

THE KID WHO COULD

Muscular dystrophy patient Patrick Seguin had a dream and thanks to a world of dreams foundation, it came true.

Patrick Seguin hunches over the kitchen table, one delicate finger of his left hand pushed against his tiny wrist, helping it guide the pen he clutches across the page.

It hurts to watch him struggle to sign his name .it's almost impossible to conceive that he has written every word and drawn every picture in the book he is autographing. Patrick is 16 year old victim of a rare muscular dystrophy that has wasted away all but nine percent of his muscles .but through determination and sheer guts, he has produced a 40 page "intergalactic adventure" comic book called the crime busters. It's filled with intricate drawings of space ships, aliens, computers and futuristic trucks as it details the story of mark and Luke, two friends from Montreal, who team up with and extraterrestrial to fight the forces of big city crime .each page took a minimum eight hours to complete often stretched over weeks-bent, as he is now, over the kitchen table in the simple, rural home he shares with his family outside lachute, about 97 km west of Montreal. He can sit strapped into bright orange plastic seat bucket for only an hour at a time. Then his mother carries him to his room off the living room to rest on the bed. Patrick finished crime busters in September –two and a half years after he started "he said lots of time,'hey daddy, when are you going to get my book published? 'Recalls his father real "and I would say 'well when you are going to finish it? One day I came home and he said "daddy it's done.' Real Seguin set about fulfilling his young sons wish to have his "life's work published, to leave behind after he is gone."

Along came a world of dreams foundation a group devoted to making the dream terminally ill Canadian children come true. When President Deborah Sims of Montréal heard Patrick's request in mid-October, she contacted Annabel Slight, president the young naturalist foundation Toronto publishers of the children's magazines owl and chickadee. Slight set to work with the vengeance and within a month, the crime busters had been translated printed and published in both French and English with all involved donating their services. Patrick collected royalties on every book sold and the remaining proceeds are divided between the young naturalist foundation and a world of dreams, both nonprofit charitable organizations. The response since the book came out has been remarkable. Cole's bookstores across Canada quickly ran out of the first English printing of copies and called for a second printing of 1500.

Patrick has gone to Montreal for television, radio and newspaper interviews, even signing autographs in a Coles bookstore one busy Saturday and his father the only family member who speaks English has fielded telephone calls from across the country .the Christmas tree isn't up yet in the living room because, he explains CBC's "the journal "has asked them to hold off until later in the weeks. They want to film the family decorating it "I'm very happy, it's beautiful, fantastic," Patrick says though his father, his brown eyes sparkling. He's enjoying every moment of his new found fame, even slyly slipping notes to the Toronto star photographer, asking her if she has a boyfriend .like most teenagers, he likes fast cars ,girls and rock music. The walls of his room are plastered with posters of Corey Hart, U2 and his futuristic drawings of cars and trucks, and he's an avid fan of the Montréal Canadians. But life in this household is far from easy. Patrick was a normal

happy baby, pictured in the family album blowing out the candle on his first birthday cake. But he never learned to walk and when he was two, real and janette Seguin learned he had Kugelberg-Welander disease, a form of spinal muscular atrophy that wastes away the body's muscles.it was the second blow for the Seguin's .four years earlier they had learned there daughter ,Sylvie, now 20 has the same genetic disorder. Their other two children Josie, 21, and Eric, 15, are not afflicted.

No one knows how long Patrick will live, says his father.it could be several months or several years, depending on how quickly his other muscles including his heart wastes away. He has severe curvature of the spine because of his wasted chest muscles, which makes it increasingly difficult for him to breath. "We will try to keep him as long as we can, "real says simply .Sylvie grew normally for many years and although she is now confined to a wheelchair, she works at an office job in Montreal and shares an apartment with two other handicapped young women. But the disease. But this disease hit Patrick so early and quickly that his muscles never developed. He weighs less than 18kg, is only 104 cm tall and wears size five cloths. His tiny legs dangle uselessly .it's difficult for him to speak. For many years his mother, janette, cared for two children in wheelchairs. Now she gets up every 20 minutes all night long to change Patrick's position in the bed since he can't move on his own. Until two years ago, he went to high school in lachute, traveling with Sylvie on a special bus for the handicapped. But school is too tiring for him now, although he still gets marks in the 90s with the help of a tutor who comes to the house twice a week. He quickly points out that he is a year behind in his studies –from the year he spent 22 weeks in the hospital. Confined to home, Patrick

began his comic book in earnest after watching his brother Eric do a one-page comic as a home work project. “But I didn’t know it would turn into this,” he says with a grin. He wanted the book published so he could earn some money-like his brother does cutting the lawn and helping with chores. But he almost turned down the chance to have it published when A World of Dreams asked if he’d rather take his family to Disney land – or anywhere else in the world. “Patrick asked all of us,” says real “he said ‘the book is only for me and I could do something for the whole family instead, ‘but everybody told him to publish his book .we can go on a trip some other time,”

The money he says ,will go into a special bank account for Patrick to use as he pleases-a special thrill for a teenager who has always had to ask for everything ,money has always been tight in this house .real who works as a shipper at general motors in nearby St Therese ,makes \$22 000 a year ,and often half of that has to go the extra costs for caring for Sylvie and Patrick. “We try to do what we can but we don’t have any choice says real, “life is life “

Buoyed by the success of crime busters, Patrick has already started work on second book-this one a comedy. “It’s about a cowboy who looks after a lot of babies at home while his family is away on trip,” he says with a shy giggle. “He has lots of trouble .I think that somebody will steal the babies and he’ll have to get them back.”

Despite his wasted hands, he draws all the lines in his picture without even the help of a ruler. But he would like a computer to make all the work easier he says. "It could do everything. I could write a really big book. "Right now, his big worry is that they haven't printed enough books for all the people who want to buy them

"Patrick knows everybody" says his father. "He has lots of friends who come to see him and phone and when we take him to high school, everybody wants to talk to him. "a string of Christmas cards decorate one wall of his room-from well-wishers and from other young handicapped people who heard about his book .one woman in Lindsay writes to say his effort was as inspiring as that of terry fox ,the young cancer victim who ran halfway across Canada, "I want to help other handicapped children, "Patrick says. "I want to show them that if I can draw a comic book, everybody can do something. "Patrick "has been an inspiration to us, "says his father. "When he's sick, he's very sick but he never complains. He's always got a small laugh. If Patrick can do this and never cry, then we can't complain about little things. "in fact, Patrick keeps the family-which now includes two foster sons -laughing most of the time. Asked what he'd like for Christmas if he could have anything, he first says maybe the star photographer, or the French singer mitsou.His foster brother, 10 year old Pascal Normand, excitedly urges him to go for a Porsche. Patrick just smiles and shakes his head. "To be healthy, "he says softly.

1) What is Muscular Dystrophy? (1)

2) What is Patrick's book called? (1)

3) How long did it take him to do a page? (1)

4) How long did it take him to write his book? (1)

5) How has muscular dystrophy affected Patrick? (2)

6) How is Patrick a hero? Explain. (2)
