



COMMUNICATING THE VALUE OF ONLINE ADVOCACY AND SOCIAL MEDIA FOR PUBLIC AFFAIRS

JUNE 21, 2017

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ALIGN. ADVOCATE. ADVANCE.

BUT... HOW WOULD YOU KNOW IF YOU'RE NEAR CINNABON?



McCANN
WORLDGROUP

TRANSFORMING BRANDS
& GROWING BUSINESSES

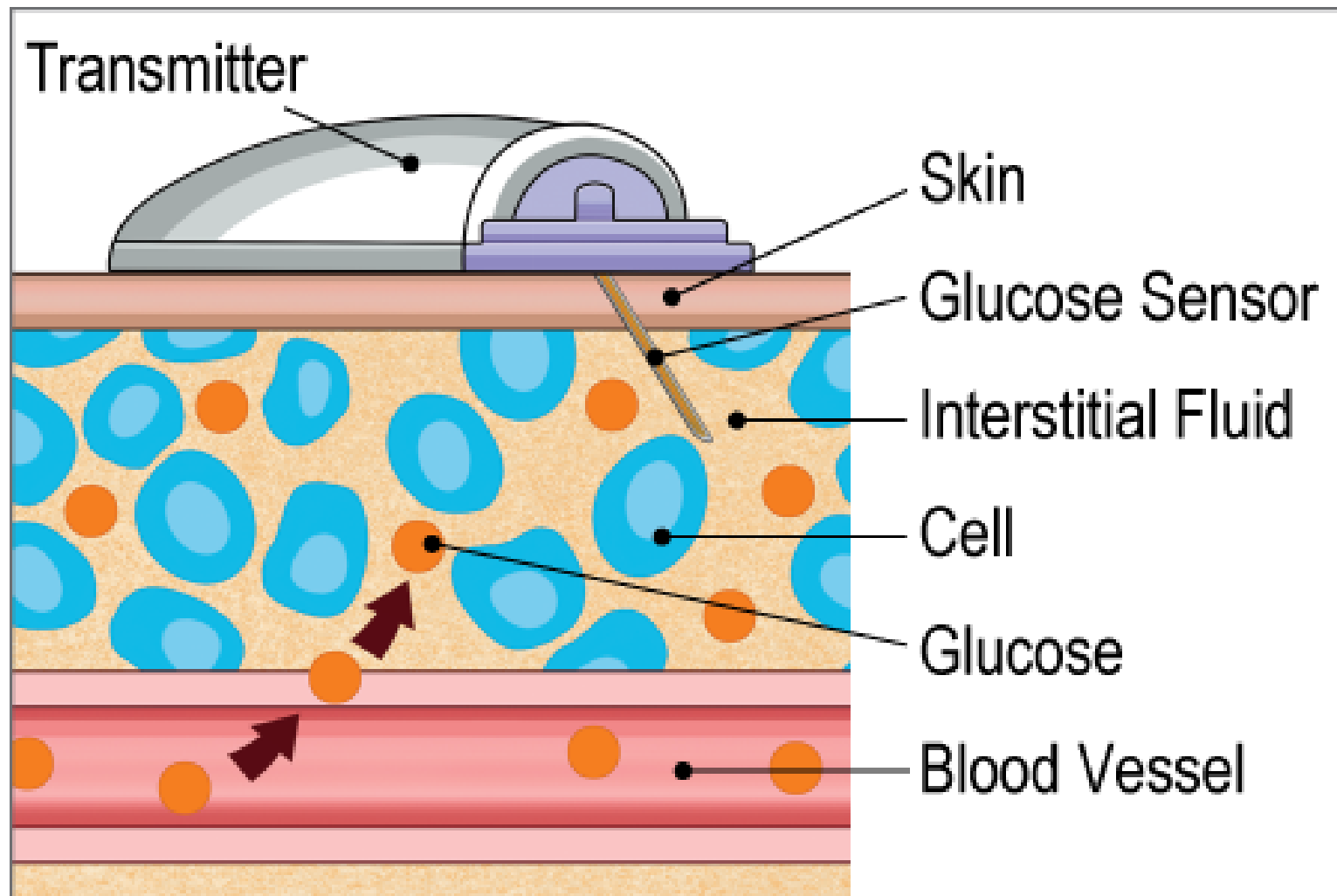
TECHNOLOGY

53% of Young People Would Trade Their Sense of Smell for Technology

While technology has often been referred to in jest as an appendage of today's youth, over half (53%) of 16-22 year olds said they would rather give up their sense of smell than give up their technology. For this generation, technology is not an add-on. It is a tool that enables them to sense the world and make sense of the world.

