

'Orphan' cancers get a spin

Cycling fundraiser to help expand treatment options

By Ed Finkel

SPECIAL TO THE TRIBUNE

While most 4-year-olds don't get too worked up by a cycling event, this weekend's Cycle for Survival is very much on Emma Krzak's mind, says her dad.

"When we ask her what her favorite team is, she says, 'Emma's Eight. Cycle for Survival,'" said Michael Krzak, who heads the team along with his wife, Nicole. "We're telling her that mommy and daddy are riding bikes to help kids like her. She's very, very excited about that."

Emma was diagnosed with a rare eye cancer called retinoblastoma when she was 5 weeks old.

The Memorial Sloan-Kettering Cancer Center's Cycle for Survival will help raise funds for so-called orphan cancers like Emma's. More than 200 teams of up to eight riders will participate in the event, held Saturday at Equinox Fitness' Loop location, 200 W. Monroe St. (The event is fully booked.)

After she was diagnosed, Emma underwent eight months of chemotherapy and more than 20 laser surgeries. The family, from Elmhurst, then turned to Sloan-Kettering in New York, where Emma received a new procedure that had been used fewer than 20 times. It involved injecting chemotherapy directly into the arteries of the eye.

That "miraculously knocked it out," said Michael Krzak. "We were inspired when Emma got her cancer to do something. We vowed to do whatever we could to fight her disease. ... We haven't been involved in anything at this level."

The National Institutes of Health defines orphan cancers as any with fewer than 200,000 cases per year — which amounts to everything but breast, lung, prostate and colorectal cancer. Those four make up slightly less than half of cancer cases, yet they receive 80 percent of research funding.

Even scarier than receiving a



Emma Krzak, 4, sits in her father Michael's lap while mom Nicole holds Faith, 2, at their Elmhurst home. Ernie the dog, meanwhile, waits for an opening. BENJAMIN CHERNIVSKY/PHOTO FOR THE TRIBUNE

cancer diagnosis is then being told that the treatment for your cancer is experimental, says supporter and race participant Kristen Novelline, of Wilmette, who has friends who have gone through that experience.

"You want to know, 'What's the plan?' To be told there isn't a (well-defined) plan is really frightening," she said. "To be able to give doctors ammunition and answers to fight for these patients is a great thing."

Novelline is a longtime friend of Cycle for Survival founders David Linn and Jennifer Goodman Linn. Six years ago, Goodman Linn was diagnosed with MFH sarcoma, a particularly persistent form of cancer that has required two surgeries and "we lost track of how many chemotherapies" in the last year alone.

"In September, the doctors were preparing David and me for the worst," she says. "They're now calling me a medical miracle. With rare cancers, there aren't so

many treatments. We were very committed to the cause before this year. But now more than ever, we realize the importance of why so many treatment options are needed."

Goodman Linn needed nine different chemotherapy "cocktails" to find the right one to knock out her cancer for the time being. "There's nothing (designed) for me," she says. "Pharmaceutical companies are not going to invest billions in drugs if there are not a lot of people affected."

The Cycle for Survival event began four years ago in New York and is coming to Chicago for the second time; there will be new Cycle for Survival locations this year on Long Island, N.Y., and in San Francisco.

The Linn's chose Chicago as the event's second location in part because David Linn grew up in Deerfield, attended Northwestern University and played professional soccer for the minor-league

Chicago Sting before enrolling in business school at Harvard University, where he met his wife.

The \$4.5 million raised in the first four years has funded 13 clinical trials and studies that are run through Sloan-Kettering in New York but have included researchers from Northwestern Memorial Hospital, the University of Chicago Medical Center and Northshore University HealthSystem.

As of a week ago, the organizers had raised \$2.7 million this year, and "usually a lot of money comes in at the last minute," said Goodman Linn.

The initial clinical trials and primary research don't require "hundreds of millions of dollars," says David Linn. "With the type of dollars we're raising, we can actually make advances. Without that initial push that a Cycle for Survival provides, unfortunately it's not going to happen."