Mom Knows Best

State can’t make her give son meds

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Under the nation’s glare, Valerie Emerson, 27, played tug-of-war with the Maine Department of Health Services (DHS) over control of her child’s anti-HIV treatment until September, when she won the right to withhold meds from her 4-year-old son, Nikolas.

Once Emerson’s doc got wind of her decision to stop treating the asymptomatic Nikolas -- after 10 weeks on AZT, he “lay on the floor and moaned and cried,” she said -- the doc told the DHS, which filed a child-protection order, alleging that waiving drug treatment is child abuse and neglect. “The child ought to be afforded medical treatment extending his life,” said DHS Commissioner Kevin Concannon. But Emerson, HIV positive and med-free herself, argued that Nikolas’ “now” takes priority over his future. “Quantity is something I have no control over, quality I can control,” she said. “If I can delay the side effects for a couple more months so he can be a little boy, that’s what I’m going to do... Within two months after I stopped the AZT, he was on the road back.” Emerson watched Nikolas’ big sister, Tia, suffer crippling AZT side effects before becoming resistant and then dying of AIDS in 1997 at age 3. Her decision to discontinue Nikolas’ treatment, she said, resulted from research -- not depression, as the DHS contended.

Besides noting that AZT monotherapy is substandard treatment, Maine district court judge Douglas Clapp wrote: “The state of Maine is in no position to tell her, in the case of her unique experience, that she is wrong in her judgment to wait for better and more reliable treatment methods.” And that’s exactly what Emerson intends to do. She said she wants Nikolas to be “as receptive as possible” to the better drugs she believes are down the road. Although her son could likely benefit from combo therapy, Emerson said: “It’s not a cure, it’s a hopeful. If it was a cure, then yes, I’d be negligent as hell for not giving it to him.”

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