# 021

EXECUTIVE INNOVATION LAB IN DIABETES AND PREDIABETES

EXECUTIVE SUMMARY & HIGHLIGHTS



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# D21021021021

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# The dNetwork Stigma-Busting Priorities

#### What is our goal?

Reducing the impact of diabetes on society – and improving the lives of people with diabetes – by fostering understanding of the disease, eliminating misplaced blame, and ensuring access to care.

**Prevention:** Reducing New Incidence Rates for Diabetes

**Care**: Improving Lives of People Living with Diabetes

Reduce Diabetes Impact on Individuals & Society

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#### How will we get there?

#### Getting Smarter Together.

Bringing leaders together to better understand the world of diabetes and how we can work together to reduce its impact. Sharing best practices for change, and commissioning research and training to fill gaps in our knowledge & skills.

#### Educating & Influencing.

Working to reduce misplaced blame by shifting messaging in our individual and collective spheres of influence with evidence-based, stigma-busting language and frames.

#### Activating Ourselves and Others.

Building a movement and leveraging our influence to engage more and more leaders across levels to change behavior, culture, policies, and systems. Together we can pool resources and mobilize power to reach our goal!



# Module 1: Reconnecting as Stigma Busters

Over the past five years, the dNetwork has engaged in shared learning, connection, and strategic thinking to understand the <u>key levers for change</u> within the diabetes epidemic in the US as part of our dSeries Executive Innovation Labs. At <u>d19</u>, we identified one of these key levers – the pervasive stigma and misconceptions surrounding diabetes – as the primary focus of our work for <u>d20</u>.

Following the success of <u>d20</u>, we conducted interviews with experts who occupy various spaces in the diabetes ecosystem – known collectively as the Stigma Strategy Group – to identify key audiences and develop different work streams to dismantle diabetes stigma which would become the focus of d21.

In line with these work streams, the primary objectives for the d21 Executive Innovation Lab were to develop and refine critical communication tools, develop viable and fundable campaign ideas to address stigma, and activate participants to address stigma in their personal and collective spheres of influence.

### A new year of learning – laying the groundwork

- The Stigma Strategy Group interviews identified a number of key ideas:
  - Stigma is complex, intersectional, and individual
  - More research is needed but other efforts can be pursued in parallel
  - Diabetes organizations can amplify impact by working together
  - We're still early in the process of addressing stigma around diabetes.
- These interviews also explored the question: "What do you want people to know about diabetes and diabetes stigma?" Summarizing results, diabetes stigma:
  - Directly and negatively affects a person's ability to manage their diabetes.
  - Directly and negatively affects people's thoughts about themselves, which then indirectly affects people's motivation and their behaviors.
  - Directly affects how providers interact with patients.
  - Is directly connected to how we talk about people with diabetes. (We cannot separate words from the context of people's experience; when words are so often negative and judgmental, they impact stigma.)
  - Is also communicated through actions and choices, implicit and explicit biases.

#### Identifying areas with the greatest impact and potential

• Five work streams were identified as having potential for significant impact and potential success. Participants participated in project-specific breakout groups to



- <u>Stigma Information Hub</u> An expertly curated, easily-accessible, easily-shared web resource about diabetes stigma including what stigma and bias look like, why it matters, how to challenge it, and how to avoid stigmatizing people with diabetes.
- <u>Healthcare Provider Education</u> Aimed at raising awareness of diabetes (and weight) stigma among healthcare providers by providing medical education (at multiple points in training), contact-based learning experiences, CME courses, and conversation guides or language aids.
- <u>Industry-Driven Stigma Initiative</u> Aimed at tapping pharma and device companies and other diabetes-related orgs to raise awareness of diabetes stigma and how intentional communication in the industry can help.
- <u>Market/Ethnographic Research</u> Research to (a) learn about and document the lived experiences, attitudes, and perceptions of stigma and bias among people with diabetes, and (b) identify and describe key target audiences.
- <u>Academic Research Agenda</u> The goal is to create and publish a research agenda to serve as a roadmap, developed by experts in diabetes and related fields, for guiding academic research and funding on diabetes stigma.

### Translating ideas into progress

Dr. Rebecca Pearl delivered a presentation on a research proposal submitted to the APA for a \$20,000 research grant. In a study of 800 adults with type 2 diabetes, participants would complete a 15-minute self-report survey online.

- Aim 1: To establish the prevalence of type 2 diabetes stigma in a diverse sample of 800 adults.
- Aim 2. To identify participant characteristics associated with type 2 diabetes stigma.
- Aim 3. To determine the clinical significance of type 2 diabetes stigma for depression, anxiety, health-related quality of life, and diabetes management.

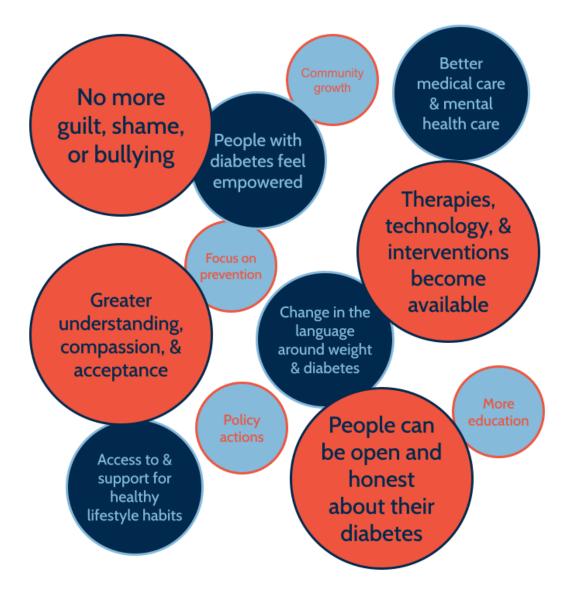


# Module 2: Honing Pathways for Change

#### Envisioning a future without diabetes stigma

Participants engaged in a flash visioning exercise to imagine we live in a world where diabetes and obesity are not stigmatized...

