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Teen's Care Spurs Wider Fight

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By Joseph De Avila
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Linda and Lou Pelletier of West Hartford, Conn., in their kitchen. The couple is fighting over custody of their daughter, Justina. Julie Bidwell for The Wall Street Journal

When Lou and Linda Pelletier sent their 15-year-old daughter, Justina, to Boston Children's Hospital in February 2013, they thought it was a worrisome but temporary stay for a severe bout of the flu.

But within days, the Connecticut couple had lost custody of their teenager to the state of Massachusetts over allegations of medical child abuse.

Justina had previously been treated by Tufts Medical Center in Boston for an uncommon genetic disorder, but Boston Children's doctors disagreed with the treatment plan, successfully arguing to child-safety authorities that she was receiving unneeded medical care and that the girl also needed mental-health treatment, according to an account from her parents.

The hospitals declined to comment.

On Monday, the family heads to juvenile court in Massachusetts, hoping, they say, to hear whether Justina can leave a mental-health and social-service agency for children in Framingham, Mass. A juvenile court judge, who has reviewed Justina's medical history, has declined for over a year to award custody back to her parents.

The parents also say they expect to learn whether the father's public comments about the case—despite a judge's gag order—will be subject to any penalty or other action.

The case has drawn attention nationwide as medical practitioners and child-safety officials grapple with how to handle sensitive disputes between doctors and parents over appropriate treatment for children.

The Pelletiers, who live in West Hartford, Conn., said they brought Justina to Tufts for specialized treatment in 2011 at the age of 13, when she began experiencing stomach pain and digestive issues.

She began treatment for mitochondrial disease, a genetic disorder that can cause a decrease or failure in function of several bodily organs.

Her treatment included a regimen of prescription drugs and vitamin supplements. Boston Children's doctors later objected to some of the drugs she was prescribed.

The Pelletiers now see their daughter under supervision once a week and for an hour at a time. Mr. Pelletier said he and his wife are worried their daughter isn't receiving the treatment she needs, complaining that she can't sit up, is physically weak and has generally declined in health since they lost custody.

The facility where Justina is receiving care, Wayside Youth & Family Support Network, declined to comment specifically on the case, citing privacy laws. In an email, the agency said: "We are confident in the quality of care we provide to all individuals."

Boston Children's Hospital declined to address specifics, also citing health-privacy laws and a court-ordered gag order on the case, but issued a statement: "Boston Children's and our clinicians are particularly distressed that the inaccuracies surrounding this case have caused undo concern for the many children and their families with Mitochondrial Disorders in our care.

"This is a very complex case that presented an array of challenges," the hospital continued. "We act in the best interest of our patient's health and well-being. We are pleased with the progress our patient made as an inpatient and now that progress continues at another facility."

The Pelletiers want Justina to receive treatment back in Connecticut from Tufts specialists.

"My job as a father is to save my daughter's life," said Mr. Pelletier, a financial planner who has three other children with his wife.

The Pelletiers' case highlights the thorny issues involved in alleged medical child abuse, which occurs when parents or guardians give unneeded and sometimes damaging medical care to their children.

"It's an area that is not well defined in ethics. It's not well defined in medical care," said Aviva Katz, chairwoman of the bioethics committee for the American Academy of Pediatrics.

Adam Kolber, a Brooklyn Law School professor who teaches health law and bioethics, said courts have to weigh "the risks of child abuse to the risks of separating a child from a safe and nurturing parent."

At Tufts, a metabolic-disorder expert handled Justina's treatment for mitochondrial disease. Her parents said they took her to Boston Children's to see a gastroenterologist, who previously worked at Tufts and performed medical procedures on Justina in the past. Tufts, in declining to comment, cited patient confidentiality.

Boston Children's doctors questioned whether Justina had mitochondrial disease, Mr. Pelletier said, adding that he and his wife disagreed and refused to sign off on a new treatment plan. Hospital officials then filed a report with the state Department of Children and Families, stating that they suspected that she was suffering from abuse or neglect. Medical practitioners are required by law to report any instances to the state where they suspect there may some sort of abuse or neglect.

Boston Children's also told the Pelletiers that Justina has somatoform disorder, a condition where a person experiences pain that has no underlying medical causes, according to Mr. Pelletier.

The symptoms of mitochondrial disease resemble many other conditions so it can be difficult to diagnose, said Philip Yeske, science and alliance officer with the United Mitochondrial Disease Foundation. Boston Children's and Tufts both have specialists who treat the disease.

Mr. Pelletier said his family is exasperated by the separation from Justina. He said he hopes to regain permanent custody but is currently focused on getting her transferred to a facility closer to home.

"Now we are fighting about where she can be seen medically," Mr. Pelletier said.

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