

Faces of LADA



Name: Cherise Shockley

Age at Diagnosis: 23

Cherise's story: "In June of 2004, I went to the doctor because I had a yeast infection that I couldn't get rid of. I didn't know I would walk out of the appointment with a diabetes diagnosis at the age of 23. The nurse practitioner was a little confused; I did not fit the build of a type 2, but I wasn't a juvenile to have type 1. I was told I needed to see an endocrinologist because she couldn't figure out what was going on with me. A few weeks later I saw one who ran a few tests and confirmed that I had LADA.

"What is LADA? LADA is the slow onset of type 1 diabetes that occurs in adults. When I was diagnosed with LADA, my c-peptide was 1.4 and the GAD65 test came back positive for antibodies. I decided to start taking oral medication as my treatment but was told by my endocrinologist that I would need insulin therapy within 4-6 years of my diagnosis. He was correct.

"In January of 2008, I was placed on insulin and my honeymoon phase was over. My situation is a little unique. I was not misdiagnosed with type 2 diabetes like many other LADA patients. I was blessed to have a nurse practitioner who realized I had diabetes, but did not try to act as a specialist. I was blessed to have an endocrinologist who recognized the signs, understood the test, and diagnosed me correctly. I am asked all the time, "Why don't you just say you have type 1?" My response? "I do not have type 1 diabetes. I have LADA. The type I have didn't progress over night." Healthcare professionals need to know LADA exists, and so does the rest of the world."



Name: Michelle Kowalski

Age at Diagnosis: 30

Michelle's story: "I was actually diagnosed with nearly every form of diabetes before someone finally got it right. And even that was an accident. My first diagnosis was pre-diabetes in February 2005. I was put on oral medications, and two months later I found out I was pregnant with my third child. I was then diagnosed with type 2 based on the logs I had been keeping, and used long- and short-acting insulin for the duration of my pregnancy. After the

baby was born I tried several combinations of medicines—long-acting insulin with metformin, long-acting insulin with Byetta, etc.—but what really worked was long- and short-acting insulin together.

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"By this time I was in the care of an endocrinologist who suggested that I was a candidate for an insulin pump since I was using multiple daily injections. My insurance company required a c-peptide level before approving the pump, and my level came back at <0.1, which indicates that my pancreas had all but shut down. At this point I had only been diabetic for about three years and my highest A1C was 9, which quickly came down (with the use of insulin), so it was highly unlikely that my c-peptide level was a result of overworked beta cells. My endocrinologist and I surmised that I was type 1.5, also known as LADA. Several years later, after moving across the country and meeting with another endocrinologist, more lab tests confirmed that I am indeed type 1."



Name: Manny Hernandez

Age at Diagnosis: 30

Manny's story: "I can barely remember when I first heard of it: 'LADA? What is that?' It was back in 2007, when we launched our diabetes social network. I had been living with what I considered to be type 1 diabetes. But, let me start from the beginning....

"In mid-2002, I showed up to my doctor's office for my scheduled annual checkup. We went over my lab work and he pointed his finger at the fasting blood glucose number: 'Too high!' or something to that extent, he said. He put me on the Atkins diet and summoned me to his office a few weeks later. Sure enough, I had lost weight, but the number still refused to go down: 'You have diabetes.'

"He sent me home that day with a prescription that combined diet, exercise and the first of many attempts to help lower my blood sugar through oral drugs. I took his advice to heart: I started training for a half marathon to help raise funds for diabetes and to help lower my blood sugar...and lower it I did! For the months I was training, the treatment 'worked' (I would later learn that my pancreas was still not completely dead, so that sure helped too!) But when the race was over and I wasn't running as much every week as I was prior to it, reality set in.

"I couldn't keep my blood sugars under 150 no matter how hard I tried. After exhausting every possible oral-based therapy he had in his arsenal for people with type 2 diabetes, my doc gave up and referred me to an endocrinologist. My endo tested me for GAD antibodies and C-peptide levels, the two markers that accompany people with type 1 diabetes. I had high levels of GAD antibodies (meaning my body was 'fighting off' beta cells in charge of making insulin in my pancreas) and low C-peptide levels (meaning my pancreas was not producing enough insulin any more). So I heard the new diagnosis:

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'Type 1 diabetes.' It was early 2003.

"Starting then, I began taking insulin shots, more specifically shots of peakless basal insulin every night. Over time, I started also taking rapid acting insulin shots. The switch from pills to shots was not an easy one and it gave me a newfound respect for people who have grown up taking shots since they were kids. I now was 'one of them' or so I thought...which takes me back to the beginning of this story.

"In 2005 I started wearing an insulin pump, continuing to ride the therapy path that many people with type 1 diabetes take. Then finally, in 2007 I realized that I was not alone: there are actually lots of people who lived with this crazy little thing called LADA (Latent Autoimmune Diabetes in Adults), also called type 1.5 diabetes by some."



Name: Barbara Campbell

Age at Diagnosis: 46

Barbara's story: "June 24, 2009 is a day I'll never forget. It's the day everything changed forever. My name is Barb and I am a person with LADA.

"I hadn't been feeling well. In fact, I'd been feeling horrible. I had every textbook symptom of diabetes: excessive thirst, frequent urination, a wound that wouldn't heal, sudden weight loss. The only positive I could see was that I was losing a pound a day and eating everything in sight AND I was able to see perfectly without my glasses.

