

Judge seeks options for disabled mother, dying son

DA's office seeks to end parental rights because of baby's needs

By MARY ZAHN

mzahn@journalsentinel.com

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Luke, who is 18 months old, has eyes that dance and sparkle and a smile that lights up a room. He is oblivious to the tragedy that faces his family and the courtroom hearings his life has sparked.

Luke is dying of a rare genetic disease, and doctors believe he has already lived half his lifespan. His 28-year-old cognitively disabled mother, Anastasia Schoenfield, known as Annie, is fighting for the right to remain his mother until he dies. Her son, she says, is the most important person in her life.

The Milwaukee County district attorney's office filed a petition to terminate Schoenfield's parental rights as quickly as possible because of her limited mental abilities and because complicated medical decisions will have to be made on Luke's behalf as his life draws to a close.

Luke has been in a foster home since shortly after birth because of his many medical needs.

No one disputes that Schoenfield and Luke have a loving bond. When Luke was born sickly, she often slept in the hospital room, so she could be close to him. When she was told that he had Menkes syndrome - a rare and lethal disorder of copper metabolism that also killed her younger brother - she wept and had the hospital chaplain baptize him. Since his birth and placement in foster care, she has continued to visit him regularly, sometimes with other family members.

But it is equally clear Schoenfield is not able to care for Luke's physical needs - something she and other family members acknowledge. Records show she even had difficulty with bottle feedings in the hospital. However, Schoenfield has signed documents authorizing Luke's continuing medical care when asked and has cooperated with the Bureau of Milwaukee Child Welfare. In June, she signed a do-not-resuscitate document for her son.

'There has to be a way'

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Schoenfield's Struggle



Photo/[Jack Orton](#)

Anastasia Schoenfield (left) and her mother, Barbara Tanis, look at a family photo album at Tanis home in Waukesha last Saturday.

Quotable

“In five volumes of Wisconsin statutes, there has to be a way to continue to let her be a mother to this child and prepare for what ultimately is going to happen.”

- Childrens Court Judge Dennis Cimpl

ultimately is going to happen," Children's Court Judge Dennis Cimpl said at a hearing in late June. "The problem is the state has brought a lawsuit to terminate her rights as a mother forever."

The main reason for the move to end Schoenfield's parental rights is to allow Luke's foster parents, who have agreed to adopt him, to make final decisions regarding his complicated medical needs and end-of-life care, Cimpl was told.

Schoenfield and her mother, Barbara Tanis, would continue to be able to visit him, authorities said. However, if Schoenfield's parental rights are terminated - and unless a special agreement is reached - she would no longer have to approve or be informed about medical decisions for Luke and biological ties would be forever severed by the legal system.

"My son makes me happy," Schoenfield said with a sweet smile as she clutched a pink photo album. Inside were pictures of Luke and her brother, Justin, who died of the same disease in 1979 when he was a little more than 3 years old - the general life expectancy for children with the illness. (The Journal Sentinel has changed Luke's name in this story at the request of the family and to protect his confidentiality.)

For Schoenfield's mother, the court hearings have a tragic *déjà vu* quality. After Justin was born with the disease in September 1976, child welfare authorities tried to remove him from her care because of bone abnormalities that doctors thought were fractures caused by physical abuse. In fact, the abnormalities were part of Menkes syndrome, and the allegations against her and her then-husband were dropped.

That case was reported in Madison and Milwaukee newspapers and in at least one national magazine.

"We were abused by a bureaucracy that got out of control," Tanis was quoted as saying at the time. Today, she told a reporter, her feelings are similar.

"I would just like Annie to be able to be his mother to the best of her ability until the end," Tanis said. She stressed that Luke's foster parents and case managers have "been wonderful" and that her daughter is not asking for physical custody, only to remain as his mother.

In recent months, Luke's care needs have increased as he has become lethargic, is no longer able to roll or push himself up on his arms and has had a feeding tube inserted, according to court testimony. Luke is also part of a National Institutes of Health research study on the disease. He has been receiving daily injections as part of the study.

Luke's "personality and spirit have not changed, however, and his smile and giggle can still light up a room," case managers wrote in a report to the court.

Guardianship considered

At last month's hearing, Cimpl said he was not convinced that terminating Schoenfield's parental rights was the only option and asked the district attorney's office to consider a

guardianship action. That would enable the foster parents to make medical decisions for the child without the mother's permission but would allow Schoenfield to remain Luke's mother, Cimpl indicated in the hearing.

However, Mary Sowinski, an assistant district attorney, said in an interview that legal guardians have a right to make routine medical decisions, but that it is unclear under state law whether a biological parent still has the right to intervene in end-of-life decisions.

Her office, she said, is negotiating a settlement with Schoenfield and her attorney and is considering all options. Cimpl ordered the case back into court on July 20.

Meanwhile, Schoenfield and her extended family have scheduled another baptism for Luke - this one in a church - for this summer.

"Her main concern is that she be allowed to see her child until he passes away," Tanis said. "And that he get buried next to her brother."

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