CONTINUOUS GLUCOSE MONITORS

CONTINUOUS GLUCOSE MONITORS



TWO PATHS TO VICTORY

Legislative Regulatory

Amend title XVIII
(Medicare) of the Social
Security Act to provide
Medicare coverage of
continuous glucose
monitoring (CGM)
devices furnished to a
CGM qualified
individual.

Create new benefit
category, OR amend
labeling to ensure
device fits within
existing category, clarify
criteria and coverage

LIGHT READING

The Potential Cost Implications of Averting Severe Hypoglycemic Events Requiring Hospitalization in High-Risk Adults With Type 1 Diabetes Using Real-Time Continuous Glucose Monitoring

Journal of Diabetes Science and Technology
1-9

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THE LEGISLATIVE TRACK

MAXIMUM SATURATION



100% of the House
100% of the Senate
100% of Governors

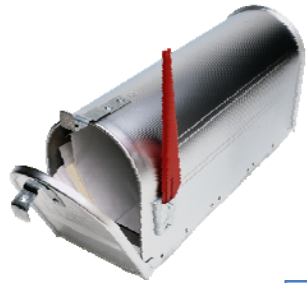


100% of the House
100% of the Senate
100% of Governors



100% of the House
100% of the Senate
100% of Governors

GO SLIGHTLY MORE VIRAL



Email/Snail
Mail



Intern/Front Desk



Legislative
Correspondent



Phone
Call



Intern/Front Desk



Appropriate
Staffer



@Tweet



Communications
Director

Chief of Staff

Member

General Public

CGM MATTERS

Private insurance covers continuous glucose monitoring. Medicare doesn't. This needs to change.



CGM Matters
@CGMMatters

CGM vastly improves glucose monitoring and patients' quality of life. Private insurance covers CGM; @CMSGov does not. We aim to change that.

District of Columbia, USA

Joined October 2015

Tweets 486 Following 819 Followers 512 Likes 259 [Following](#)

Tweets **Tweets & replies** **Media**

Pinned Tweet

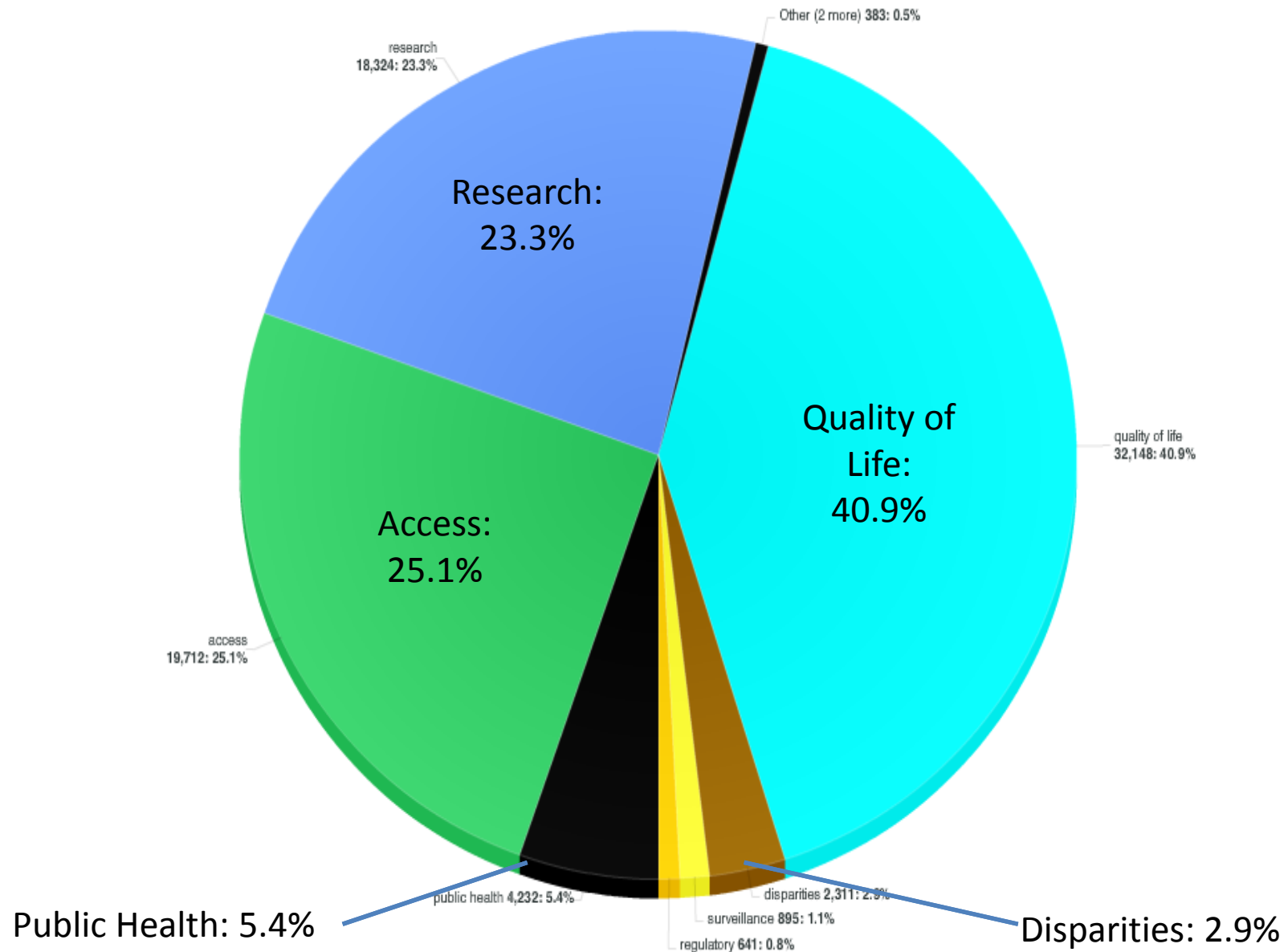
CGM Matters @CGMMatters · Apr 11
@MedicareGov to reimburse #CGMs! HUGE win for the #diabetes community after yrs of patient advocacy! @diaTribeNews

