



Issue 3, Summer, 2016

Letter from our CEO

It's been an exciting quarter for Diabulimia Helpline! Spring brought its usual aggravating trends of "How to get ready for beach body" articles, and we found the only way to fight off the societal burnout was with the hope of change on the horizon. Nothing says hope quite like conference season and the sense of change as more and more programs see the need for diabetes specific protocols.

In March our Client Coordinator and I decided we were in need of tackling more than just societal burnout; we also had some diabetes burnout creeping in. So we signed up for a conference we had heard *nothing* but good things about. [The Diabetes UnConference](#) turned out to be all that we had heard and more - three days of real bonding with fellow diabetics. What sets it apart from other conferences is that the entire agenda is based on a questionnaire filled out several weeks prior by the conference attendees. It's a conference truly by the people, for the people, and we were not at all surprised to see that one of the most requested topics was diabetes and food. I was honored to be asked, along with We Are Diabetes founder Asha Brown, to help facilitate this talk. The details, like all details from the weekend, are kept in strict confidentiality - what's said in Vegas stays in Vegas. It keeps the room, the talking, the emotions, all of it in a safe bubble that keeps the weekend in a safe bubble that lets the UnConference be the successful place it's tribe needs it to be. (That reference will make sense to you when you sign up to attend the next one in [Atlantic City from September 9th – 11th!](#))

In April we flew out to Orem, Utah to tour Center for Change's new [Eating Disorder & Diabetes Program](#). Every time an eating disorder center creates a specialty track for diabetics with eating disorders we consider it a win in the field, and Center for Change blew our expectations away! They brought in a full time endocrinologist and implemented gold standard insulin reintroduction protocols- a requirement for any center before we even consider an on-site visitation. The two things that really took their program to the next level were the use of several different experiential therapies and the inclusion of a chronic illness group. I especially liked the use of the chronic illness group, which highlighted that while diabetes makes our recovery uniquely challenging, it also bonds us to one another in a special way!

In early May Diabulimia Helpline flew to San Francisco, CA to attend the Academy of Eating Disorder's annual ICED conference, this year themed, '*Building Bridges Across the World*'. We saw a great many amazing presentations, but none excited us quite like the Norwegian team's session "Comorbid Type 1 Diabetes and Eating Disorders—A Dangerous Combination" (obviously!) Line Wisting, PhD, MA, Eline Alten, MD, and Kathrine Gislingrud, RN gave a top notch presentation of their research on the impact of gender, age and health related functioning on eating disorders in type 1 diabetes. It was fun to see Dawn Lee-Akers, our Family and Friends Liaison, who had been looking forward to meeting the team for months, engage in passionate discussion with Line Wisting about the correlation between attitudes toward insulin and eating disorder pathology. (Read their entire paper [here](#).)

In late May Diabulimia Helpline was honored to meet with the heads of [ACUTE Center for Eating Disorders](#). Unfortunately, by the time someone struggling with the comorbidity of diabetes and an eating disorder seeks help, they can be quite medically unstable. We've had calls from family members sitting with their loved one in ICU hoping to be able to go directly into a treatment center. As part of the Denver Health Medical Center with its focus on intense, comprehensive medical treatment and high ratio of professionals to patient, ACUTE is an excellent place for someone to begin their recovery journey. Plus, they maintain good relationships with all the top eating disorder centers in the country, including those with vetted diabulimia experience, so once a person is medically stable they can smoothly transfer to a residential program for continued treatment .

It was nice to take a break from traveling in July to focus on clients and rest up a little. Because our journey continues August 12th – 15th at the [AADE conference](#) in San Diego, California. Look for Diabulimia Helpline at booth 136 in Hall D. We know that the most important first step on a person's road to recovery is recognition and diagnosis, thus we bring our message of awareness, education and support to the world of Diabetes Educators, part of the true front line in our fight against eating disorders in diabetics.

