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CHILDREN AT RISK
HIGH COURT RULES IN FAVOR OF YOUNG CANCER SURVIVOR, EXPOSING LITTLE KNOWN EXCLUSIONS
IN HEALTH CARE POLICIES

Judith Davidoff The Capital Times

Kevin and Amy Summers have always considered themselves responsible citizens. They live modestly, pay their taxes and make sure their family is covered by insurance.

But when the Appleton couple's then 3-year-old son, Parker, was diagnosed with a rare form of brain cancer in 2002, their carefully constructed safety net turned out to be illusory. The stem cell rescue therapy recommended by Parker's pediatric oncologist at UW Hospital and Clinics was turned down for coverage by Touchpoint Health Plan, the Summers' insurance company.

The couple tried to get approval a second time after Parker's oncologist, Dr. Diane Puccetti, agreed to treat Parker outside of a clinical trial, but Touchpoint again refused to cover the therapy.

The couple were faced with an excruciating choice: go forward with the stem cell therapy without knowing how they'd pay for the expensive treatment, or put Parker through a regimen of radiation that was covered by insurance, but was more likely to inflict damage on his internal organs.

They chose the first route and their gamble paid off. This past weekend, Parker, now 8, celebrated 5 years of remission with a large party at his home.

The family had another reason to celebrate. Late last month, the Wisconsin Supreme Court agreed that Touchpoint should not have denied coverage and it ordered that the HMO retroactively reinstate benefits and "resolve any other collateral issues."

Attorney Bob Dreps of Godfrey & Kahn, who represented Touchpoint (and who has also represented The Capital Times on First Amendment matters), says he is not planning to appeal the decision. He admits he is "disappointed" with the ruling but offered no further comment, deferring to officials at Touchpoint, who also declined to

comment.

Steve Meili of the UW Consumer Law Clinic, which represented Kevin and Amy Summers along with attorneys from **Lawton & Cates**, said such cases are not easy to win under federal law because plaintiffs need to prove that the denial of coverage was "arbitrary and capricious."

"That's a difficult standard to meet," he says.

Meili says the ruling sends a strong message to insurance companies that they need to be "transparent in the way they deal with their customers."

Moreover, when insurers draft policy exclusions, they have to be unambiguous and "not so broad that they become the rule rather than the exception," Meili adds.

Patient advocate Meg Gaines says the decision should also alert consumers to the fact that virtually all health insurance policies contain provisions excluding coverage for clinical trials - where the treatment is monitored and results are quantified - and anything deemed experimental.

This is particularly problematic for families whose children get cancer, since most childhood cancers are treated - and usually treated successfully - within the context of a clinical trial, say Gaines and others.

"Greater than 90 percent of children are treated on these clinical protocols," says Puccetti, who adds that upwards of 80 percent of children are "cured" after treatment.

"If an insurance policy has an exclusion for clinical trials, that's a huge number of children who should be treated in that way and are not getting coverage for it."

Adds Gaines: "The vast majority of people don't know their children are not covered for cancer care as a technical matter. It is at the discretion of a profit-making enterprise, not your doctor."

(Drop cap) Parker's symptoms first appeared when he was just 3.

"Mommy, my hand is not working," Amy Summers recalls her son saying.

Soon thereafter Parker was diagnosed as having a cancerous brain tumor known as an anaplastic ependymoma, a rare form of childhood cancer. His doctor referred him to the UW Hospital for removal of the tumor and Touchpoint paid for the surgery.

After surgery, Parker was referred to Puccetti for follow-up treatment. Parker recommended stem cell rescue and high-dose chemotherapy as the best course of treatment.

That's when the trouble began.

Touchpoint refused to pay for this treatment even after Puccetti agreed to treat Parker outside the confines of a clinical trial. In its final decision, the insurer ignored even its own external review agency, which concluded that the therapy proposed by Puccetti "would be one of the standard approaches for 3-year-old children with this disorder There is no alternative with superior or proven results and is therefore medically necessary ."

