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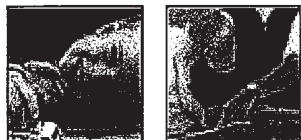
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Family fights an HMO for 4-year-old's life

C.W. Nevius

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Somewhere in a corporate office at Health Net Inc. is someone who needs to meet Jack Zembsch. Jack is 4, he loves SpongeBob SquarePants, and he is going to die.

One doctor in the country just might be able to save Jack, but the nation's largest HMO won't let Jack see him because the doctor is not within its network.

Jack, who lives in Moraga with his parents, Mark and Kim Zembsch, has an extremely rare form of dwarfism called metatropic dysplasia, or MD. It leaves his bones extremely soft, and before long, they'll simply stop growing even as his body continues to get bigger. Eventually, his lungs will be so constricted by his ribs that breathing will become a chore, and an infection could kill him.

That is, if his spine doesn't simply snap from something as simple as a fall.

"There is literally only one metatropic kid born in this country each year," Mark Zembsch says. "Jack fits into the category of you-can't-believe-it rare."

HMOs never want to hear about rare diseases. And the news that only Dr. William Mackenzie, the nation's acknowledged expert in MD, who works at the Alfred I. duPont Hospital for Children in Delaware, has any chance of saving Jack is unlikely to make them any happier.

I tried repeatedly to get someone, anyone, at Health Net to comment, but they wouldn't return any of the messages I left on Friday.

But it doesn't come as any surprise that Health Net would drag its feet.

"When you have to fly a patient out to the East Coast, it is the fundamental HMO no-no," says Jamie Court, a Santa Monica-based health care advocate and co-author of "Making a Killing," a book on the health care system. "It is the M.O. of health care providers to deny access to expensive treatments. They give you the runaround and hope you go away."

We all know about that. If we haven't been through it, we know someone who has -- the automated

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telephone merry-go-round, the paperwork snowstorm, the mind-boggling protocols that must be followed to the letter. With weary resignation, we fight and complain and yell until -- grudgingly -- the insurance company pays up.

But, see, this is different. This is a 4-year-old boy. And if he can't have a series of difficult and touchy operations -- by the only doctor in the entire country with the expertise to perform them -- his spine will bend his body until it either crushes his lungs or snaps.

Jack is just a few degrees from that point now.

His parents have told the story several times, but it isn't just another long, sad tale of how health care is screwed up in this country. Mark Zembsch gets most of the way through it, but his voice tends to get hoarse, and he's prone to running his hand through his hair and looking away.

"You just keep thinking that you are going to wake up and it is all resolved," he says. "It is so clearly the right path for Jack. I keep thinking I am going to get the letter from some guy saying, 'Sorry, he fell through the cracks. We will get this done.' "

That isn't going to happen. It didn't happen when the Zembschs' primary-care physician, Dr. Jane Hunter at Alta Bates Medical Center in Berkeley, wrote a note to Health Net saying "it is imperative" that Jack see Mackenzie.

It didn't happen when Health Net sent Jack to the highly regarded UCSF medical center to be treated by Dr. Mohammad Diab, a surgeon who is in charge of pediatric orthopedics. Diab told the family he essentially had no experience with the surgery Jack needs and wrote to Health Net that Jack should see Mackenzie immediately.

"The door is closing, if not closed," Diab wrote.

It doesn't get any plainer than that. Jack needs an operation. He will die without it.

"I thought it was a no-brainer at that point," says Arnold Levinson, a San Francisco health care insurance attorney.

Apparently not. In all there were four appeals. Some were filed twice. In every case, Health Net took the entire 30 days allowed by law to respond, then came up with another rejection or roadblock. Finally, on Oct. 12, Health Net ruled that Jack should go back to Diab.

So after eight months of appeals, pleas and medical forms, the Zembsch family had gone in a big, pointless circle.

It was maddening. But that isn't what keeps Kim Zembsch up at night.

"Dr. Mackenzie said he could be walking one day and fall on his bottom," she says, "and his spine could snap, just like that."

Instead of being beaten down by this runaround, they decided to step up.

They contacted Levinson, who is not to be trifled with. In 2003, he won the 10th-largest verdict in California history, \$32 million, in a disability insurance case. That might get Health Net's attention.

The lawsuit will be filed Monday.

You want a fight, Health Net? Better suit up. Jack's coming after you.

C.W. Nevius' column normally appears Tuesday and Saturday in the Bay Area section and on Fridays in East Bay Life. E-mail him at cwnevius@sfchronicle.com.

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