"I arrived at the lab after a 14 hour fast to have blood drawn for the second time. A few minutes later, sitting in the exam room, I was told I had type 2 diabetes. I had to assume I was diagnosed with type 2 because of my age. After all, type 1 is for kids, right?

"I started noting my BG creeping higher and higher, no matter what I did. Diet, exercise, and more exercise. In all my research, I had also stumbled upon dLife.com. That's where I learned that I was not dealing with type 2, but LADA.

"Cherise, a new friend in the dLife Community, had been diagnosed with LADA and shared her story with me. Another new friend, Scott, made arrangements for me to speak with his CDE and I was able to get an appointment with the endocrinologist at his clinic. Within 5 minutes, Dr. Robbins had determined that I had Latent Auto-Immune Diabetes as an Adult. I know I'm just one of many."

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Name: Jessica Apple

Age at Diagnosis: 35

Jessica's story: "Since my first pregnancy in 2000, I've had a lot of diabetes diagnoses thrown my way: gestational diabetes, pre-diabetes, insulin resistance, and one doctor even told me I had type 2 diabetes. But I was young, thin, in good shape, and no one in my immediate family had diabetes, so a type 2 diabetes diagnosis made no sense. Yet, no one thought to test me for type 1 diabetes, an autoimmune disorder, because I had none of the classic type 1 symptoms like extreme thirst, weight loss, frequent urination, or diabetic ketoacidosis.

"Eight years later, while pregnant with my third son, it became clear that something more than gestational diabetes or pre-diabetes was at play. I was exhausted all of the time, and an oral glucose tolerance test performed very early in the pregnancy showed blood glucose numbers over 250. 'I want to be tested for type 1 diabetes,' I told my doctor. My doctor agreed and ordered a test for the antibody GAD, a marker of type 1 diabetes.

"I went to the doctor's office to receive the results of my blood test. I had indeed tested positive for the GAD antibody.

"'You have type 1 diabetes,' he said. 'But it's probably LADA.'

"'LADA?' I said. I was vaguely aware of the term, but I had no idea what it meant. It turns out, I'm not alone."

Jessica Apple is the co-founder and editor-in-chief of the online diabetes magazine ASweetLife.org. Check it out!



Name: Chris Frankie

Age at Diagnosis: 23

Chris's story: "My story begins in the year 2000 as I was preparing to graduate from college. I was having trouble sleeping and began losing weight. At first I attributed my symptoms to the stresses of final exams and the impending end of a five-year relationship with my high school sweetheart.

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"However, it quickly became apparent something was seriously wrong. In the span of five months, my weight dropped from 235 pounds to 168 pounds, leaving me looking like a skeleton in my 6'4" frame. As my symptoms grew worse I became scared that I might be dying.

"I sought treatment from my doctor, who told me that I had diabetes. If I stayed on top of it, I could control it; however, my doctor misdiagnosed me with type 2 diabetes. In the ensuing months, I followed classic recommendations for type 2 diabetics, such as taking my medication, altering my diet, and continuing to stay physically active. My blood sugar remained out of control. Tired of feeling constantly fatigued and frustrated with the lack of improvement in my condition, I turned to a highly recommended endocrinologist. She told me I have a rare but growing form of diabetes that doctors have dubbed type 1.5 (LADA).

"Today, I check my blood sugar levels eight times a day and rely on numerous daily injections with two types of insulin to maintain blood sugar control. In addition to having type 1.5 diabetes, both of my parents have been diagnosed with type 2 diabetes, making this subject matter deeply personal to me.

"Following my diagnosis, I was struck by what appeared to be a lack of useful news about diabetes. I could either stay uninformed or dedicate a significant amount of time weeding through tons of websites for news and information that lacked context or held little application to my life. I decided to take matters into my own hands, and in July 2009, I launched *Diabetes News Hound*."



Name: Kelly Layne

Age at Diagnosis: 31

Kelly's story: "I was diagnosed with LADA in March of 2009, but my journey began more than six years ago when my boss told me the pictures I was taking were all out of focus. I agreed to get my eyes checked and the optician told me my prescription had worsened so drastically that I might have diabetes. I went to the local clinic, was sent for a blood test, and heard nothing back.

"When I got pregnant with my first son two years later, the midwives who were treating me told me the sugars I was spilling in my urine were normal and the blood test I took was 'borderline' diabetic. They advised me to avoid high carb foods and assured me everything would be fine. I developed preeclampsia and my son was born at 8 lbs. 7 oz. and three weeks early.

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"I got pregnant with my second son in August, 2008 and the pregnancy started much the same as the first: I was spilling sugar, losing weight, and throwing up day and night. I took a gestational diabetes test at five months that put my blood sugar at 18 mmols. I was told I was a gestational diabetic and was put on insulin until I gave birth.

"About six weeks after my son was born, I was diagnosed as type 2 when my sugars 'didn't settle down.' I couldn't be type 1, my endocrinologist and family doctor told me, because I would've been very sick, very quickly. It was only when, a few months later, I developed Hashimoto's Thyroiditis, and after an unsuccessful trial on Glumetza, that autoimmune diabetes was even suspected. Finally in March, I was diagnosed with LADA and I've been living on insulin happily ever since.

"I belong to an online community called TuDiabetes.org where I meet people from all around the world whose experiences are strikingly similar to mine. I believe this points to a universal, systematic problem. In the spring I gathered these stories together to ask the Chair of the National Diabetes Management Strategy in Canada for better diagnosis and treatment of LADAs. Last week I received a letter from him saying my concerns will be discussed at the next Canadian Diabetes Association clinical practice guidelines meeting." 