

The Man Who Was Saved By A Mouse

I suffer from an excruciating illness with no known cure. So I'm pinning my hopes on infusions of mouse DNA

By Robert Mason Lee

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My face was pallid and streaming with sweat as I staggered through London's Heathrow Airport, aware of the crippling pain in my gut and an incipient nausea at the back of my throat. I walked over to the klm desk, knowing I was about to throw up. I hoped it would not be on the staff.

I told them I was a diabetic and needed a place to inject myself with insulin. They nodded sympathetically and told me of a quiet departure lounge where I might find an empty toilet. I grabbed my travelling companion and we headed there.

The whole thing was a lie. In fact, I had twenty milligrams of pure heroin in my pocket and I desperately needed a place to shoot up. We found an empty baby-changing cubicle and broke out the kit: rubber hose, syringes, and two ampoules, each containing a pellet of snow-white powder. I wrapped the hose around my upper arm and pulled it tight with my teeth - not too tight, I remembered, or I would cut off the artery. What you want to achieve is about eighty millimetres' worth of diastolic pressure.

Meanwhile, my companion mixed the white powder with liquid prochlorperazine to combat the nausea brought about by that much opiate entering my bloodstream at once. She tapped the side of the syringe with her fingernail and made a few drops of heroin come out of the needle, which I always considered a waste. Then she rubbed the inside of my elbow with her fingertips, tickling the vein. By this time, my heart had nearly shut down in anticipation.

"Found it," she said. She punctured the vein and a silky banner of scarlet blood streamed backward into the syringe, turning the opiate mixture a dark pink. In some mysterious way, I always found this moment to be erotically charged, my flashback of blood held in suspension in her hands, release only a moment away.

She plunged the syringe home. I felt the shock to the chest, then the blessed relief of melting ice and birdsong.

Now is the time to pull back the veil: the heroin was not some illicit street drug, but a chemically identical



substance called diamorphine hydrochloride. It is prescribed in the U.K., where I live for several months of the year, and doctors use it there to treat the severe pain of Crohn's disease, a debilitating condition I have lived with for more than two decades. The junkie scene at Heathrow Airport was merely my way of reducing the agony to the point where I could

endure my flight.

Crohn's disease - named after the American physician, B. B. Crohn, who first diagnosed it in 1932 - is one of a number of chronic inflammatory bowel diseases that afflict about 100,000 Canadians. If you are among those who get it, then you are one sorry bastard, because it is considered among the most painful of diseases. It is a mystery illness, probably a virally triggered autoimmune disorder, but no one knows for sure. It has no known cause or cure and it can strike the digestive tract anywhere, but it usually does so at the point where the small and large intestines meet. By its very nature, it is dark, secret, hidden, and frightening. There are many worse conditions to contract - patients are far, far more likely to live with Crohn's disease than die from it. But there are few diseases so enigmatic, nor many which entail so much physical suffering.

When Crohn's strikes, it does so without warning or predictability. It could be five hours or five years between flare-ups, but the result is the same: grinding pain, accompanied by frequent vomiting and diarrhea, followed by worse pain, accompanied by obstruction and distention of the abdomen. What does Crohn's disease feel like? It feels like three processes at once. First, a mule is kicking you in the stomach. Second, some maniac is inflating your abdomen with a bicycle pump. Third, you are being impaled up the ass with a pointy stick. I suppose the sensation must compare with labour, as the pain comes in waves triggered by abdominal contractions. A better comparison would be an ectopic pregnancy, since the pain is also overlaid with distress and panic and a sense of something having gone terribly wrong. Still, all comparisons are odious. What it feels like most of all is that you are suddenly, and without warning, very, very sick.

The intestines are wired only to feel pain when they are distended, and then they register pain without

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mercy. By the time my abdomen is twice its normal size, I am usually riding the extreme fringes of distress, the place where weeping and praying to God and lashing out blindly at nurses has given way to mute, silent, death-like reproach and resignation. It is a place I have been hundreds of times, and the only thing that can bring relief, while waiting hours or days for the symptoms to abate, is the kindly intervention of the great god Morpheus, in all his opiate guises.