Erin M. Akers
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Diabulimia Awareness FB Support Group

Diabulimia Helpline Hosts Dinner at AADE

Diabulimia Helpline is proud and honored to have [Susan Weiner, RD](#), AADE 2015 Diabetes Educator of the Year, as our Guest of Honor for dinner Friday, August 12, 7:00 pm, in San Diego. Susan has blogged about diabulimia/ed-dmt1, and recently led a superb webinar on The Dangers of Diabulimia. Please join us to learn more about how to recognize and treat this deadly disorder, get to know some of your peers, meet the staff of Diabulimia Helpline, and of course enjoy some delicious food. Our immense thanks to [ACUTE Center for Eating Disorders](#) for sponsoring this event!

Seats are limited; if you are interested in attending please email info@diabulimiahelpline.org or call 425-985-3635.



Family & Friends Support Group

Research Article

[“Adolescents with Type 1 Diabetes – The Impact of Gender, Age, and Health-Related Functioning on Eating Disorder Psychopathology”](#) Line Wisting, Lasse Bang, Torild Skrivarhaug, Knut Dahl-Jorgensen, Oyvind Ro. PLoS ONE 2015 10(11): e0141386.

Objective: To investigate correlates of eating disorder psychopathology in adolescent males and females with type 1 diabetes.

Method: A total of 105 adolescents with type 1 diabetes (42% males), aged 12–20 years, were recruited from the Norwegian Childhood Diabetes Registry in this population-based study.

Results: Among other findings, illness perceptions, and insulin restriction remained significantly associated with eating disorder psychopathology.

Discussion: Greater clinical awareness of illness perceptions, attitudes toward insulin, and insulin restriction may potentially decrease the risk of developing eating disorders among adolescents with type 1 diabetes.

For complete list of academic articles on ED-DMT1, go to [DiabulimiaHelpline: Case Studies](#)

Type 2 Diabetes & Eating Issues Support Group

ED-DMT1/Diabulimia Resources

Students with Diabetes: [Body Image, Eating Disorders, Stress & Diabetes](#)

Huffington Post: [One Tragedy at a Time: Diabulimia](#)

Diabetic Lifestyle: [Dying to be Skinny with Type 1 Diabetes](#)

Diabetes Resources

[The Chronic Scholar](#): Where academia and patient life meet.

[There's More to the Story](#): Life, Diabetes, and Mental Health (A Patient's Perspective)

[DPAC](#): Diabetes Patient Advocacy Coalition, stand up for effective diabetes policy



Exclusive Interview with Scott Johnson

QUESTION: We have seen community support become SUCH a vital part to many in the diabetic community. This online movement, known as the DOC (The Diabetes Online Community) has taken on a huge importance for many diabetics. (In fact you co-host DSMA Live on twitter through your handle @[ScottKJohnson](#). What do you think is so important about the DOC and what they do?

ANSWER: The diabetes online community continues to be a huge part of how I cope with diabetes and how I manage the many psychological and emotional ups and downs. I get tips and tricks, I get multiple perspectives on life with diabetes, and most importantly, I get a sense of normalcy. In other words, I can see that the things I experience and struggle with are the same as so many others are experiencing and struggling with. Feeling normal is a powerful force for good in the daily walk with diabetes.

QUESTION: On your blog, [ScottsDiabetes](#), you've published a list of your A1C's. For many diabetics this number carries a great deal of shame or embarrassment. Why did you decide to make your history public?

ANSWER: Great question. For one, it's a matter of logistics. It's an easy place for me to keep a record of my A1Cs. But making them public came from a desire to show that I don't have it all figured out. I consider myself pretty knowledgeable about diabetes. I have over 36 years of experience. I have access to most of the tools and medication I want. I am motivated. I am engaged. I try hard. And my A1Cs are far from ideal. Diabetes is hard. I hope by sharing this part of my story I can help people persevere.

QUESTION: In your blog post “[Dude! You Can Stop Eating Now](#)” you talk about the pull of perfectionism and guilt over eating. Beautifully put, you say, “*I think there is a very delicate balance here, fighting the urge to jump right into some obsessive perfectionist trap, and instead being gentle and forgiving with myself.*” How do you deal with those two conflicting desires?

ANSWER: It’s a constant struggle, and there’s nothing like diabetes when it comes to exploiting vulnerabilities. I think my pendulum swing back and forth all the time. Too far on the perfectionism side, and I go crazy, yet too far on the gentle forgiving side and I’m not doing enough to take care of myself. My best strategy is being aware that it’s normal to swing back and forth but going too far either way isn’t healthy.

