Finding My Diabetes Community

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For some time now, “Get involved with diabetes community” has been on my to-do list. I am a physician with type 1 diabetes, but I’m not an endocrinologist; rather, I’m a pediatric hospitalist. At my institution, as I expect is true at other academic centers, many of the physicians, nurses, and ancillary staff in the Division of Endocrinology have diabetes. There is a community within a community that doubles as a support system. My own work community is supportive, but I’m all alone when it comes to having others *really* understand my day-to-day life with diabetes.

To find a true diabetes community, I would need to look beyond the walls of the wards. I hoped to connect with a group that mirrored the camaraderie I’ve only experienced at diabetes camp. I have been both a counselor and a doctor at diabetes camps in the past, and I *love* the sense of community that camps create. I’ve even heard from many who attend camp and don’t have diabetes that *they* feel left out! Diabetes camp truly is a unique society and was the one place in my life where my diabetes didn’t draw any attention or make me stand out. Camp was the best! But does that camp feeling exist in the real world?

I needed a group of people who, like me, have type 1 diabetes and thus “get” the hourly, daily, and weekly frustrations and victories of living with type 1 diabetes. But I didn’t just want to connect with people to whom

I could relate. More importantly, I wanted to find a community in which I could also be a resource and mentor. Objectively, I’m a success story, right? I am a full-time physician. I am married. I had two easy, well-controlled pregnancies and am the mother of two beautiful girls. I am active and physically fit. I have no complications from my type 1 diabetes (knock on wood). So, maybe I have a piece or two or three of advice to share with others who share my diagnosis.

For a few years, I was on the board of directors of a local fundraising group, but that didn’t seem like the best use of my expertise, and the group consisted mostly of individuals who had a family member with type 1 diabetes. I started to doubt the existence of that “camp feeling” outside of camp. I almost gave up.

Then, last spring, I had a long-overdue phone call with my former pediatric endocrinologist, who is now a colleague and friend. He suggested I get involved with the local university’s chapter of the College Diabetes Network. A few emails back and forth, and I was invited to join the chapter’s group text-message thread. To be honest, I was a little let down. I wanted to meet these students and connect face to face. It was the end of the spring semester, and they were finishing up final exams and making summer plans. I added myself to the group text thread, virtually intro-

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duced myself, and expected a “Hello!” or “Welcome!” but no more.

Once I was part of this group text thread, however, the messages started coming in, and frequently! Suddenly, I was part of a community that was venting about misinformed people, celebrating carbohydrate-counting victories, getting tips and tricks about continuous glucose monitors and insulin pumps, and just being part of a virtual support family. They celebrated my “silver dia-versary” (25 years with type 1 diabetes), allowed me to reflect about my work-diabetes-life balance, made me literally laugh out loud at funny diabetes-related gifs, and expressed concern when members got sick. There is activity on this thread almost daily. Full disclosure: I do silence the notifications at night because college students definitely keep different hours than I!

Perhaps to some, this discovery isn’t that profound. Many people with chronic illnesses have found

social media to be of value. But I’ve always been more skeptical of these virtual relationships. Since 1980 is my birth year, technically I’m on the Generation X–Millennial cusp. I differ from many of my peers in that I’m not that into social media. Yes, I do have a Facebook account, but my profile picture is 8 years old, and I’ve had three posts in the past 6 years. Call me old-fashioned, but I still think face-to-face interactions will always be better than something virtual.

Still, I was and am surprised at just how real the sense of community feels in my diabetes group text thread. Mostly, I’ve been surprised by how much I’ve gained from this group. I went in search of a community with a primary goal of helping others realize their full potential living with diabetes. I didn’t expect the positive effects the group has had on me and on my own ability to more fully embrace my diagnosis, feel less embarrassed about

my diabetes, and be more forgiving of myself on the inevitable bad days.

I encourage the readers of *Diabetes Spectrum* to consider incorporating questions regarding their patients’ diabetes community during routine clinic visits. Suggesting this type of support group for any of their patients who may be struggling to find their own diabetes community may have dramatic effects. Optimizing basal insulin rates, using continuous glucose monitoring, testing blood glucose frequently, and limiting and correctly counting carbohydrates are all important components of a winning strategy for diabetes management. But a support group may just provide the extra synergistic effect needed to get a person’s A1C within target range.

Duality of Interest

No potential conflicts of interest relevant to this article were reported.