

Helping with music

Two local bands, past and present, share the stage to help young Penticton teen

When you look at young Ciara Walls, she looks like a vibrant, happy 13-year-old. What you can't see is the terrible disease she lives with.

Ciara suffers from Hashimoto's Encephalopathy, an incurable brain disorder.

"My daughter lives with this disease, which causes life-threatening seizures and memory loss," said her mom, Jacki Walls. "She contracted it about two years ago and we don't know how." There's a lot we don't know about this invisible killer, especially since it is very difficult to diagnose in its early stages and can be missed completely, especially in young people. It is also quite rare.

According to one of the many websites on the Internet:

"Only 34 case studies on Hashimoto's Encephalopathy have been published since 1966, and still this disease is underdiagnosed and misdiagnosed.

"The majority of cases are women. But it is imperative to note that this disease knows no gender or age.

"Case studies show ages 12 to 82 afflicted and just recently, titles indicating Pediatric Hashimoto's Encephalopathy. Studies are from

all over the world and include multiple patients in each study. India, Italy, Greece, Scotland, Norway, The Netherlands, Spain, Japan, Germany, Great Britain, France and others." Although it is difficult to diagnose in early stages, if caught early, its symptoms can be alleviated with treatment and medication.

The mother and daughter team must travel to Vancouver every three months for treatment.

But six months of chemotherapy had minimal success.

"We are going to try a new treatment next month," mother Jacki said.

"We're not sure if it will help but we'd rather try new treatments and have them fail then not try anything at all and say 'What if?' At least we can say we tried."

But trying new treatments requires time and money, of which the pair has neither.

Jacki is unable to work, due to the constant care and supervision required to monitor

Ciara's condition and, due to the disease's rareness, no charity organizations are set up to support sufferers and their families.

This is where the community can get involved.

Sport Tourism Penticton, along with two local bands, one past and one present, wants to help.

"Jacki and Ciara are friends of almost everyone involved," said Sport Tourism Penticton spokesperson Bruce Millington.

"In fact it was the one of the band members' ideas to try and help them out."

On Friday, Aug 18 the legendary Great Canadian River Race and Kyle Anderson's Amazing Rubber Band will provide four hours of nonstop entertainment at the Penticton Trade and Convention Centre to raise funds for Ciara's continuing treatment. Even though their name might confuse some, The Great Canadian River Race does not play in the river channel.

When they first reformed last year after a more than 30-year hiatus, keyboard player Duncan Meiklejohn explained the quintet's quirky name.

"In the late '60s and early '70s every band was looking for a catchy name," he explained.

"Sort of like 'Sgt. Pepper's Lonely Hearts Club Band', we thought of 'The Great Canadian River Race'."

After adopting the new name, the band, consisting of Meiklejohn on keyboards, guitarist Selwyn Redivo, his brother Marcus on bass, lead vocalist Darrell Quast, and drummer Lyle Shepard, was very successful playing dances around the valley.

“**My daughter lives with this disease, which causes life-threatening seizures and memory loss ...**

-Jacki Walls

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Colour Photo: Submitted / 13-year-old Ciara Walls, right, with mom Jacki.

The group moved to Edmonton in 1971. Their polished vocal sound and image made them big on the circuit in Western Canada.

They decided to reform last year for their 35th grad reunion and performed with another popular local band from the '60s and '70s, Crosstown Bus.

Fast-forward one year.

The success of last year's performances encouraged the group to play more. Though playing on the road full time was out of the question with the current life and location each member was in, the enjoyment of playing together allowed them to get together again in their old hometown.

On Friday, Aug. 18 The River Race, as it is sometimes referred to, will share the bill with popular local group Kyle Anderson's Amazing Rubber Band.

"These guys were my musical heroes in high

school," Anderson remembered.

"I was one of those geeky guys who hung off the front of the stage while the band played.

"Now, 35 years later, I'll have a chance to actually perform with them. Wow!"

Anderson, along with band mates Steve Jones and Patrick d'Aoust, will alternate sets with the River Race during the four-hour event.

"Just like one of the old Peach Bowl dances," Anderson added.

The Community Dance and Fundraiser is Friday, Aug. 18 from 9 p.m. to 1 a.m. at the Penticton Trade and Convention Centre. It is a licensed event for 19 and over.

Tickets are \$20 per person and are available at the front desk of the Community Centre on Power Street, The Dragon's Den on Front Street and at the door. Net proceeds will go through Sport Tourism Penticton to assist 13-year-old Ciara Walls.



Penticton Herald, file photo

The Great Canadian River Race standing from left: Selwyn Redivo, Duncan Meiklejohn, Marcus Redivo. Crouched: Lyle Shepard and Darrell Quast.



Colour Photo: Submitted / The Amazing Rubber Band from left: Patrick d'Aoust, Kyle Anderson and Steve Jones.

