

Patient 13 – taking the quest to cure type 1 diabetes to the big screen

Lisa Hepner

Award-winning documentary filmmaker, Lisa Hepner, diagnosed with type 1 diabetes more than 20 years ago, is not one to shy away from a challenge. Initiating and realizing her latest project has provided her with a big one: to reach as many people as possible with a production that will engage and entertain, and raise awareness about diabetes. *Patient 13* follows the 30-year quest for a cure for type 1 diabetes. And, as they say in the movies, ‘this time it’s personal’! Here, Lisa tells the story behind *Patient 13*.

It was an unusually hot summer day, even by LA standards. I was cranky. My blood sugars were all over the map, and I had scheduled an appointment with my endocrinologist at UCLA, Andrew Drexler, to help me figure out what was going on.

He sat me down and, in his inimitable way, sorted out my insulin needs. As usual, he had me laughing by the end of the hour. Just before I left, he asked if I was still looking for a subject to profile for my next production, a film about diabetes. “You have to meet Scott King. He has cured diabetes in rats!”

“Rats.” I chewed on that for a while. I have had type 1 diabetes since 1991; over the years, I have heard a lot about rodents being cured. I was intrigued but I was not overly enthusiastic.

It was 2010. My husband and filmmaking partner, Guy Mossman, and I had been looking for a few years to make a character-driven film about diabetes. A particularly terrifying night of hypos convinced us: we should apply our documentary skill set to a subject very close to home – what it is really like to live with type 1 diabetes and why the world so desperately needs a cure.

A terrifying night of hypos convinced us to apply our documentary skill set to show the reality of life with diabetes.

A few months later, Guy and I were at a restaurant in Irvine, California sitting opposite Scott King, a biotech entrepreneur



Randy Dorian collecting seaweed, which is used to produce the Islet Sheet.



Scott King injecting insulin.

gloom surrounding diabetes as I grew up.” Now, he says, he has assembled the best team to cure it.

Scott King, a biotech entrepreneur with type 1 diabetes, wrote Wall Street’s first investment report predicting a biological cure.

All for one...

Guy and I knew we were onto a great story. The four men have been friends for more than 25 years. They resemble the implacable team assembled in the film *Ocean’s Eleven* (see also *The Great Escape* or *The Seven Samurai!*) – experts in their field, at the top of their game, each with a specific skill essential to the success of the Islet Sheet transplant.

Randy Dorian is the inventor. He devised the idea of placing isolated insulin-producing islet cells into an ‘insulin tea bag’, which eventually became the Islet Sheet – an implantable device about the size of a credit card. The islet cells are protected by a thin membrane, derived from seaweed, that keeps the immune system from attacking the cells while still allowing the insulin to pass into the bloodstream. This approach is revolutionary because it eliminates the need for harmful anti-rejection drugs.

Rick makes the sheets. A graduate in biochemistry from Stanford, he works with Dorian in their lab in San Francisco. Jonathan Lakey is one of the top islet cell surgeons in the world. He isolates the islet cells that are then transplanted into the sheet.

A sequel to the Edmonton Protocol?

I remember the Edmonton Protocol vividly. It was 2000 and I was living

with type 1 diabetes. Sitting next to Scott were his core Islet Sheet team – Randy Dorian, the inventor of the Islet Sheet (read on for more on this); Rick Storrs, the scientist who makes the sheets; and Jonathan Lakey, the co-pioneer of the famous Edmonton Protocol. The Edmonton Protocol is a method of transplanting human pancreatic islets to treat type 1 diabetes – specifically in people with type 1 diabetes who are prone to hypo unawareness. The protocol gets its name from the islet transplantation group at the University of Alberta, in Edmonton, Canada, where the protocol was first devised in the late 1990s.

By the entrée, Guy and I had heard how Scott had been working on the Islet Sheet for nearly 30 years. We learned how, after graduating from Harvard, he had gone to Wall Street to work as an investment analyst, focusing on the viability of a cure for insulin-dependent diabetes. He wrote Wall Street’s first investment report on diabetes that predicted a biological cure.

Scott says he became a ‘professional diabetic’ in part because his grandfather was one of the first people in the USA to receive insulin. “My grandfather died of type 1 diabetes, so there was unspoken

in New York City. I had read about Dr Lakey and his colleague James Shapiro of the University of Alberta, and how they had successfully transplanted islet cells into people with type 1 diabetes. The Protocol enabled people with diabetes to cease insulin therapy, although since then, research has demonstrated that insulin independence wears off over time. The necessary immune-suppressant drugs make people who have undergone transplantation very vulnerable to infection.

How often do you get a front-row seat to witness an historic medical breakthrough in the making?

I had wanted to participate in the Edmonton Protocol. I even asked my endocrinologist where I could sign up for a clinical trial. He advised me against it, arguing that I was in fact 'too healthy' to participate, and that the health risks and discomfort provoked by the anti-rejection drugs would be too high a price in my case. Still, the Edmonton Protocol is perhaps the closest anyone has come to curing this annoyingly complex and demanding disease of mine.

Now the world was ready for a sequel: The Protocol II! "The Islet Sheet is huge step forward," said Dr Lakey. "I am optimistic and hopeful it will work."

By the end of lunch, Guy and I had committed to making a feature documentary about the team's quest for a cure. How often do you get a front-row seat to witness an historic medical breakthrough in the making? If the Protocol is successful, it will affect many millions of people around the

The film will not sugar coat the reality of life with diabetes.

globe – which is quite a story. In terms of our responsibility as filmmakers, whether the Protocol is successful or not, we will have chronicled an epic struggle and put a face on this silent – yet deadly – condition.

Lights, camera, action...

Filming of *Patient 13* has been under way for 18 months. The research is about to enter large animal trials at the University of California Irvine and, if successful, is projected to enter the human trials phase in Europe some time in 2013. Our crew will be there. We will follow the selection process, hopefully capturing the moment when the first person ends his or her insulin therapy. If events unfold according to Scott's plan, he will be the 13th participant in his own clinical trial – *Patient 13*.

Our goal for *Patient 13* is to reach general audiences worldwide through cinema screenings, television broadcasts and educational showings in schools, hospitals and other relevant public venues. We want the film to entertain audiences and raise awareness about diabetes and diabetes research.

I have lived with type 1 diabetes for 20 years and Guy sees me toil with it on a daily basis. So we will not sugar coat the reality of life with the disease and *Patient 13* pulls no punches.

Nonetheless, we are hoping for a happy ending to this film! Like our audiences,

we want to see Scott realize his dream of curing the disease that has affected him since he was 21. But nothing is certain. What is certain is we have an opportunity to bring diabetes to the big screen and, in the process, support efforts to find a cure.

Lisa Hepner

Lisa Hepner is a Canadian-born journalist who produced a variety of films and programs, she is the director and producer of the *Patient 13* documentary.

Visit www.patient13thefilm.com for more updates on the film's progress and learn more about *Patient 13*.