Now Available: Medicare Reimbursement for Dexco...
People with type 1 or type 2 diabetes on intensive insulin therapy can qualify. A major win for the diabetes community following years of patient advocacy!

Who to follow · Refresh · View all





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DIFFERENT CONVERSATIONS



QUALITY, NOT QUANTITY

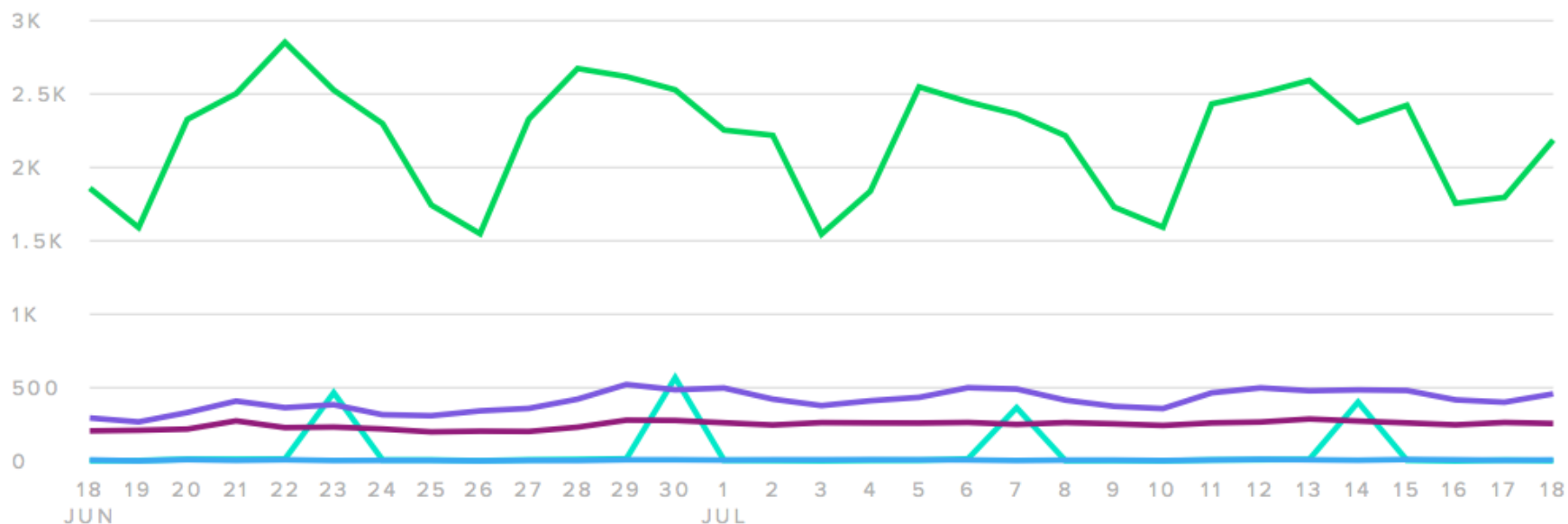
followerwonk »
A Moz App

follow		Diabetic Girl @type1girl nineteen and insulin deprived • t1d since 2010 • Omnipod and CGM lover • 80% machine and like 20% coffee • #curebecause	3,556	5,540	7,861	4.58 years
follow		Shane @T1DShane Type 1 Diabetic, Insulin Pumper, and CGM User. Dx 49 Years Ago at Age 4 and Still Going Strong! Will Follow Back Cos I'm Nice Like That! #T1D	852	1,332	1,144	8.22 years
follow		type1diabetes probs @type1_problems 27 female Dx T1D - 2001 insulin pump 14 years CGM 10 years Diabetes, the struggle we all face. Yea, I relate.	181	1,309	792	3.02 years
follow		Jackie @jackiedagoalie T1D for going on 11 years now, pump and CGM . Ninja goalie, epic bari sax player, college student. Go Huskies!	924	1,881	779	5.94 years

EBBS AND FLOWS

Keyword Volume

VOLUME, BY DAY



diabetes
#diabetes



DSMA
#dsma



OurD
#ourd



T1D
#t1d



Type1Diabetes
#type1diabetes

TAGS & HASHTAGS



MarieBe

@MarieBe

Follow



As a diabetes caucus member, [@RepGarrett](#) please cosponsor HR1427 to provide [#MedicareCoverCGM](#) to keep USA seniors safe [#Vote4Diabetes](#) [#NJ5](#)

Retweet

1

Like

1



10:08 AM - 12 Sep 2016



1



1



Importance of Medicare Covering CGMs

Based on a new study looking at the impact of CGMs in seniors with type 1 diabetes, all clinicians saw improvement in both Glycemic Variability and reduction in Hypoglycemic Events with CGM use. *So, it's not surprising that all of the clinicians agreed that Medicare should provide coverage for CGM devices for needy patients.*

More telling is the information below from actual patients.

Seniors WITHOUT CGMs in the Last 6 Months:

80%

experienced at least one hypoglycemic-related event that required assistance

18.7%

experienced at least one hypoglycemic-related event that required a paramedic visit

18.7%

experienced at least one hypoglycemic-related event that required an ER visit

8%

experienced at least one hypoglycemic-related event that required hospitalization

