

CONTINUED FROM PAGE 1A

McKenna

(continued)

Shannon and her husband, Rand, are forced to do it anyway.

Their situation also forces them to confront issues of medical ethics as they make decisions about McKenna's treatment. With Drew, they didn't know what was wrong; it took almost a year before doctors correctly diagnosed why he was having seizures. During the time that he was sick, the Olsons had faith and hope that he would recover.

Then he tested positive for Alpers' disease. They found out nine days before he died in August, just shy of his second birthday. McKenna was 5 months old.

"It's so hard to do this with McKenna because we think of (Drew) every day," said Shannon Olson.

"There's no way she won't die."

DISCOVERING ALPERS'

Alpers' disease is estimated to affect fewer than 1 in 200,000 people, according to Dr. Frank Ritter, a pediatric neurologist who specializes in epilepsy at Children's Hospital of St. Paul.

The first symptoms usually begin with seizures early in life. In most cases, the disease kills a child within three months after the onset of symptoms.

"The most difficult thing is treating someone ... so young," said Ritter, who treated Drew and is now treating McKenna. "They start out looking so good and you know that they will probably die by the time they're 2."

Drew had his first seizure after waking up from a nap shortly after turning a year old in 2004, said Rand Olson. His father noticed his son's left leg twitching while changing his diaper. He tried holding it to see if it would stop, but within minutes the twitch spread to his arm. Drew was awake and alert but having a seizure.

At first, doctors at Children's Hospital thought viral encephalitis was the cause of the nearly nonstop seizures. Drew had episodes of seizures four more times last year. After each one, he would learn how to move again in physical therapy. He went blind for three months after his third episode. By his fifth seizure, he lost his sight again and stayed in the hospital until he died, five days before turning 2.

The couple had a 1-in-16 chance of having both children affected by Alpers', according to Ritter. They say that if they had known they were genetic carriers, they wouldn't have had children.

"We wouldn't have taken the chance," Shannon Olson said.

Her son from a previous relationship, Cameron, who lives with Shannon and Rand, is a carrier, too. But nonetheless, the disease has taken a toll on the 8-year-old. The Olsons try to maintain a normal life for Cameron by keeping him in



In a family snapshot, Cameron Olson, 8, reads to his baby sister, McKenna. Cameron is a genetic carrier of Alpers' disease, the fatal inherited neurological disorder that killed his year-old brother, Drew, last year and afflicts 11-month-old McKenna.

school and shuttling him to hockey practice, but his mother feels guilty for her absence. "I don't even remember him being 7 or 8. I just remember being here (in the hospital)," she said. "It was hard for him with Drew. It's just too hard for him (now). He deals with it by not being around (McKenna)."

MCKENNA' FIGHT

McKenna had her first seizure on Valentine's Day while on a vacation at Disneyland. The family took the trip hoping to create memories with McKenna before she got sick. On the last day there, Rand Olson picked her up from the crib and noticed her left leg started twitching — just as Drew's had done. "Her whole life we've been on pins and needles knowing something is going to happen, but not knowing when," said Rand Olson. "Anytime anything goes on you ask yourself, 'Is this the beginning of the end?'"

Doctors at a children's hospital in Orange County, Calif., had never treated anyone with Alpers' disease. They put her in a drug-induced coma for a week while her parents desperately tried to get her back to Ritter in Minnesota.

Because she couldn't fly commercially, McKenna returned on a private medical plane — which her insurance refused to pay for. A distant relative of the family, who paid for the trip to Disneyland, picked up the bill for the \$20,000 flight.

The Olsons accepted the money, but plan to repay him. Shannon Olson also quit her job as an import custom broker to

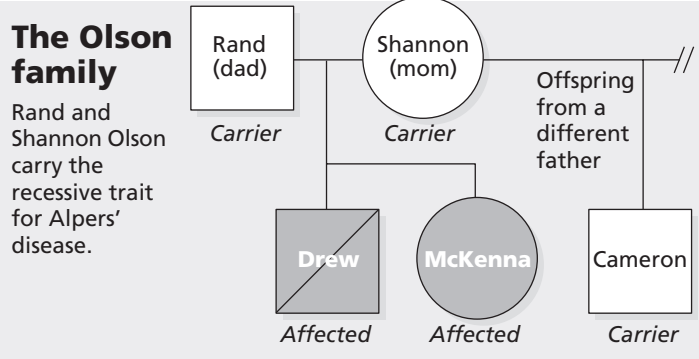
Inheritance of Alpers' disease

Alpers' is a genetically determined disease of the brain, usually found in very young children. The gene responsible for the disease is autosomal recessive, which means it is a nuclear gene, not found on the sex chromosomes. Symptoms can include: seizures, developmental delay, low muscle tone, dementia and conditions that can lead to liver failure. Treatments for the seizures are available, but no cure has been found.