I've injected him in my veins and my buttocks, I've eaten him in tablets and drunk him in syrup, I've shoved him up my ass and I've worn him in a skin patch usually applied to the terminally ill. He never fails to offer relief and companionship and he is, perhaps, my greatest ally. Taking leave of him is always difficult, however, a hard and lonely voyage past the black dogs that surround him before returning to the land of the clear. I am talking here about withdrawal, cold turkey, the monkey. It means days of having every muscle ache, of craving another hit, of throwing up, of the feeling of being sealed inside a dark iron box, of sheer, precipitous hopelessness. I endure. It passes.

And it is worth the cost. When other medical treatments fail - and they always, eventually, fail - it is only opiates that make life worth living. The pain of Crohn's is so great that it makes patients of my vintage a risk factor for suicide.

It was twenty-odd years ago when Crohn's disease made its first appearance in my life. I was twenty and had been living in Sweden, in the town of Linköping, when I began to sicken with abdominal pain and weight loss. The condition was undiagnosed until doctors performed an exploratory surgery.

The Danish doctor in the Swedish hospital leaned over me and whispered that no matter what I thought of the next few minutes, I must remember that I wasn't going to die. If he intended to calm me, he had the opposite effect.

During the surgery (as with all my subsequent surgeries), doctors had examined the entire length of my intestine looking for Crohn's. In other words, I was eviscerated like a chicken in a factory; after the Crohn's was chopped out, the intestines were stuffed back into the abdominal cavity to sort themselves out. It was a

lengthy operation and it left me with a mysterious bruise on my hip: "I think," said my Swedish nurse, "it's where the surgeon sat on you."

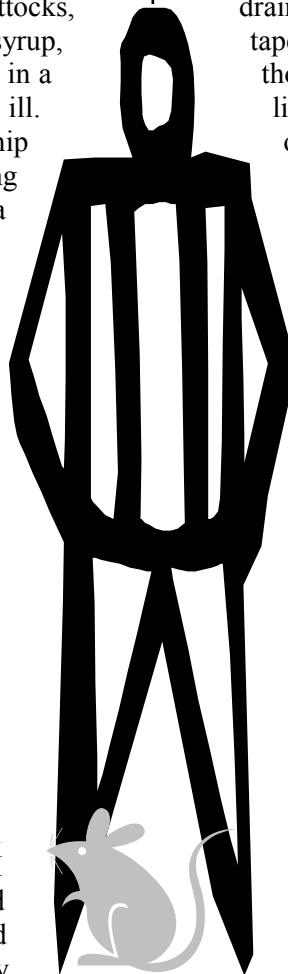
Some weeks after my discharge from hospital, I had to go back with swelling, heat, and redness along the suture, which ran the length of my abdomen from sternum to pubis. I was informed that the suture had become infected with staphylococcus, a bacteria strain resistant to antibiotics. The site would have to be drained at once. The doctor removed the surgical tape from the incision and the wound reopened as though a zipper were being drawn. About two litres of dark-brown chocolate pudding spilled out of the wound. This was the infection. It was followed by a ruptured membrane - my omentum wall - which was followed by the necks of pink flamingos - the loops of my intestine.

Standing at the foot of the bed, my girlfriend fainted. I felt nothing, either physically or emotionally. I felt oddly detached as the nurses cleaned my guts and stuffed them back. Even I knew that the inside bits of a person are supposed to stay inside, so evidently this was happening to someone other than me. Only, the doctor was right. That other guy did not die.

Surgery is no longer considered an option, except in the case of several life-threatening curve balls that Crohn's can throw at a patient. One is when the disease forms obstructions that can lead to the bowel bursting under pressure, which in turn leads to septicemia - blood poisoning - with an attendant risk of death. This has happened to me almost to the point where it is routine. Another is when Crohn's creates a fistula, a channel that it may decide to burn between one intestinal loop and another, or between itself and the surface of the skin, or it may content itself with rupturing a duodenal artery. Or the Crohn's may simply inflame such a length of gut that surgery is needed to feed the patient through a tube inserted in the abdomen. One thing you can say about Crohn's: it is busy, busy, busy.

