

FROM THE FRONT

Group

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Wanosik said that people with Ehlers-Danlos can also be at risk for fragility fractures, particularly when the disorder is paired with a vitamin D deficiency, as it for four of the board members' children, including Wanosik's daughter Zeydn.

"When you have these hyper-mobile things, and then you pair it with a weakened bone state from a vitamin D deficiency, you're asking for trouble," Wanosik said. "Your bones are weak, so now they're not able to just flex like they were; now they're cracking."

Wanosik said that the medical community is divided about whether EDS is associated with bone fractures, but Dr. Michael Holick, who diagnosed Zeydn with EDs, recently published a study that concluded it is.

Wanosik's ordeal began on Feb. 24, 2015 when she and her husband took then-two-month-old Zeydn to see a doctor about the baby's unexplained arm pain. Two x-rays later, the Wanosiks were informed that Zeydn had a broken arm and three fractured ribs. They were also told that they the police and the Children's Division were already on their way.

After a preliminary investigation by the Missouri Department of Social Services Children's Division, Zeydn and her four siblings were removed from the



Photo courtesy of Rebecca Wanosik

Rebecca and Anthony Wanosik pose for a picture with their children and the Easter Bunny. Rebecca has started a group called Fractured Families to help other families that have had medical conditions mistaken for abuse.

Wanosiks' custody.

Not long after losing custody of her children, Wanosik saw a 20/20 episode about Cynthia and Brandon Ross, whose child also had unexplained fractures. The episode also included a clip of Bria and Andrew Huber.

After a feverish Facebook search failed to turn up contact information for the Rosses, Wanosik thought that Bria's first name might be unique enough to get results — and it did. Within a few days, Wanosik, Hu-

ber and Ross were talking to each other.

When Wanosik and her husband received permission to fly Zeydn to Boston for the medical evaluation that led to her diagnosis, it was a Fractured Families board member who donated their airfare and hotel fees — as well as airfare for the two social workers who accompanied them on the trip.

Wanosik's children were returned to her in August 2015, and Fractured Families asked her to join its board shortly

afterward.

"About a year and a half ago, when our case was winding down and finishing up, because I was such a strong advocate for my family with everything that we went through, that's why they decided to pull me in."

Although Fractured Families has existed for about three years, Wanosik said that until recently its main focus has been support. A few months ago, the group

started lobbying for the passage of a bill in the Texas House of Representatives that would require officials involved in abuse and neglect investigations to have access to consultations with physicians who specialize in rickets, EDS, osteogenesis imperfecta, vitamin D deficiency and similar diseases and disorders. Wanosik is currently looking for a Missouri Representative to sponsor a similar bill. Wanosik said that the

organization's ultimate goal is to help families pay for medical, legal and travel fees associated with cases like hers.

However, Wanosik said that experts who work with Fractured Families won't take a case if they think parents are actually abusing their children, and Fractured Families board members have their own stories to guide them.

"You kind of know," Wanosik said. People's stories either add up just like yours did, or they don't at all. And sometimes we turn people away. ...You have to weed through it."

Additionally, one of the board members' husbands, who is a videographer, is currently making a documentary to educate people about EDS.

Wanosik said that the group is also advocating for improvements to the health care and child welfare systems. For example, she said that the American Academy of Pediatrics standard is that children with fractures but no redness, swelling, bruising or other signs of abuse should be tested for rickets — and that didn't happen for Zeydn, she said.

"Advocating for these families — I know it sounds repetitive, but it really is so important because it could be anybody," Wanosik stated.

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