Patient to Advocate: Leading the Charge for Diabetes Innovation

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I AM ADVOCATE
(AND SO CAN YOU!)
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HELP!!
The Vision

- Patient’s Family
- Health Care Team
- Health Care Instructions
The Reality
Glucose Meter Accuracy: FDA’s New Dual Call for Tighter Standards

By AmyT on January 22, 2014 | Edit

Our patient community has been up in arms for quite some time about glucose meter accuracy, or rather lack thereof. Fortunately, the patient-initiated StripSafely campaign seems to have struck a chord, and the FDA has recently — at long last — issued new “draft guidance” on accuracy standards. What surprised a lot of people, though, is how FDA chose to split their recommendations into two categories: one set of requirements for meters purchased over-the-counter and used by patients in everyday life, and another for meters used in clinical settings by healthcare professionals. And guess which is required to be more accurate?

You guessed it: +/-15% for home-use meters and a tighter +/-10% for clinical meters.

On top of that, the new guidance is only aimed at NEW products getting ready to undergo FDA evaluation for the first time; it doesn’t address the accuracy of meters already on the market — which disappointed many of us calling for better “post-market surveillance” of meters that may be doing a crap job after some years of use. Also, the new guidance is “non-binding” for manufacturers, so not mandatory. Huh?

Last week, the FDA hosted a teleconference led by Courtney Liaus, Director of CDRH/Division of Chemistry and Toxicology, to address these concerns with patient advocates, physicians and interested members of the media.
TOP 10 ONLINE INFLUENCERS

Making a difference in the world of DIABETES

An in-the-trenches group of communicators with diabetes, these impressive and inspirational men and women reach across multiple online channels—including Twitter, blogs, forums, mainstream news and video—to influence diabetes conversations online. That’s why they’re Sharecare Now’s Top 10 Online Influencers:

1. Amy Tenderich, DiabetesMine™

Diagnosed with Type 1 in May 2003, Amy Tenderich is founder and editor of DiabetesMine.com, VP and chief patient advocate at Alliance Health Networks, Editorial Board member of the Journal of Participatory Medicine and co-author of the book, Know Your Numbers, Outlive Your Diabetes.
Know Your NUMBERS, Outlive Your DIABETES

5 Essential Health Factors You Can Master to Enjoy a Long and Healthy Life

A1C • BLOOD PRESSURE • LIPIDS
MICROALBUMIN • EYE EXAM

RICHARD JACKSON, MD
Director of Outreach at the Joslin Diabetes Center
and AMY TENDERICH
Tips for the Newly Diagnosed Diabetic

So you’ve been diagnosed with diabetes? Welcome to the club nobody asked to join.

Learning to live with diabetes is nobody’s idea of fun. Words like “confusing” and “overwhelming” come to mind. But rest assured that you CAN live a long and healthy life with diabetes – with a little learning and diligence. You’ll need to get familiar with the basics: food, exercise, medications, and using a glucose meter to measure blood glucose levels.

The very first step, however, is taking a deep breath and spending a little time to “get your head around” this new life you’re going to lead with diabetes. We’re right here with you.

If you’re a newbie, this month’s edition of “Living with Diabetes: The Real-Life Stuff You Need to Know” is for you!

Tip 1: Chill Out

You ARE going to be OK! The fact is, you are different now; your body no longer automatically regulates blood sugar like other people’s bodies do. You are going to have to work harder than they do to keep yourself healthy. But this does not have to ruin your life. What exactly is happening ... Read more >>

Tip 2: Take It Day by Day

If you think about diabetes control as a lifelong struggle stretched out ahead of you, it’s easy to feel defeated before you even start. So take this tip: don’t think long-term! In the beginning, especially, it really is better to focus on the here-and-now. Each day when you wake up, focus only ... Read more >>

Tip 3: Learn the Basics + Know Your Numbers
Finding Our Voice
What Is Advocacy?
Patients = People
diabetic connect + diabetes daily + tudiabetes.org + typeone nation

> 500,000 members

As big as Las Vegas!
LISTEN!!

CGMS Denial Campaign

Has your request for a CGMS been DEnIED

RAISE YOUR VOICE
SIGN THIS ONLINE PETITION
“Markets are conversations”
– The ClueTrain Manifesto

(Levine, Locke, Searls & Weinberger, 2009)
LifeScan Marketing Gone Awry

By AmyT on October 6, 2007 | Edit

I am just cringing here, Folks. CRINGING.