What are the odds

If both parents carry the recessive trait, each child would have a one in four chance of getting the disease.

MOM	A	a	A = Normal gene	a = abnormal gene
DAD	A	AA	25% AA	= Non-affected/ non-carrier
	a	Aa	50% Aa	= Non-affected/ carrier
		aa	25% aa	= Affected



Source: Matthew Bower, genetic counselor, University of Minnesota Medical Center, Fairview; National Institute of Neurological Disorders and Stroke STEVE THOMAS, PIONEER PRESS

care for her children. Their friends and family are organizing benefits to repay the debt and their medical bills.

Back in Minnesota, Ritter woke McKenna from the coma. On Feb. 28, after a week in the hospital, her parents met with Ritter and Dr. Don Brunnquell, a psychologist and director of the Children's Hospital office of ethics. Brunnquell educates and

counsels families faced with ethical dilemmas.

He asks them three questions:

- What are the harms and benefits of each treatment and the treatments together?
  - What do you need to do to be a good parent to your child?
  - Are we doing things to a child or for a child?
- "Often there are no good

choices, but (parents) still need to do something," he said.

Shannon and Rand Olson understand that Drew's life was prolonged by the aggressive treatment they sought for him. He endured MRI and CT scans. He took different types and dosages of drugs to stop his seizures — at a time when everyone thought the battle was with seizures.

"I don't know if it was a good life. He suffered a lot," said Shannon Olson. "I would take Drew back in a minute any way that I could get him, but I feel that's selfish."

They know what will happen with McKenna. Shannon and Rand believe it's just a matter of time before their daughter will lose her vision, and then her life.

"If our kids had cancer, we could fight it," Shannon Olson said. "But we've got nothing to fight. We just sit and watch them die."

McKenna's parents didn't discuss with Brunnquell how long they would sustain life for her once she gets really sick. It's one of the toughest questions for a parent: How far will they go to keep their daughter alive knowing she has a fatal disease?

"They're really being very courageous in taking the child's point of view and trying to understand what's best for McKenna," Brunnquell said.

Ritter tried to predict at the meeting how much time McKenna has left, but it's difficult to say whether she has three months or a year to live.

McKenna's parents know they want her to be comfortable and pain-free. Although her

HELPING MCKENNA'S MIRACLE FUND

■ Little Learner Super Store, Kenrick Plaza, 16442 Kenrick Ave., in Lakeville: The store will donate 20 percent of its proceeds between 9 a.m. and 4 p.m. Saturday to the fund.

■ Chevys Fresh Mex, 2251 Killebrew Drive, in Bloomington: The restaurant will donate 15 percent of its proceeds from patrons dining between 11 a.m. and 10 p.m. Sunday to the fund. You must present a flier, found at [www.caringbridge.org/mn/drewolson](http://www.caringbridge.org/mn/drewolson), to donate.

■ Olson benefit at the Prom Center, 484 Inwood Ave., in Oakdale: Participants can enjoy food and a silent auction April 9. Tickets are \$20 for adults, \$10 for children, and children under 2 are free. Proceeds will be donated to the fund. Send e-mail to [mckennasmiracle@yahoo.com](mailto:mckennasmiracle@yahoo.com) to purchase tickets or for more information.

■ To donate to McKenna's Miracle, go to Lakeview Bank, 9725 163rd St. W., in Lakeville.

■ More information about McKenna Olson is available at [www.caringbridge.org/mn/drewolson](http://www.caringbridge.org/mn/drewolson).

mother is relieved to put a name to the disease, in the end it doesn't change the fact she knows her daughter is going to die.

Shortly after the meeting at the hospital, the Olsons were able to bring McKenna home. She's on medication that reduces her seizures to 10 to 15 a day, which may be the best they can ask for. McKenna turns a year old on March 22.