I have lived with Crohn's long enough to have seen it understood primarily as a psychosomatic disorder (what I think of as the Dark Ages) to where it is understood, as it is today, largely as an autoimmune

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disorder (the Age of Enlightenment). No longer do Crohn's sufferers bear the additional burden of the belief that their illness is self-induced, the result of nerves, worry, or a flawed mental constitution - at least among doctors, though this misapprehension is still common among lay people. Today, doctors understand the illness as a complex chain of events, probably triggered by an infectious agent such as a virus or bacteria that causes the body's defences to attack an otherwise healthy gut. One curiosity: the disease occurs more frequently among northern peoples, and Canada may have the highest incidence in the world. Nobody knows why.

At the same time as my disease has seen the evolution of medical understanding, it has also followed the course of pharmaceutical progress. At the beginning of my illness, there was nothing more than war-vintage medicines to throw at Crohn's, and surgery was a frequent recourse. Since then, the medicines have improved as my condition has deteriorated, and, between them, the two have achieved a sort of balance. It's been a decade since my fourth, and last, abdominal surgery. But in order to stay well, I some years ago advanced to the forward reaches of modern pharmaceuticals. "You're pretty much a New England Journal of Medicine article, all by yourself," my doctor says.

I well remember my graduation to "big-gun" medications - things like chemotherapy and neuroleptics - because they made me so sick. Big-gun medicines are impressive - you know they must be good for you because their side effects are so frightening. They are the result of lengthy research, they are expensive and, sometimes, they even work.

Because research into Crohn's is so sorely underfunded, patients tend to be served from the Hadassah bazaar of the medical community - we get hand-me-down medicines, usually well worn from use in cancer, arthritis, organ transplant, and palliative-care treatment. The medicines I am prescribed (other than painkillers) total something like twenty-one tablets a day. I take chemo drugs to control my immune system, anti-inflammatory drugs to control the Crohn's activity, drugs to shut down one hormonal secretion and drugs to stimulate another - bottles and bottles, all labelled, "Alice, take me." I also formerly had regular surgery to remove the damaged intestine, until doctors reasoned the chance of relapse was 100 percent within three months of the operation.

A few years ago, I awoke one morning to the familiar agony of the mule kicking me in the belly, and called my daughter in from the next room. She lives with her mother in another city. I had to tell her her visit was being cut short, since I had to go to the hospital.

A few phone calls later and my friends had rallied around. I had a ride to the hospital and she had one to the airport, but as we parted my daughter looked at me, for the first time ever, fearfully. She pulled away as I hugged her goodbye, curled herself up, and said nothing. She had never been like that before, I thought.

But I had never been that sick before. Doctors quickly diagnosed a burst bowel and consequent blood infection. They flooded my body with intravenous antibiotics and inflammation-fighting steroids. As my temperature soared, my venous system became inflamed with the infection - including the venous system of my brain. At the same time as I was fearful of losing my body, I had reason to fear losing my mind. I felt the tethers of reality loosen, one by one, as I slipped into another world. It was a magical and mythical world, but it was not this world. I felt immortal and empowered, but this was the result of a psychosis. Despite this, I remained self-aware: I knew there was a risk of death and that I was going insane.

I also knew the depths of my own reserves and I trusted my physicians' hands. My doctors reassured me that I would surely recover in both body and mind, but not for some while. For the next several months, I would have a psychosis induced by inflammation and steroids. I would simply have to live through - and learn from - the experience of insanity.

"Mankind has used psychosis to treat disease for ten thousand years," my doctor said. "I'm not about to interfere with that process now." I understood that he was talking about shamanism, mind-body medicine, whatever you want to call it, the idea that an otherworldly experience can effect a cure. After all, when a church prays for a parishioner, what is that but a shared psychosis? Mine would be more immediate and overwhelming, but it was not beyond the ken of human experience. This notion was comforting to me, and it goes without saying my doctor is a very wise man. Eventually, as I hope my writing allows, I recovered my lucidity. But the mind-altering experience of living for months in the moon's intuitive darkness, without the illumination of the intellectual sun, is one that I carry in my pocket, like a secret.