In what I consider to be a prime example of patient exploitation, LifeScan stepped over the line late last week when it sent out a so-called “Public Service Announcement” (PSA) pitch to bloggers about its OneTouch Ul. “Flash of Color” campaign. The email alert I received, which I assume was also blasted out to a host of diabetes and health bloggers, insists that “choice of color may help diabetics reassess clinical and more personal about their diabetes, which will encourage them to test regularly” — which they claim translates into “an important health message to diabetics.”

Therefore LifeScan’s promotional agency WestGlen Communications implores, “We are hoping you can place the banner and Public Service Announcement pro bono” — meaning that we bloggers should be willing to post on our sites for free a variety of promotional banners in pre-packaged sizes (or the agency can resize it to fit your blog) all for the greater good of the diabetes community, of course.

Check out THIS VIDEO that LifeScan’s agency is pushing, and prepare to CRINGE.
1,264...

Reader comments to date
1,430...

Dexcom group members on TuDiabetes

(+ DiabetesMine post #5 in Google search)
Overview

Roche Social Media Summit

On June 30, 2010, 36 social media leaders from around the world attended Roche’s second Social Media Summit in Chicago. The event was strategically placed between ADA and CWD. This year saw a 2 percent increase in attendees from last year, when the Summit was held in Indianapolis. The 2009 summit established a precedent for the event, held without a formal agenda. The 2010 summit focused on open conversations and candid dialogue about what it means to use social media, BGM accuracy, relationship building, and best practices in online participation.
“Medtronic Diabetes Advocate Forum”
sixuntilme @stacyDraper There's nothing concrete YET for a cure, but there are many people who have had T1 for decades who are happy & strong. #dsma
1 day ago via TweetDeck

PatrickMcConnel RT @j2hanson: Q5. Advocate. Advocate. Advocate. Make our voices heard and don't let anyone telling us we are 'being too loud'. #dsma
1 day ago via TweetDeck

DiabetesSocMed Closing statements: #dsma
1 day ago via web

Dream4Muse RT @scottkjohnson: RT @tailsofrachel: Q5: time for a shout out to @act1diabetes for their assistance program! #dsma
1 day ago via TweetDeck

AbbyBayer Q5 I think making it known is helping, think about a year ago, nobody was getting CGMs covered, now a lot more are. Our voices matter #dsma
1 day ago via web

kimucooper @dream4muse @DiabetesSocMed - do they work?!?! I've never re-tryed the error strips! #dsma
1 day ago via Twittorrific

cericrichards21 Would @Act1diabetes take meters w/ no lancet devices? #dsma I've bought a meter to get a device before...
1 day ago via web

diabetesalic @danielpdunn i get it, bt i tweeted that so people would maybe realize that the depressing diabetes stuff is important to discuss #dsma :/
1 day ago via web

victoriacumbow Q5: I wanted to send insulin and supplies to Haiti, but couldn't. Safety reasons. #dsma I was so frustrated.
1 day ago via TweetDeck

MHoskins2179 I feel that my insurance company judges my diabetes care, everytime they try to override my doc. #dsma
1 day ago via TweetDeck
Meet the Diabetes Advocates

The Diabetes Advocates is a not-for-profit program that connects diabetes advocates, helps them work together, and pools their resources to help people with diabetes. Here are our members.

We envision a world where everyone who wishes to advocate for people with diabetes can connect with other like-minded advocates and get the support they need to help people with diabetes.

- **2011 Application Process has now closed.** If you want to join the program in 2012, please contact us at: info@diabetesadvocates.org.

**What will DA do in 2011?**

- Host an active newsgroup to discuss diabetes advocacy best practices and plans
- Hold regular conference calls
- Create an annual brochure to distribute among health professionals
- Maintain a website with a member directory and member blog
- Write letters to the editor and distribute press releases
- Have a presence at industry events
- Coordinate programs and events among the members

**Background**

In 2009, several of us thought it was important to more formally organize the online diabetes community. We believe that by banding together, we can create a stronger presence in the online and offline world. We can do things that are not possible acting alone. As the end of 2009 approached, we (David Edelman from Diabetes Daily and Manny...
In a Nutshell, We...

- Connect PWDs and affected others, online and off
- Share real-world information
- Acknowledge challenges, vent, commiserate
- Motivate and cheerlead
- Battle misconceptions
- Spread awareness
- Change the relationship with Pharma and providers
YOUTUBE HAS A NEW KING

JUSTIN BIEBER

YouTube
Broadcast Yourself™

YouTube
Broadcast Yourself™
Pushing for Innovation
Dear Steve Jobs,

I’m writing to you on behalf of millions of people who walk around wired to little tech devices and won’t leave the house without them. No, I’m not talking about the iPod — and that’s the point. While your brilliant product line enhances the lifestyle of (100) millions, I’m talking about the little devices that keep us alive, the people with chronic conditions.

