lyme Western Blot be performed only if there is a positive or equivocal Lyme ELISA. In my practice of over 7000 children with Lyme disease, 30% with a CDC positive Lyme Western Blot have negative ELISA's. The Lyme ELISA is a poor screening test. An adequate screening test should have false positives not false negatives.

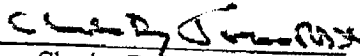
Aeneas is responding to IV Rocephin and vancomycin. These, or other, antibiotics should be continued for at least two months after his Lyme symptoms and signs have resolved. If antibiotics are stopped prematurely, such as now, he will relapse and have more body and brain injury from a more resistant, difficult to treat residual Borrelia burgdorferi spirochete. Aeneas must not become a victim of erroneous concept that all Lyme disease can be successfully treated and all Borrelia burgdorferi spirochetes eradicated with an arbitrary 3-6 week course of antibiotic therapy. There is ample evidence in the peer reviewed medical literature that the Borrelia burgdorferi spirochete can survive prolonged antibiotic therapy of one month, six months and even several years of intensive IV antibiotic therapy. This evidence must not be ignored in any objective determination of what constitutes adequate, curative therapy for treating Lyme disease. Enclosed is a recent expert consensus panel report published on the treatment of chronic Lyme disease by the International Lyme and Associated Diseases Society (ILADS) which supports the use of long-term antibiotic therapy in chronic Lyme disease. It should also be noted that longer courses of antibiotic therapy are appropriate when indicated for other disorders as well, such as acne, malaria, tuberculosis, leprosy, etc. Three-quarters of the over 7000 children I have treated for Lyme disease have been treated with 3 months to 7 years of continuous oral, IM, or IV antibiotic therapy. These children are well and without symptoms 2-15 years after stopping adequate antibiotic therapy. A more typical duration of treatment of children with persisting Lyme disease is 2-3 years unless a child has gestational Lyme disease. Children with gestational Lyme disease require longer treatment to eradicate their Lyme infection. None of these children on appropriate long-term antibiotic therapy have had damage to any organ or system as a result of antibiotic treatment. However, these children with chronic Lyme disease have brain, spinal cord, eye, thyroid, lung, heart, GI tract, and GU tract damage if treatment is not long enough to eradicate all of the Borrelia burgdorferi spirochetes. Aeneas is one of these children who require prolonged antibiotic treatment. Any interruption of his antibiotic therapy and/or emotional trauma will cause him to have Lyme relapse with more brain and body injury.

I am impressed with the responsible care provided by Petra Heller for her son. She has actively sought the best care for Aeneas from professionals with special expertise in treating Lyme disease. She does not suffer from Munchausen by proxy. She should

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not be penalized for having more knowledge about Lyme disease than many physicians and for using this knowledge in seeking appropriate medical care for her 9-year-old son's chronic persisting Lyme disease.

I am available to help in any way necessary to resolve this tragic error.


Charles R. Jones, M.D.