"She is so happy to be home. We even got a few smiles out of her," Shannon Olson said. "Having our family under one roof is beautiful. Right now, our goal is we'll do whatever we can with her. We have no idea what each day will bring."

When McKenna is gone, Shannon Olson realizes she will have a smaller family again with her husband and Cameron. She fears forgetting her children, like the smell of Drew on his pillowcase or his cute little toes. Her dreams of Drew help her remember.

"God and me are going to have some words," she says. "At the end of the day, I still have God. I know I will never know the answers here on this earth, but someday I will."

"It's hard to live every day with it," she adds. "I do find comfort in knowing that her brother is going to be there waiting for her."

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Moussaoui case

(continued)

shaken her confidence that Moussaoui can receive a fair trial.

"I don't think in the annals of criminal law that there has ever been a case with this many significant problems," the judge said.

Prosecutors in her courtroom formally objected to her ruling, and the judge later recessed the trial until Monday to give the government time to consider an emergency appeal before the 4th U.S. Circuit Court of Appeals in Richmond, Va.

That court is considered conservative and generally supportive of law enforcement in criminal cases.

Moussaoui pleaded guilty last year to capital murder for having a role in the Sept. 11 conspiracy. The trial that began last week is to determine whether he should be sentenced to die or spend the rest of his life in prison.

Prosecutors argue that by failing to tell FBI agents about the Sept. 11 plot when he was arrested, Moussaoui — who had been enrolled at an Eagan, Minn., flight-training school — deprived the government of the chance to boost aviation security and to try to track down would-be hijackers to foil the terrorist attack.

With due warning, prosecutors say, airport security screeners would have restricted passengers from bringing small knives and box-cutters aboard planes. Box-cutters were the main weapons used against passengers and crews aboard the four hijacked aircraft.

Without such testimony or evidence from aviation officials, the government would be hard-pressed to show the relevance of Moussaoui's arrest to the overall Sept. 11 plot. The FAA witnesses constituted about half the government's case, prosecutors said.

The official at the center of the furor is Carla Martin who, until this weekend, was a senior Transportation Security Administration attorney.

At a hearing Tuesday, a half-dozen prospective FAA witnesses described how Martin repeatedly violated the judge's written order against shaping witness testimony or allowing them to see transcripts of earlier trial sessions. They said she sent them copies of the prosecution's opening statements in the trial and pointed out errors she thought made the FAA look less than diligent in the days before the Sept. 11 tragedy.

She advised some witnesses how to testify and what to say, told one he should not agree to be a witness for the defense despite his subpoena to do so, and apprised others that she did not think the case was going well for the United States.

Martin herself was called as the first witness Tuesday. The judge warned her that she faced civil and criminal punishment for her actions, then postponed Martin's appearance until later in the week.

The witnesses collectively described a woman who was overzealous in her work, took up large amounts of their time, and often seemed preoccupied with how the FAA would look in the public's eye after the FAA witnesses testified.

They also said Martin never told them about the judge's Feb. 22 order barring witnesses from reviewing trial transcripts or watching news accounts of the

trial. The witnesses said that this past weekend, after prosecutors learned what she had done, Martin called them at home and urged them to ignore the transcripts as well as any media reports about the case.

Patrick McDonnell, a retired FAA director of intelligence, said Martin phoned him at home over the weekend, urging him to ignore her earlier e-mails and not to read transcripts or read or watch news accounts of the trial. But by then, he said, it was too late.

"We have CNN and the news networks on," he said.

Matthew Kormann, a TSA intelligence liaison officer, said Martin had instructed him not to obey a subpoena by the defense or agree to be one of their witnesses.

After the FAA witnesses described how Martin dealt with them, defense attorney Edward MacMahon urged the

judge to strike the death penalty from the case and sentence Moussaoui to life in prison with no parole.

"This is Mr. Moussaoui's trial and it needs to be fair from a constitutional standpoint," MacMahon said. He said when Martin instructed some witnesses to cooperate with the defense "it was a clear due process violation."

David Raskin, an assistant U.S. attorney and part of the three-man prosecution team, said the FAA witnesses were independent-minded and not affected by Martin's conduct.

"Martin," he said, "simply was a little too aggressive in involving herself in this case," Raskin said.

But the judge said she could not know how badly the witnesses were tainted, and that her only alternative was to ban any aviation-related testimony or evidence from the trial.

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