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Diabetes, my journey of discovery

In 1993 at the age of 28, I lost my sight to diabetic retinopathy after having juvenile diabetes since the age of 4 1/2. It was at this point in my life that the severity of my disease really sunk in. I searched high and low to find the best ways to stop any further complications from diabetes. In 1996 I underwent a pancreatic transplant in hopes of reversing my disease. Although it wasn't an easy road and my recovery was riddled with complications, I did experience for the first time in my life, real blood sugar control. Sadly in 1998 I had to have the transplant removed due to complications, but from that time on I searched for the best way to control my disease. I felt what it was like to have a normal life, and as bitter sweet as it was, I gained a wealth of knowledge in those 18 months. In 1999 I extensively researched a better form of treatment, and I found insulin pump therapy and decided that this was the best therapy for me. I was not prepared, however, to be faced with the hesitation from the medical community regarding my blindness. It was then, and even now very unusual for a blind person to be prescribed insulin pump therapy, because the pump is not accessible via speech or braille. Still, being committed to my health I pushed forward and convinced my doctor to let me try using the pump, and to everyone's amazement, I didn't have a problem filling insulin cartridges, inserting sets, or giving myself boluses of insulin.

The one drawback was that I did have to rely on a sighted person to use the other features and to change settings on my pump. This was something I had never had to do before. Having been diagnosed at 4 1/2, I learned very young to control my disease myself. I was giving myself insulin injections at age 5, so the idea of relying on someone else to change settings on my pump never really sat well with me. My wife and I are both blind raising a sighted child and our independence is very important to us. The days of blind people needing care givers have long since passed and teaching our child the capabilities of disabled people is, to us, one of the most important lessons we can teach our son.

I met my wife Brandie in 1994; not long after losing my sight, when we were both attending a rehabilitation center for newly blind adults. Together we not only learned how to overcome the physical challenges blindness brings, but also how to manage and live with diabetes blind. After my unsuccessful transplant, we needed to find a better way of managing my diabetes. I felt that insulin pump therapy was the best way to keep tight control of my blood sugars. Although she is not diabetic, Brandie is a

rehabilitation specialist for the blind with a BA in social welfare specializing in geriatrics. She has been teaching and advocating for blind adults for over 15 years. Most of her clients through the years have been blind diabetics, and she knows how insulin pump therapy could be tremendously beneficial to her clients. She is disappointed that most doctors and diabetic care providers are not open enough to give pumps to blind diabetics. Losing my sight was one wake up call regarding my diabetes, but the ultimate reality check came in 2005 when we welcomed into this world our son Garrett. Once more a startling revelation hit me. Becoming a parent not only meant having a child, but also, being there for that child, healthy and strong throughout his life. The pump did allow me the control I desired as far as the way I was receiving my insulin, but I wanted more control than that. I began to realize that in order to gain full control of my disease; I was going to have to make insulin pump therapy accessible to myself and everyone else.

Being an Electrical/Electronic Engineer, I have designed speech products for the blind for the past 10 years. I decided that if no one was going to provide speech for the insulin pump, then I would.

It is no surprise that diabetes is the leading cause of blindness today, and the need for accessible pump therapy increases daily. According to the American Diabetes Association, 1.2 million people are diagnosed each year and 12 to 24 thousand diabetics go blind yearly, making diabetes responsible for 8% of legal blindness in America. Furthermore, 21% of newly diagnosed diabetics already show signs of retinopathy. To add to this astonishing statistic, people who have had the disease for over 20 years, like myself, will unavoidably show evidence of diabetic retinopathy, regardless of their history of good glucose control. With insulin pump therapy, the diabetic can achieve far greater and more accurate control than with insulin injection alone, often preventing further health complications.

As a blind diabetic person, I felt strongly that the benefits of insulin pump therapy should not be limited to those with sight. In 2008 I began working with a colleague researching the demand for an accessible pump therapy in the blind community. What I found was that the major blindness groups i.e.; National Federation for the Blind (NFB) and American Council of the Blind (ACB) have, at one time or another, proposed the idea of a talking pump and making it accessibility compliant to pump therapy and part of the American's with Disabilities Act (ADA).

My engineering colleague has also become enthusiastic about the idea of an accessible insulin pump. Working together, we've researched how people use insulin pumps and found that many diabetics don't want the world to know of their disease and keep the pumps concealed in their clothing. Even sighted people are sometimes reluctant to

retrieve their pump from its hiding place or even from a belt attachment and operate its controls in public or at work. In addition, due to the mostly convenient small size of the devices, the display and buttons are necessarily small, but unfortunately rather difficult to see. People with poor vision or that require reading glasses find it difficult at times to operate their pumps. If they've lost their reading glasses they find themselves with the same challenges a blind person faces.

In addition, we realized that the simple concept of a talking pump is really not practical. Imagine a pump, attached to your belt, or hidden in your clothing, but with a small speaker somehow embedded, with electronics to create speech for operation menus and feedback. You would still have to retrieve it from your belt or other hiding place in your clothing, and now you'd have to hold it close enough to your ears to hear it, and to operate the buttons at the same time. And certainly attempting to add the necessary electronics and speaker and additional batteries is going to make the tiny convenient insulin pump not so tiny and not so convenient!

Since many pumps have extensive wireless communication ability built in we realized an alternative approach would be a “talking” remote control. So, the “Pump Mate” concept came to be, and has evolved to include audible speech menus, and a display with large fonts as well, serving not only blind diabetics, but diabetics with limited vision. Surprisingly, sighted diabetics have also expressed enthusiasm for the concept.

The "PumpMate" will give control with a higher degree of discretion that many desire. For many blind and visually impaired people like myself having to rely on another person to manage my insulin pump therapy is not an option. The better the accessibility the better the control and this would mean less diabetic complications for everyone. Injection truly is archaic and today's blind diabetics, including myself, are waiting with baited breath to take advantage of this new advancement in diabetes therapy.

Together we push forward and hope that we can help other families living with diabetes and blindness overcome the hurdles and obstacles that stand in the way of full independence of one's insulin pump therapy. We share our knowledge with whoever will listen and try to educate as many as we can about living with blindness and diabetes and soaring above the devastation that the disease can sadly bring. I truly believe pump therapy is the best and only way to go and I am determined to make it accessible for all that need it.

To this end, my engineering colleague, Phil Brooks, and myself have designed the “PumpMate” (patent pending) which is in its final stages of development. Among many of its abilities, PumpMate allows users to create multiple basal profiles, load them into a pump, confirm settings, issue Boluses and receive glucose readings all the while

providing speech menus and confirmation of functions, as well as visible large font display. The initial version of the PumpMate will use English language speech, but other languages will be added.

Insulin pump therapy has not been made available to blind diabetics, and those with limited vision for the very valid fear they might press a wrong button, resulting in insulin overdose with disastrous results. PumpMate, utilizing the latest 21st century technology, eliminates this issue and opens the door to diabetes care that so many urgently need.

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For more information please visit: www.pump-mate.com