

Solidarity, activism and #insulin4all

James A. Elliott

In every country on earth, from China to the Vatican, you will find people with type 1 diabetes. I chose to dedicate my professional life to diabetes research and advocacy. For a time, I was the manager of the Diabetes Canada Charter of Rights and Responsibilities, and more recently, I have been performing research work in the Middle East.

I have also lived with type 1 diabetes for 16 years.

Research and advocacy work have taken me to many interesting places. In Lebanon, I worked on operational research in diabetes with *Doctors without Borders (MSF)*. There are over a million refugees of the Syrian conflict in Lebanon and where I was based, in the Bekaa Valley, many live in shacks beside the road.

Before the war, Syria had about the same proportion of people living with diabetes as did the United States, roughly 9 percent of the population. One fellow I met in Syria was living with type 1 diabetes. We asked him a series of questions about his diabetes to assess his self-management skills. He got every answer right. As it turned out, his father had also lived with type 1 diabetes. Somehow this person living with type 1 diabetes had to balance his insulin dosing without testing his blood glucose alongside a diet of nothing more than the potatoes a farmer gave him for free.

In my travels in Lebanon, I also made it a habit to ask young people with diabetes: *“What is the hardest thing about living with diabetes for you, right now?”* The answer was always the same, male or female: *“I don’t think anyone will ever marry me.”* Their words really stuck with me. When children are forced to work in the fields instead of going to school because there isn’t much money or food, few families are willing to take on the added expense of insulin, needles and test strips.

Over the last three years, I’ve dedicated a lot of my time and effort to **T1International** which is an international organization dedicated to the rights of people with type 1 diabetes. The organization is especially focused on the right of every person with diabetes to access insulin, upon which every person with type 1 diabetes depends for survival. Our slogan is #insulin4all which does a good job of summing up T1International’s core mission. We want to show the world people in need of insulin, like those in Lebanon, or rural America, exist and can be helped. We bare witness and help advocates fight for change at local, national and international levels. Recently, I coauthored correspondence for *The Lancet*, entitled [“Access to insulin: patients will pave](#)



James Elliott (center) at a workshop on diabetic foot care. University of Yaoundé, Cameroon, February 2017.

[the way](#)” along with other Trustees and Elizabeth Rowley, Founder and Director of T1International which reflects the need for collaboration in prioritising insulin access for all people who live with diabetes.

What I’ve come to realize is that every person with diabetes, whether type 1, type 2 or otherwise, must realize we are in this together. When we hear about people dying from lack of insulin, or we see senior White House officials stigmatizing people with the disease on the news, we must understand we are all being threatened. No one is going to care about diabetes more than the people who live with it. We need to support each other with donations and by advocating for ourselves and for those who are suffering. We need to raise the visibility of people living with diabetes and frankly, convince politicians and industry that our lives are worth saving.

What I’ve seen is that with creativity and just a bit of money, diabetes is a survivable condition in nearly every setting. Santé Diabète’s work in Mali is a great example. If you can treat diabetes successfully in Timbuktu, diabetes management can be done anywhere.

Individual advocates need to call a spade a spade. I often read in academic journals how the diabetes movement must look to the HIV/AIDS movement for inspiration. HIV/AIDS activists were loud, organized and powerful, but what is often forgotten is that access to HIV/AIDS treatment wasn’t solved by Bill Gates or Bono. It was driven by patient-led groups like Treatment Action Coalition. They were the

catalysts for change, rejecting rubbish statements like “*HIV is too expensive to treat in Africa*” or “*those people with HIV did it to themselves*”. These statements are today too familiar to some diabetes advocates.

I encourage all advocacy organizations to have people living with diabetes in leadership positions – as executives and as board members. That’s certainly what we are trying to do at T1International. We must not be afraid of being the “wrong” sort of advocate or being an “angry” advocate. Our lives are at stake. We need to be direct and fearless in our advocacy for the rights of people with diabetes. We are all entitled to live strong, healthy lives.

Every person with diabetes, whether type 1, type 2 or otherwise, must realize we are in this together

Too many people who need insulin are not getting it regularly or affordably which is an avoidable calamity. The inventors of insulin clearly and explicitly wished that insulin be accessible for all. We need drops of it for a lifetime to stay alive.

My significant other’s grandmother has type 1 diabetes. She’s nearing 80 years old and has lived with diabetes for 70 years. When she was younger she had only urine dip sticks for blood glucose measurement. She also had to regularly

boil her glass syringes to sterilize them. Though this may seem prehistoric to some of us, I think the fact that type 1 diabetes is a cause of death and bankruptcy of so many is going to look woefully prehistoric before too long.

James A. Elliott is a researcher of diabetes health system policy and global health, and a T1International Trustee.

For more information: www.t1international.com