Nearly 50% felt frightened about having a serious hypoglycemic event while asleep or felt that they can never ever be safe from the possibility of a serious hypoglycemic event



Seniors WITH CGMs in the Last 6 Months:

15.7% ↓

drop in patients experiencing at least one hypoglycemic-related event that required assistance

21% ↓

drop in patients experiencing at least one hypoglycemic-related event that required a paramedic visit

12.8% ↓

drop in patients experiencing at least one hypoglycemic-related event that required an ER visit

5.3% ↓

drop in patients experiencing at least one hypoglycemic-related event that required hospitalization

Seniors using CGMs reported significantly lower hypoglycemic distress, lower diabetes management distress, and lower feelings of powerlessness

“

"I am not sitting in a rocking chair. I lead an active life and deserve the best care – just like any younger person. Most private insurance companies cover CGMs – it is unfair that seniors are denied the same access. "

Doris, CA





Not all seniors rely on trends...

But CGM users who are 65 and older depend on trending data to enable better control and live without the fear of losing consciousness. Real-time monitoring ensures that patients can take action before blood sugar levels become dangerous. *They don't need snapshots—they need streaming video.*

The problem: Medicare doesn't cover CGM systems, meaning that insulin-dependent patients 65 and older have to pay out-of-pocket for their devices and supplies. For many seniors, the cost is a major barrier to accessing this life-saving technology.

The good news is that Congress has introduced legislation to provide Medicare coverage of CGMs!

Cosponsors: S.804 — 114th Congress (2015-2016)
[All Bill Information](#) (Except Text)

Sponsor:
[Sen. Collins, Susan M. \[R-ME\]](#)
 | Cosponsor statistics: 49 current - includes 1 original

Hide Facets

Party

Check all

☐ Democratic
 [32]

☐ Republican
 [16]

☐ Independent
 [1]

* = Original cosponsor

Sort by First to Last

Cosponsor	Date Cosponsored
Sen. Shaheen, Jeanne [D-NH]*	03/19/2015
Sen. Coons, Christopher A. [D-DE]	04/14/2015
Sen. Heinrich, Martin [D-NM]	04/15/2015

Cosponsors: H.R.1427 — 114th Congress (2015-2016)
[All Bill Information](#) (Except Text)

Sponsor:
[Rep. Reed, Tom \[R-NY-23\]](#)
 | Cosponsor statistics: 274 current - includes 2 original