Puccetti says about 12,400 children under the age of 20 were diagnosed with cancer in 2007; more than 10,000 of those were under 15. The numbers are low relative to adults, which is why doctors turned to clinical trials as a way to document and treat children with cancer, she says.

"So few are diagnosed a year you don't want to base it on your own experience."

Over the last several decades doctors developed a cooperative system under which to treat children with cancer - no matter where they live in the country - in a uniform manner specific to their disease. The idea was to increase the success rate for treating childhood cancers and it worked, Puccetti says, noting, "That remarkably improved the childhood cure rate."

But success, of course, depends on getting the recommended treatment.

Here's where Gaines, a law professor and director of the Center for Patient Partnerships at UW-Madison, stepped in on the Summers case. The center, staffed by a few professionals and volunteer students from the law school and various health care fields, helps individuals and their families navigate the health care maze. This can entail advocating for second opinions, securing insurance coverage and applying for public benefits.

Gaines was able to convince UW Hospital to proceed with Parker's treatment without an upfront payment. The center, in turn, agreed to seek out other funding sources to help cover the cost.

As a result, Amy and Kevin, whose daughter, Keili, was 8 at the time, were able to concentrate on their sick son, while others fought it out with Touchpoint and dealt with the endless paperwork.

"It's hard to do all that while you're still in the process of accepting what's going on with your child," Amy says. "The day-to-day upkeep of Parker at that point was an all-consuming task."

The Center for Patient Partnerships was successful in helping the couple get funding from a state program that allows certain Wisconsin children with long-term disabilities or complex medical needs to qualify for Medicaid.

Funds from the Katie Beckett Program helped cover some of the roughly \$400,000 due for Parker's treatment, and the UW Hospital absorbed the rest.

But having to turn to public assistance never felt right to Amy and Kevin, who thought they should be able to draw on the family health care coverage they paid

for through Kevin's job as a videographer at Kimberly-Clark.

Medicaid, Kevin says, "should be used for the people who really, really need it."

(Drop cap) That's why Amy and Kevin, with assistance from the UW Consumer Law Clinic, decided to sue Touchpoint, even though UW Hospital was not hounding them for money.

Still, they say it wasn't easy sitting through the various court hearings as the case wound its way from trial court to the Wisconsin Supreme Court.

"We would hold hands throughout the whole thing and take turns squeezing each other's hand," Amy says. "Certain things push my buttons and certain things push his."

"For us, it's a no-brainer," adds Kevin. "We have been law-abiding citizens for all these years. We pay our taxes. We pay our insurance. We do all the right things. We should be taken care of."

Robert Kraig, spokesman for Citizen Action of Wisconsin, which advocates for health reform, says the Summers' lawsuit reflects the lax state of insurance regulation in Wisconsin.

"You had in this case a disagreement in the courts as to whether the decision was arbitrary or not, partly because there wasn't a clear regulatory standard to go by," says Kraig.

A law review article cited in the Supreme Court ruling goes a step further, noting that insurance companies' wide discretion in deciding "whether a medical technology should be considered 'experimental,' and, accordingly, denied coverage, can result in great disparity in the policies of insurers, with coverage decisions influenced not just by the medical data and clinical judgments, but also by factors such as lawsuits and public relations concerns."

Kraig says Wisconsin needs health insurance regulation "that clearly defines allowable coverage and, specifically, what kind of conditions an insurer can exclude based on actual medical standards, rather than just the arbitrary decision of an insurance company."

The underlying problem, says Gaines, is a health care system driven by profit, rather than medical concerns.

Due to intervention in the Summers' case, Parker today is a healthy, active boy who enjoys swimming, reading and Star Wars.

"Touchpoint is not a bunch of doctors making a medical decision about what this kid needs," says Gaines. "They are corporate managers deciding what their fiscal risk can be."

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----- INDEX REFERENCES -----

COMPANY: GODFREY AND KAHN S C; HEALTH AND FITNESS OF OREGON [INC](#); [KIMBERLY CLARK CORP](#); HEALTH AND LIFE CO LTD; HEALTH; KIMBERLY CLARK SA/NV; HEALTH AND TENNIS CORP OF NEW [YORK INC](#)

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