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Ben

Stem-cell transplant to begin this spring for Bella Coola woman suffering from MS

Erin Smith was diagnosed with the auto-immune disorder in November 2014

[CATLIN THOMPSON](#) / Mar. 10, 2016 4:00 p.m. / [NEWS](#)



Three-month old Ruby Smith sits on her dad's lap, smiling a wide grin as her parents sip their coffee.

She's the picture of baby perfection, a cherub of a girl set to charm everyone around her. Her parents are clearly enamored. "She's a good sleeper," shares her dad, Ben. "She gives us nine hours a night, so that really helps!"

The challenges of adjusting to a newborn, even one that sleeps well, can be daunting even for those in perfect health. The challenges of parenting when afflicted with primary progressive multiple sclerosis (PPMS) are unimaginable.

Erin Smith was diagnosed with the auto-immune disorder in November 2014, and since then her symptoms have gotten worse at an alarming rate. PPMS is a rare form of multiple sclerosis – only about 10 percent of MS patients are diagnosed with it. Unlike typical relapsing remitting MS, PPMS is characterized by a lack of remissions.

Drug therapies aimed at "normal" remitting MS are ineffective at slowing the progression or alleviating symptoms. PPMS sufferers slowly lose their basic functions as the disease attacks myelin (a protective layer which covers the nerves in the brain and spinal cord), and eventually leads to complete paralysis.

Erin's fine motor skills have deteriorated to the point that everyday tasks are nearly impossible. Ben delivers most of Ruby's day-to-day care, as Erin's limbs simply won't cooperate enough for her to complete the task.

"Last July I was holding a cup of tea in my right hand and then suddenly I threw it on my chest," she explains. "Since then my right arm has deteriorated so much that I cannot eat or use a pen to write a note. I have to use my left hand for everything, and I'm right handed."

After discovering that PPMS is not treated in Canada, the couple began to look at treatment options elsewhere, and they concluded their best shot at halting the disease lay in a treatment known as Hematopoietic Stem Cell Transplantation (HSCT).

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Explained in layman's terms, the treatment aims to destroy the faulty immune system using chemotherapy. It is then rebuilt with stem cells harvested from the patient's own blood, cells that are

at such an early stage they've not yet developed the flaws that trigger MS.

Following the chemo her own stem cells, now "clean" of PPMS, will be transplanted back into her body, and the immune system is reset or rebooted back to a time point before it caused MS.

The couple said that various PPMS sufferers in online forums have reported very positive results following the procedure. While the treatment is essentially intended to halt the progression of the disease and offers no guarantee that symptoms will reverse, some patients have reported that their symptoms have lessened following the procedure.

Clinical trials of HSCT in other countries, most notably the UK, have been extremely successful, with some MS patients leaving their wheelchairs behind after completion and walking on their own.

"Ongoing research suggests stem cell treatments such as HSCT could offer hope, and it's clear that in the cases highlighted by [BBC's] Panorama they've had a life-changing impact," said Dr. Emma Gray, head of clinical trials at UK's MS Society.

While Canada is undertaking some clinical trials regarding stem-cell therapy for MS, there is little incentive for pharmaceutical companies to get involved because the procedure involves no new drugs and instead re-purposes an existing therapy using the patient's own cells.

"There has been resistance to this in the pharmaceutical and academic world. This is not a technology you can patent and we have achieved this without industry backing," said Professor Richard Burt of Northwestern University, Chicago. Burt carried out the first HSCT for MS as long ago as 1995 and is coordinating the international trial which began in 2006.

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However, treatment costs for HSCT remain out of reach for most people, and the couple turned to fundraising to help. Together with the fundraising, their personal savings, and a generous donation from Ben's mother, they have managed to secure Erin's treatment at a cost of about \$73,000 Canadian.

"We estimate that about \$15,000 – \$17,000 was raised locally, just in Bella Coola," said Ben. "The generosity of this small community is really overwhelming, and we are so thankful."

Erin is slated to begin treatment this spring: a 26-day cycle of intense IV chemotherapy and the subsequent reintroduction of her own "clean" stem-cells. She will be closely monitored throughout the treatment, requiring total isolation for much of it as her immune system will be almost annihilated in the process.

Dr. Gray said people should be aware it was an "aggressive treatment that comes with significant risks," but called for more research into HSCT so there could be greater understanding of its safety and long term effectiveness.

"When I return home everything has to be completely sterile," she explains. "My immune system will be so low that any infection I contract could lead to septic shock."

She's been instructed to refrain from eating at restaurants to avoid food poisoning and the couples dogs have been transferred to another home while her immune system rebuilds.

Despite her diagnosis and impending treatment, Erin is inspirational and funny, often cracking jokes about her condition and looking to the future with optimism.

Both her and Ben mentioned a desire to "pay it forward" once Erin's treatment is complete, expressing the idea to continue the Halloween fundraiser dance with the proceeds going towards a community group or individual in need.

"We couldn't have done it without the support of this community," she said. "And we'd really like to carrying on that tradition when we return."

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