

HEALTH CARE

Family fundraiser gets stunning results

Buys second epilepsy testing bed for RUH

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THE STARPHOENIX

It was a potentially devastating prognosis for a young boy.

Brock Kolibab was three years old and having 100 seizures a day. When he wasn't seizing, he was drugged up and distant from trying medications that weren't working.

Parents Shantel and Curtis and older sister Kylie thought they were losing him.

A remarkable and unlikely turnaround has changed that, for now.

This spring, the Kolibab family pulled off an unexpectedly commanding fundraiser they hope will contribute to more success stories for people like Brock with epilepsy.

"We had said we'd give back when Brock gets better," Shantel said. "We just felt the need to give back to the community, to help out, and to make the medical system better."

And they did — to the tune of nearly \$67,000, allowing the Saskatoon Health Region to buy a second set of specialized equipment to help diagnose and treat people with epilepsy.

In 2011, Brock spent three days in Royal University Hospital's only dedicated telemetry bed, which records video and extensive data on seizures.

Based on the data, a pediatric neurologist diagnosed Brock with Lennox-Gastaut syndrome, a type of epilepsy



From left to right are Curtis, Brock, Shantel and Kylie Kolibab.
RICHARD MARJAN/The StarPhoenix

that produces many types of seizures and is difficult to identify and treat.

According to the Epilepsy Foundation's website, the condition is debilitating enough to cause developmental delays and mental disability in some patients. Seizure control is "rarely achieved," the foundation says.

"We were told he would basically end up mentally handicapped because they wouldn't be able to control his seizures," Shantel said.

With the guidance of a dietitian at RUH, the Kolibabs started Brock on a specialized high-fat diet in late 2011, called the ketogenic diet. Some people with epilepsy have had success with the diet, which results in biochemical changes in the

brain that can reduce its tendency to produce seizures.

Within six months, Brock was free of seizures and medications.

When they saw a StarPhoenix article about neurologist Dr. Jose Tellez-Zenteno and the Royal University Hospital Foundation aiming to raise \$100,000 for the equipment to open a second dedicated telemetry bed, the Kolibabs knew it was the cause for which they'd been looking.

Tellez-Zenteno says with one bed, the hospital is only able to test about 30 people a year to see if they are candidates for potentially life-changing brain surgery, or to rule out epilepsy as a cause of their problems. There are around 150 people currently on the waiting list, he said.

The Kolibabs started with the idea of a fundraising staple — the family and friends steak night. Their goal was to collect \$10,000.

The project kept growing, and evolved into a sold-out dinner and auction at the Army, Navy and Air Force veterans hall in mid-June. The event drew 325 people, and they had to turn some away.

"It was magic," said Arla Gustafson, CEO of the RUH Foundation. "It was just a magical night. It just felt like the biggest family of people who didn't know each other."

With the last-minute help of several corporate agricultural donors, the Kolibabs raised \$66,865. In combination with money already raised by Tellez-Zenteno and



GORD WALDNER/The StarPhoenix file photo
Dr. Jose Tellez-Zenteno with specialized equipment used to help diagnose and treat people with epilepsy at Royal University Hospital.

the RUH Foundation, the health region was able to order the new equipment immediately, Gustafson said.

The second bed should be open to evaluate patients by the fall.

Tellez-Zenteno was delighted. He expected it to take years, not months, to raise the money, he said.

"It was a tremendous effort," said the neurologist, (who is not Brock's doctor). "Really unexpected for me. That night, I was very happy going there."

About half of patients whose seizures are evaluated by the telemetry equipment are candidates for brain surgery that has the potential to dramatically improve their quality of life.

Some of Tellez-Zenteno's patients have gone from

lives ruled by seizures to becoming seizure-free after surgery.

The equipment can also be used to identify patients with true seizures, as some patients with mental illness may have symptoms that seem like epilepsy, he said.

There is a chance Brock's seizures could return, and the Kolibabs live with that uncertainty.

Meanwhile, Shantel and Curtis are merely surprised by their previously untapped fundraising skills.

"Hopefully other kids and families will benefit from this machine and be able to live a good life like Brock now is, and be healthy because they had early treatment and intervention," Shantel said.

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