

Amazing Diabetes Advocates: Michigan Family Dreams

By Mike Hoskins, DiabetesMine, October 19, 2012

When he was just a kid during the '60s and '70s, Evan Kramer saw both his older brother and sister diagnosed with type 1 diabetes. But he didn't learn much about the chronic condition at the time, because his siblings didn't talk about their diabetes and his parents seemed to shield him from knowing more.

Throughout the years, they also didn't share much about their D-Lives, so it was, for all practical purposes, an invisible aspect of their lives.

That all changed Oct. 3, 2005, when Evan's own 10-year old son Tyler was diagnosed with type 1. The diagnosis hit the family hard, bringing back long suppressed childhood memories and a new world for the Michigan family to endure.

Turns out Tyler's diagnosis marked a new beginning for the Kramers: a new era of becoming a family of advocates — not only in their immediate community of West Bloomfield (about 30 miles northwest of Detroit), but also throughout the nation as their work is having ripple effects on many other families.

For that reason, they're the perfect addition to our [Amazing Diabetes Advocates series](#) and we're happy to bring you their story!

When their son Tyler was diagnosed, Evan and his wife Peri vowed that their son wouldn't have to live like his uncle and aunt, keeping his diabetes quiet and out of the public eye. The parents recognized the psycho-social need to be able to connect with others and share his story, celebrating the triumphs and venting frustrations as he might want to.

And so they encouraged that in Tyler as they all got a handle on diabetes.

“That prompted our advocacy,” Evan says. And about his siblings: “We weren’t going to live like that.”

Like many families living with diabetes, they began raising money for the large national advocacy organizations, and Tyler started riding in the American Diabetes Association’s Tour de Cure following his diagnosis; he actually set a chapter fundraising record of \$26,000 in his third year!

In 2009, the Kramers teamed up with another local diabetes family in Southeast Michigan to create their own their own not-for-profit organization. The name: D.R.E.A.M., which stands for **Diabetes Research & Education Advocates of Michigan**. The other family had a local non-profit of their own in honor of their two boys with type 1, though in the past few years they’ve since left D.R.E.A.M in the Kramer’s care.

Partnering with the **University of Michigan’s C.S. Mott Children’s Hospital**, the Kramers and D.R.E.A.M. fund diabetes research conducted at that facility and raise awareness about the latest D-treatment options available to PWDs until a cure can be found. To date, they’ve raised \$40,000 to fund Mott Hospital research and they’re working to raise another \$60,000 by 2014. The money goes into a fund administered by **Dr. Ram Menon**, who is Mott’s director of pediatric endocrinology, and also Tyler’s endo!

On top of the research funding, D.R.E.A.M. also raises money for annual scholarships to incoming U-M students with type 1. They’ve provided two scholarships to students so far.

The Kramers also began a recent partnership with Michigan-based **Diabetic Life Magazine**, which is working in that same part of the state to raise awareness about type 1 and type 2 diabetes.

Sure, this may sound similar to what the national JDRF and its many chapters do. Why not join an already existing organization that's one of the top fundraising entities for type 1 research?

On a recent trip up to Michigan, I had the chance to sit down and talk with the Kramers over a cup of coffee. They're great people and it was inspiring hearing them tell their story. It became clear why they are doing what they are:

"We have the ability to be completely grassroots," Evan Kramer said. "To focus on helping the labs that we want, to plant the seeds for a hypothesis that turns into something that could become a cure... that's very enticing."

Unlike traditional D-research grants provided by larger nonprofits and money from the U.S. National Institute of Health (NIH), this seed money can go to researchers who might want to venture outside a particular grant's scope. The D.R.E.A.M. money can essentially take away some of the limitations imposed by those not-yet-approved research parameters (see last week's ["conspiracy" post](#) for more on that). Additionally, the money has helped buy microscopes and cameras for labs, and also research mice that can cost \$300 or more per mouse to take care of. A clever fundraising motto they adopted for that funding specifically: *"Buy a mouse for the Big House!"*

Another aspect of what D.R.E.A.M. has been doing, the Kramers said, is a mentoring program, called the "Family Centered Experience" for 1st and 2nd year University of Michigan medical students that's now a required course in the university's medical school curriculum. The students are able to shadow D-families, meeting with them four times a year to get a close-up sense of what PWDs are going through. It's so important for future doctors to learn to actually listen to patients, Peri Kramer points out.

"We've been very fortunate to be a part of all this, and really that Tyler has all of this as part of his life," Peri Kramer said. "We are proud that he takes his health seriously, and it's very rewarding to be

able to help so many families. That benefit has been invaluable — identifying with others that can help him cope.”

Now 17, Tyler is a senior in high school and through the family’s advocacy he has found a place of his own. He took on the role of being the ADA’s Youth Ambassador in 2008. And he’s gone to the [ADA-run Camp Midicha](#) in Fenton, Michigan (the same camp I attended back in the mid-’80s after my own diagnosis!). Overall, he says he just “talks to anyone about it.”

His mom says the whole family’s been active in the Sanofi-sponsored [A1C Champions](#) program, and they’ve led interactive family support groups called “Our Diabetes Journey – For Parents and Kids” at diabetes camps, hospitals, and conferences regionally and nationwide. (Tyler actually introduced our own Amy when she gave a talk at an A1C Champions conference in Las Vegas last year!). They have upcoming speaking engagements that include Fargo, ND, this coming weekend on Saturday morning, one in Muskegon Heights, MI, on Nov. 3, another in Maumee, OH, on Nov. 7. and finally at the University of Michigan on Nov. 15.

Tyler is also exploring what he might take on for the future, possibly becoming a pharma rep selling diabetes supplies, she says.

Most recently, the family discussed and gave Tyler permission to get a [diabetes tattoo](#) on the inside of his left wrist — something he first saw on a D-camp counselor about five years ago. At first, his parents said no. But after many conversations, they told him to write an essay about why he wanted a tattoo and research the design. Instead of “a boring essay,” Tyler wrote a poem that convinced Evan and Peri to grant permission; he got the tattoo as a 16th birthday gift, just as he was getting his driver’s license as a way to let emergency crews know about his type 1 diabetes, should the need ever arise.

My First Tattoo



Five years ago times were different.

Five years ago things were not the same.

*The time has come to make a mark,
Hopefully it's not as hard to parallel park.*

My left wrist is where it will sit.

When it goes down, I hope I don't have a fit.

People might think the design is unique.

This will come in handy when I cannot speak.

Kids will stare, adults will wonder.

I think I'm ready to face the thunder.

I know this will stay on forever.

The same with diabetes,

It will always be with me wherever.

I do hope for a cure later in life,

But when there is, hopefully I will have a wife.

So please, let me get this tattoo.

As long as I live,

It will always remind me of you.