Let’s talk about diabetes, the disease that affects 20 million Americans, and I’m one of them.
Meet the Charmr
The Design Challenge
The Design Challenge

Sure5
Intuitive emergency alert device for diabetic patients
DiaPETic for Teens
Patients Want...

FLEXIBILITY

comfort

Choices!
SHARE YOUR INNOVATION for living a better life with diabetes
The 2013 DiabetesMine Innovation Summit
Delivering on the Promise of Diabetes Technology
The DiabetesMine™ Innovation Summit

Year 1 – focus on design culture

(tools must be life-friendly)
The DiabetesMine™ Innovation Summit

Year 2 – focus on a systems approach

(well-designed technology can’t succeed in isolation)
The DiabetesMine™ Innovation Summit

Year 3 – focus on the ROI issue

(real-world outcomes)
Patients

The 2013 DiabetesMine™ Innovation Summit

Industry

Payers
Hot Topics

• How has or can technology improve life with diabetes?
• How do we show improved ROI?
• What are the barriers, and how can we topple them?
• How can patients help define the future?
Patient Voices!

Allison Dunning

Simon Carter

Christel Aprigliano

Melissa Lee

Corinna Cornejo
Sharing Those Patient Voices
DIABETES MINE: PATIENT VOICES SURVEY
Patients Speak Out on Diabetes Technology

TOP FRICTIONS WITH CURRENT TOOLS

- 67% Too EXPENSIVE
- 37% Too much HASSLE
- 36% Unappealing & UNCOMFORTABLE
- 33% Complicates my LIFE

796 ENGAGED PATIENTS SURVEYED

67% of participants say insurance companies are extremely/very influential in their choice of diabetes technology.

BIGGEST DRAWBACK of a CONTINUOUS GLUCOSE MONITOR (most advanced tool available) = OUT-OF-POCKET COSTS are TOO HIGH

Participants Rank the Most Important QUALITY OF LIFE Improvements as:

1. Fewer glucose highs and lows
2. Feel in control of my own care
3. Less daily hassle

PARTICIPANTS SAY: "WE NEED TOOLS THAT":
- Are comfortable, discreet and accurate
- Can predict glucose highs and lows
- Can assist with more time in range, less hypoglycemia
- Allow data sharing for a "full picture" of diabetes management

86% agree or strongly agree that spotting trends would make diabetes logging more valuable to patients.

TOP MOTIVATORS FOR PATIENT ENGAGEMENT

- POSITIVE FEEDBACK on patient efforts regardless of results
- INCENTIVE PROGRAMS

REAL PATIENT VOICES should lead the way

@2013 DiabetesMine.com
Asante Partners with Tidepool on Open Source Diabetes Data Platform!

By AmyT on January 29, 2014 | Edit

This is a big deal, Folks! Asante Solutions, maker of the new Snap insulin pump, just signed an agreement to make its data protocols open and available via the new open-source Tidepool Platform. This means that for the first time ever, a pump maker is going straight to the cloud, committing to an open system that will allow users to combine their pump data with CGM data and other records, and view and share that data in any app they choose!

"Tidepool has more work to do before this is available, but we are very excited about the future. Once Snap users can get the data from the Snap Insulin Pump into the Tidepool platform, they can then use their data to fuel other apps and dashboards. Imagine an app that uses your CGM data and the data from your Snap Insulin Pump to recommend a change to your typical breakfast that could better keep your morning BG in control. Isn't that the kind of integration that will make the management of diabetes simpler? That is just one example of the hundreds of ways that we believe our partnership with Tidepool will help make your life a little easier. In the end, that is our promise to those that use our pump. It is also the commitment of Tidepool. After all, the data is yours..."
Calls to Action
AMY TENDERICH

Now with more A1C focus!!

I AM ADVOCATE
(AND SO CAN YOU!)
What’s Hot Now

• Tackling Insurance Issues
  – CGM Medicare coverage
  – New ways of evaluating D-technology

• Data Access & Interoperability Standards
  – WeAreNotWaiting.org

• Collecting Our Experiences
  – “Do more of what works, less of what doesn’t”
Want to Get Involved?

• Explore the many D-Mom and D-Dad blogs
• Join in a #DSMA chat, Wed 9pm EST/ 6pm PST
• Talk to Tamar about new Carb DM programs

• Find your own niche and jump in!
Thank You!

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