People are always telling me that because I have Crohn's disease I shouldn't be doing the fun things they

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are doing - like having a beer, for example, or eating something other than brown rice. It is hugely annoying, because almost without exception these people do not know what they are talking about, recommending foods I know would leave me in hospital or warning me away from foods that I enjoy. I do my best to forgive these people their helpful instinct, because I understand the desire to heal as one of the primal social imperatives. We all think we are healers and feel called upon to help those in our tribe who are suffering (in particular, before it spreads). It's just that very few of us are good at healing, or tendering advice.

What I have found, instead, is that just about everyone is good at offering comfort. I have had the hands of compassion laid upon me by doctors, nurses, ambulance attendants, the women in my life, friends, the wives of friends, complete strangers in bus terminals. When it comes to offering solace, people have a natural ability, which transcends social place or relationships. We just give, naturally, of ourselves to those in need. One small consolation of having such a painful illness is the many opportunities it allows others to show kindness; the one great reassurance is how seldom I have been disappointed. And I have accepted compassion willingly in my life, knowing that I am a small, cracked vessel for others to pour in their love.

Of course, because it involves the bowels and shit and puke, Crohn's disease will always be the subject of fear and prejudice - as though the bowels and shit and puke were not essential parts of living. Crohn's patients have suffered nearly as much from society's distaste for anything to do with the bowels as from the disease itself. As evidence, I refer to the brief and inglorious appearance of Crohn's from the pen of Canada's leading man of letters.

In his 1997 Giller Prize-winning novel, *Barney's Version*, Mordecai Richler captures an aspect of social attitudes towards Crohn's that is undeniably sad, but just as undeniably true.

In the novel, a wealthy Duddy Kravitz is seeking to pave his way into high society through philanthropy, and is looking for a good cause to support. He briefly considers bulimia, since Princess Diana suffered from it, so "it could have lots of appeal for Westmount

types." But he finds all the good diseases are taken. "I need a disease," he tells a doctor.

The doctor suggests Crohn's disease, explaining its symptoms to Duddy. "Oh, great," he replies, ". . . a charity for farters." He imagines inviting celebrities to sit on the board of a charity "for people who shit day and night." He imagines his wife throwing the annual Diarrhea Ball. "Listen," he concludes, rejecting the idea. "For my wife, it has to have some class."

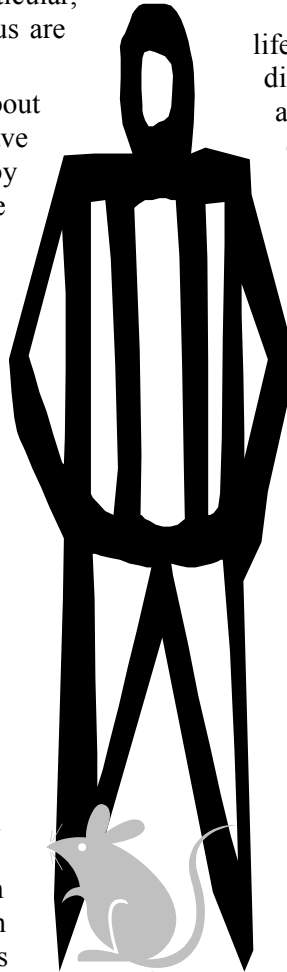
I agree. Crohn's has no class. For most of my life, I hid from any public mention of having the disease. It was internal, and unpalatable, and about as socially acceptable as leprosy. I don't care about that any more. It is also my body's condition and my life's experience and this makes it, in a certain way, sacred. Even if it doesn't appeal to Westmount types.

The specialist in internal medicine sat across from me, a respectable-looking man with greying hair and cufflinks. I had already passed through the obstacle course of seeing three other doctors, two of them specialists, before meeting this man. I was a candidate for an experimental medicine intended to control Crohn's disease. The medicine is known as infliximab, or by its trade name, Remicade. Infliximab was developed as an anti-inflammatory drug that was discovered to be useful in controlling Crohn's disease in its active phases, and also in inhibiting the joint damage caused by rheumatoid arthritis. The trials were already full, but I was being considered on compassionate grounds. If approved, I would be the thirty-seventh person to enter the drug trial. I realized only when I sat across from him how desperately I wanted the doctor to say yes, how tired I had become of being

sick.