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Party

Check all

☐ Democratic
 [154]

☐ Republican
 [120]

* = Original cosponsor

Sort by First to Last

Cosponsor	Date Cosponsored
Rep. DeGette, Diana [D-CO-1]*	03/18/2015
Rep. Whitfield, Ed [R-KY-1]*	03/18/2015
Rep. Flores, Bill [R-TX-17]	03/23/2015

THE REGULATORY TRACK

GREAT IDEA FOR A WORKSHOP

Public Workshop: Diabetes Outcome Measures Beyond Hemoglobin A1c (HbA1c)

[!\[\]\(2bdfe261b986065ee0ac76460d6528c9_img.jpg\) SHARE](#)[!\[\]\(dfbd6b3763a6d1d9afaa974f64e2e4b5_img.jpg\) TWEET](#)[!\[\]\(e78f798d4ea5c530c9db49e7d26e6b95_img.jpg\) LINKEDIN](#)[!\[\]\(23d9fc146e83b5c3013cfa32c784f8d5_img.jpg\) PIN IT](#)[!\[\]\(c694a3ff3b077d76910920a6a1593ab4_img.jpg\) EMAIL](#)[!\[\]\(ec9132f1d27c8919987d92907322654d_img.jpg\) PRINT](#)

The Food and Drug Administration's (FDA) Center for Drug Evaluation and Research (CDER), is sponsoring a public workshop entitled “**Diabetes Outcome Measures Beyond Hemoglobin A1c (HbA1c).**” The purpose of this public workshop is to have a forum for dialogue with the public, patients, patient advocacy groups and industry to gain greater appreciation on the extent to which the current regulatory paradigm for antidiabetic drug therapies addresses the needs of patients with diabetes and to identify additional outcomes, beyond HbA1c, that are of direct relevance and importance to patients living with the disease.

The ultimate purpose of identifying and qualifying these outcomes for regulatory purposes would be to continue to support the development of novel therapies that directly address the needs of diabetes patients living with the disease. There will be an opportunity for questions and answers following each presentation.

DATE, TIME AND LOCATION:

August 29, 2016, from 9:00 a.m. to 5 p.m.

YOU WANTED SOMEONE TO LISTEN....

Living with diabetes is HARD. Telling FDA is EASY!

We are creating a video to bring the patient voice to the Food and Drug Administration (FDA) during a public workshop on August 29th. We want to highlight the community's stories about living with diabetes and what outcome measures matter in your life.

Here's how you can be part of this effort:

Take a video on your phone or computer (under 10 seconds) and answer these two questions:

- o **What I struggle with most in managing my diabetes is.....**
- o **Beyond helping me with A1C, I wish a new diabetes drug would.....**


Upload your video here: bit.ly/DOCasksFDAvideo

Share it on social media with #DOCasksFDA and #BeyondA1c

YOU WANTED SOMEONE TO LISTEN....




COMING AT YOU LIVE

**CGM Matters**
@CGMMatters


Following

Dr. Robert Califf, @US_FDA Commissioner with remarks on getting patients involved in outcome measures #beyonda1c



Retweets
3

Likes
2



9:23 AM - 29 Aug 2016

SHOWTIME

diaTribe
@diaTribeNews

Following

@kellyclose and Richard Wood share video on patient perspectives on #diabetes outcomes #beyondA1c @SweeterCherise



Retweets
3

Likes
7



12:34 PM - 29 Aug 2016

THAT JARGON MEANS VICTORY



FDA expands indication for continuous glucose monitoring system, first to replace fingerstick testing for diabetes treatment decisions

WE'D LIKE TO THANK THE ACADEMY...



Diabetes Community Oscar Awards for 2017!

Best Diabetes Advocacy Moment: #BeyondA1C

This was a tough one, as we had some serious contenders -- [#DiabetesAccessMatters](#), born from the above-noted Medtronic-UHC deal and blossoming into real advocacy efforts and policy discussions; and past-winner [#WeAreNotWaiting](#) for the new burst of energy in do-it-yourself D-technology on the open-source, closed loop front. But in the end, for 2017, the [#BeyondA1C movement](#) stands out. Our D-Community saw a groundswell of advocacy on this particular issue, from our friends at DPAC and [DiaTribe](#) and many others who shared their stories directly with the FDA. The big mic drop moment was the [FDA September Beyond A1c Workshop](#), that marked the first time the regulatory agency seriously considered reviewing measures beyond just our A1C in deciding what might make a drug or device worth approving for diabetes care. And from that meeting, we saw real change at the government level, which leads us right into our next category...