QUESTION: As we see in your A1c history you haven’t always had what endocrinologists would consider low or “ideal” numbers. Was that hard on the perfectionist in you? If so, how did you handle those tendencies?

QUESTION: In your blog post, “[Invisible and Invincible](#)” you talked about a feeling that, as you said, weighs “tired to your soul.” Can you expand on that feeling a little bit? What makes an invisible illness so different?

ANSWER: Great question, and it’s really difficult to explain, yet somehow, anyone who lives with something like diabetes understands it in an instant.

QUESTION: You work as Communications Lead of [mySugr](#), can you explain a little about how that app works?

ANSWER: Sure. Our motto at mySugr is “we make diabetes suck less.” We have a handful of apps and services, but our most popular is mySugr Logbook. As you might guess from the name, at its core, it’s a digital diabetes logbook (with a bit of an attitude). We’ve taken one of the most boring and ugly parts of diabetes (tracking data) and made it beautiful, fun to use, and immediately useful. As much information as possible (and desired) is collected automatically through connected devices and sensors on the smartphone, and the rest is manually entered. We use elements of gamification to help you stick with it, and reward you with points and little reactions from your “diabetes monster” (who you can name, by the way – my daughter helped me pick “Chewcarba” for mine). Additionally, we try to make the information useful and actionable right away, rather than being just a pile of numbers that doesn’t do anything for you until you visit your doctor or diabetes educator. One great example of this is using the location services. Imagine walking into a restaurant and being able to instantly see every meal, blood sugar, insulin dose you’ve ever done there, and how your blood sugar reacted over the next few hours. That sounds helpful, doesn’t it? We think so.

QUESTION: Many diabetics know the diabetes app mySugr Logbook, what they may not know is that though it was developed in Austria you were instrumental in bringing it to the US. What made you so passionate about this particular project?

ANSWER: Absolutely. After gaining a good amount of traction and attention for mySugr Logbook in Europe, mySugr (the company) worked through the FDA approval process (many don’t realize that mySugr Logbook is a class 1 medical device and is registered with the FDA) and asked for some help spreading the word about their launch here in the US. My work in the social media space here along with an existing relationship with one of the early team members at mySugr made it a very natural project to collaborate on. I enjoyed working with everyone at mySugr so much during that project that I’ve been working with them full-time for a few years now.

QUESTION: There are many diabetic apps on the market these days to help you log your blood sugar, what made this particular app stand out to us for our diabulimic clientele is its game-like feel. The cute monster and points you get for testing, regardless of the number, makes it ideal for diabetics getting back into the routine of blood sugar management. Any tips for our new users to the app?

ANSWER: The biggest key is to make it your own. You can name your diabetes monster if externalizing is a useful coping mechanism for you. You can also customize your logging screen to fit your individual wants and needs. If you don't care about tracking pills, turn that field off. If tracking your mood with a tag is most important to you, move that field to the top of the screen so it's easy to access. You are in full control of how it looks and what you track. It feels good to have some control over this stuff, doesn't it?

QUESTION: Absolutely! && on a personal note, I LOVED the ability to truly customize my diabetes monster to *MY* diabetes monster! You're also on the Board of Directors for Diabetes Hands Foundation, who sponsors both TuDiabetes and DiabetesAdvocates. What is the number one piece of advice you would have for those looking to get into diabetes advocacy?

ANSWER: There is incredible power in each of our stories. And it's therapeutic to tell your story! It doesn't matter the form or channel (blog, twitter, youtube, whatever), just find something you enjoy and tell a little bit of your story. Even if it's just talking to a friend. The exercise of processing your thoughts and feelings through language is important and the world is waiting to listen.

QUESTION: Any last words for our readers about your many projects in the diabetes world?

ANSWER: Thank you for the great questions and for the wonderful opportunity to share! I really appreciate it!

Thank you SO much for talking to us Scott!! If you live in the San Diego area or plan on attending [#AADE16](#), you are invited to join us for DSMA on August 11th. You do not have register for AADE to attend this event it is opened to the Diabetes Community and Diabetes Educators. I promise we will have an engaging and thought provoking conversation which will include PWDs, Caregivers and CDEs!