I had been in pain for months despite my regimen of medicines, and while infliximab held out the prospect of relief, it also held out the prospect of devastating side effects, from catastrophic infections to anaphylactic shock. But these seemed remote in comparison to the immediacy of my symptoms. The specialist explained the side effects, and also explained that my body might reject the medicine, since I was, essentially, about to be injected with a laboratory mouse.

Infliximab is a new generation of medicine, my
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specialist explained. Here, he said, drawing four lines across a page of paper. Here are your lines of defence. The first was diet. Many Crohn's patients find it difficult to eat, since eating can be so painful, and the specialist emphasized the importance of maintaining vitamins and protein to fight the illness. The second line of defence were the anti-inflammatory drugs such as sulpha and corticosteroids. I had taken as much of these as my body could handle. The third was the chemotherapy drugs to suppress my immune system, since Crohn's is an immune response gone awry. Again, I was at the maximum safe dosage. There was a fourth defence, I knew - the dreaded anti-rejection drugs - but he didn't mention those. Instead, under the fourth line he wrote, "biologics."

Biological medicine works inside the body at the molecular level, he explained. In the case of infliximab, a mouse-human hybrid antibody is manipulated in such a way that it binds to a certain rogue protein molecule in the human gut, rendering it incapable of making a mistaken attack on the body's healthy intestine. This rogue protein has a marvellous, horror-movie name. It is called "tumour necrosis factor-alpha," or $\text{tnf-}\alpha$, and it plays a fundamental role in triggering the cataclysmic chain of events that leads to gut inflammation. While no one yet knows the cause of Crohn's disease, the new medicine holds out the promise of interrupting its activity at an earlier stage.

While the drug has been approved in the United States for the treatment of Crohn's disease since August, 1998, it is still not openly available in Canada. Health authorities here were unconvinced that enough research had been done on dosage levels, so I was to be a guinea pig. The medicine is not only experimental, but high-priced - each of my infusions would cost about \$4,500 and I could require one every couple of months for a year. Luckily, the cost of the drug is covered while under trial.

The specialist finished his explanation and leaned back in his chair, crossed his arms and regarded me. "I can induce a remission in you, young man," he said. "I can't guarantee how long it will last."

He had said the magic word: remission. I didn't care how long it would last. A day without pain would be good. I left his office and walked out into the pale winter sunshine. It seemed a long time since anyone had called me a young man. It seemed a longer time since I had experienced the thing called hope.

Muriel Spark called the question of pain, or Job's

question, "the only problem," in a novel with that title. So, what then, is the answer? How could a merciful God allow suffering to exist?

My own response has been to accept both pain and pleasure as a richer, fuller experience of life than to experience either on its own. There is nothing more intimate than the relationship with the body. Living so routinely with pain as I do makes my relationship with my body more complex and involved. Not everyone feels the progress of a sandwich, inch by painful inch, through his digestion. I have. Not everyone nurses himself through day and night of unremitting agony, finding he still loves his body in spite of everything. I have. This involves a powerful commitment to the body, a loving kindness, and a forgiveness. I have noticed I do not feel the same connection to myself when I am feeling well. I take myself, my body, for granted.

What frightens me is the extent to which this primary relationship is reflected in all the others - the extent to which I may have become a pain-seeking missile in all my relationships. Pain, after all, at least has the advantage of being real and deeply felt, two qualities missing from many connections. "The problem with you people who have a chronic disease," my doctor once said, "is that you begin to think that pain is normal."

My body knows this much, this it has learned: Nature is much kinder than She is made out to be; and God is not always as merciful as He lets on.

The morning of my first infusion of infliximab - the mouse medicine - found me both nervous and excited. I read again the pamphlet from the doctor's office, which warned me against taking the infusion if I had a sensitivity to "mouse products." I wouldn't know, having never eaten one. I remembered the research nurse warning me against fathering a child in the next year, in case of genetic complications. I thought of the changes that were about to occur deep inside my body. Weird alchemy, mad science. I prayed to the powers that be for the best.

