Athletes With Impact

STORIES THAT WILL INSPIRE YOU

THE SON RUN

ROAD RACING
FAMILY HELPS FIGHT
MITOCHONDRIAL DISEASE

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FOR ANY PARENT, it is a heartbreaking story. Blaine and Sarah Penny made sure they didn't fall to pieces, too.

In 2008, their son Evan was a happy, healthy, energetic four-year-old. But he complained of a sore stomach and was hospitalized for appendicitis. Seizures, brain impairment, and quadriplegia soon followed. About a year later, he was finally diagnosed with mitochondrial disease — a rare disorder, often caused by a gene mutation, that can cause anything from respiratory problems to loss of muscle co-ordination, to heart, liver or kidney disease. There is no known cure.

Now in a wheelchair, Evan has trouble producing enough energy to hold his head up or digest food, and needs constant care. But through every parent's worst nightmare, Blaine and Sarah have both shown an inner core of steel, and relied on each other, their families, their sprite of a daughter Julia, 4, and their friends in the running community.

"After Evan got sick, one of the doctors told us, 'Don't forget to look after yourselves,' " says Blaine, a project manager for engineering firm WorleyParsons. "They said, 'There are a lot of people around here who don't leave their kids' bedsides. They crumble as a person, and their families fall apart.' If that were to have happened, we couldn't really help Evan."

In April, Blaine and Sarah established MitoCanada (www.mitocanada.org), a charitable support network for Canadians affected by the disease. Blaine and his friend Trevor Baine completed the TransRockies Run in 2009 for Evan. Blaine decked Evan out in his chariot for this year's Stampede Road Race half-marathon and, through sheer willpower, finished fifth overall. He became a Canadian champion by winning the Iron Legs 50-mile ultramarathon, setting a new course record.

In the past six months, Sarah has shaved 12 minutes off her 10K race time, and is toying with the idea of qualifying for the Boston Marathon. In September, the Penny family and others in the running community staged the first Running on Empty event, a 100K charity run through Kananaskis Country that raised $30,000 for MitoCanada.

Blaine says his family has been his biggest inspiration through this ordeal.

"Sarah is the strongest woman I know. She has endured more pain and heartbreak than any other mom I know, and it has only made her stronger," says Blaine. "Julia has such a zest for life, and is such an uplifting part of our lives.

"Evan is truly a fighter . . . in my mind,



Julia leans in to give big brother Evan a kiss.

Evan is running every day, and his life is an ultramarathon. The most important thing for us as a family is to maintain a good life balance and keep plugging along, in the hope that one day we'll see better treatments, and maybe even a cure." ➤