The infusion took four hours to complete. In contrast with the high-tech medicine I was about to be administered, the scene at hospital was mundane. I followed a rat's maze of linoleum corridors to the research unit, where a nurse guided me to a gurney. She set up an intravenous drip through a flow monitor and took my vital signs, then broke open the expensive vials of medicine. Normally, being treated for Crohn's involves hospital gowns and painful violations of the

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bodily orifices. This time, I didn't even have to remove my street clothes. Midway through the process, my specialist appeared, to put my fears to rest about being injected with an animal product. After all, horse urine has been used to make estrogen, pig pancreas has been used to make insulin. But it was, he warned, a "one-shot" deal. I would get only one round of infusions - a "round" consisting of a number of infusions spaced over a year, according to need. After that, there was a high risk of developing a rejection mechanism against the foreign - mouse - protein. If the medicine did not work during the first round, I would not have a second chance.

I was told it would take about four weeks or so to feel the benefits of the infusion. I left a few days later to spend the winter holidays in England and actually felt better within a week - a placebo effect? I enjoyed a brief respite from symptoms and downed great quantities of ale and fruitcake. This was not a great idea. Soon, I was taking more heroin to cope with the pain. The first infusion had not been strong enough. I returned to Canada after the holidays and phoned my specialist, begging for a second. There was a boring detour when routine blood work turned up an iron and B12 deficiency. Both are absorbed by the ileum, where my Crohn's is active. A normal person has iron stores of about twelve to three hundred ng/ml; mine were at one. I received a big bag of brown stuff through the veins, and a few weeks later, was declared fit for a second infusion.

The second infusion was more nerve-racking than the first - what if this, too, failed? But this time, they got the dosage right. The mouse medicine overwhelmed the $\text{tnf-}\alpha$ protein, binding to their nasty little receptors so they couldn't cling to the intestinal membrane. This time, I experienced a dramatic reduction in pain and an increase in energy. For the first time in months, I had no need for opiates. For the first time in years, I could eat anything I wished.

Grapes are wonderful! Carrots are snappy! Eating a peach is a lush, incredible experience! Having returned to them after such a long absence, I can say that if I had to choose between sex on the one hand, and fruits and vegetables on the other, I would choose the food. After all, a man without an appetite for food soon loses his

taste for sex as well, whereas a man with a healthy appetite has an appetite for all things.

Lucretius, the Roman Epicurean philosopher who had his own brush with divine madness, said that one has no right to complain about being removed from the banquet of life if one has been sitting there without taking part. I never again want to sit idly at the table of life. Give me food, cascade me with peaches, for as long as I live.

One summer, in my youth, I worked as a labourer on a farm in France. I knew nothing of Crohn's disease then, had no hole in my belly. At times in my dreams, I am returned there and to the sense of being intact, without disease. I slept in the barn's loft, which was used for the storage of apples. The loft had wide doors that I left open at night, so I could look at the stars while resting among the scent of fresh-picked apples. One night, I took a girl up there with me. That is the kind of banquet I am talking about, of life in abundance.

When I reflect on a life spent in the company of Mr. Crohn's, he hasn't kept me from the banquet. All of the important things in life - enduring emotional relationships, the satisfaction of a writing career, the thrill of adventure, the joy of raising a child - all of these have been granted to me. I owe Mr. Crohn's a debt of gratitude for the lessons he has taught. Having said that, should he now take his exit, I won't miss him one bit. He was a teacher, but his lessons were harsh, and I am now prepared for gentler instruction.

Robert Mason Lee is an award-winning journalist and a Gemini award-winning broadcaster. He has been a regular contributor to Saturday Night and a columnist for the Globe and Mail, while his television program, "Mason Lee: On the Edge" airs on Sundays on the CTV network.

Editor's Note: Remicade was approved in Canada on June 6, 2001. However, this does not necessarily mean that all patients have access to this medication as it has to be approved separately by each provincial formulary (e.g. Pharmacare in BC). Basically, what this means is that while many private insurance companies will pay for the medication, those that require provincial coverage will have to wait for completion of reviews and approval by individual