- 1. What does this world look like; how is it different from today?
- 2. What becomes more possible for people with diabetes?
- 3. How would your area of work be affected; what might become easier?





#### Mapping our interests in the fight against stigma

Participants shared, one by one, where they felt their personal work, interests, and passion most closely aligned with areas of the stigma fight – even if that area was not one of the five core areas diaTribe identified in Module 1. Though many participants coalesced around research, the stigma information hub, network development, healthcare provider engagement, and media advocacy, they also identified gaps where attention could be focused, including storytelling, and community engagement. Although not specifically mapped in this exercise, we know that policy is another area of interest for dSeries participants.

				Media Advocacy	Community
Research	Website	Network	Healthcare	Storytelling	Engagement
Jim Carroll	Scott Johnson	Julie Heverly	Orville Kolterman	Eileen Opatut	Phyllisa Deroze
Richard Wood	Jennifer Hahamian	Kelly Close	Robert Gabbay	Michael Howerton	James Corbett
Karen Talmadge		Deana Zabalda	Rebecca Puhl	Anna Norton	Andrew Vilcinskas
Larry Soler		Kate Marshall	Luigi Meneghini	Thom Scher	
Alan Moses		Cherise Shockley	Nicolas Cuttriss	Urmimala Sarkar	
Ananta Addala		Kyle Jacques Rose	Elaine Chiquette	Angie Bricco	
Marjorie Sennett			Stephen Brunton	David Lee Strasberg	
Kelly Brownell			Karmeen Kulkarni	Ansley Dalbo	
Rebecca Pearl			Shreela Sharma		
			Lee Kaplan		
			Virginia Valentine		



### Advancing the work in each action area

#### Research

• Jim Carroll presented recent dQ&A survey results that show the real impact of stigma on people's healthcare.

	Diabetes Type					
	Total		Type 1		Type 2	
	Count	Column %	Count	Column %	Count	Column %
Have you eve	Have you ever felt that your doctor, nurse, or other professional in a healthcare setting blamed you for having diabetes?					g blamed you
Yes	33	26%	10	20%	23	29%
No	94	73%	39	80%	55	69%
I don't know	2	2%	0	0%	2	3%
Total	129		49		80	
Did your experience(s) with diabetes-related stigma ever keep you from seeing your healthcare provider?						
Yes	15	45%	3	30%	12	52%
No	18	55%	7	70%	11	48%
I don't know	0	0%	0	0%	0	0%
Total	33		10		23	
Have you ever made a decision to delay an insulin injection or bolus because you were afraid of being judged by the people around you?						
Yes	38	36%	20	41%	18	32%
No	66	63%	29	59%	37	66%
I don't know	1	1%	0	0%	1	2%
Total	105		49		56	
Have you ever made a decision to not wear a diabetes device (e.g. a CGM or pump) because you were afraid of being judged by the people around you?						
Yes	22	32%	9	23%	13	43%
No	46	67%	30	77%	16	53%
I don't know	1	1%	0	0%	1	3%
Total	69		39		30	

• The group then discussed how to chart a path towards a research agenda. They identified that research will be vital to the overall stigma efforts, that further studies beyond



establishing prevalence are needed, that figuring out a method to fund research is vital, and that there is a need to consider the intersectionality of diabetes stigma.

#### Stigma Information Hub

- Chris Barnes presented an overview of what the stigma information hub should accomplish and led a discussion around outstanding questions, helpful tools, the motivation behind using this site, and what success of the site looks like.
- There was a desire to uncover who the people communicating about diabetes stigma are and how to contact them, how to develop ready-made resources that include consensus around the key messages, and how to measure success with one idea being the adoption of non-stigmatizing communications and language as an element of policy at major organizations and inclusion in standards of care.

#### dNetwork Development

- Brooking Gatewood guided the group to develop a goal for dNetwork Development: to shape a strategy for growth. Namely by developing a healthy community that feels supported for their diabetes and has a sense of pride in belonging to a supportive community.
- There was an interest in thinking big to accomplish our goals an initial, attention-grabbing campaign with social media, influencers, or celebrities followed by strategic partnerships and corporate or institutional guidelines and pledges.

#### Healthcare Provider Engagement

- Caroline Pappajohn led the healthcare provider engagement group to focus on identifying "small but doable actions" that will produce "high-value wins" and one big idea focused on long-term, high value and high impact projects.
- Small but doable actions that arose included surveys around bias, campaigns directed at healthcare professionals, raising awareness at conferences and scientific sessions, and targeting residency programs, medical students, and pre-medical students.
- Brainstorming produced the big idea for a consensus statement on bias towards people with diabetes and obesity (or all chronic conditions) to be published in an academic journal.

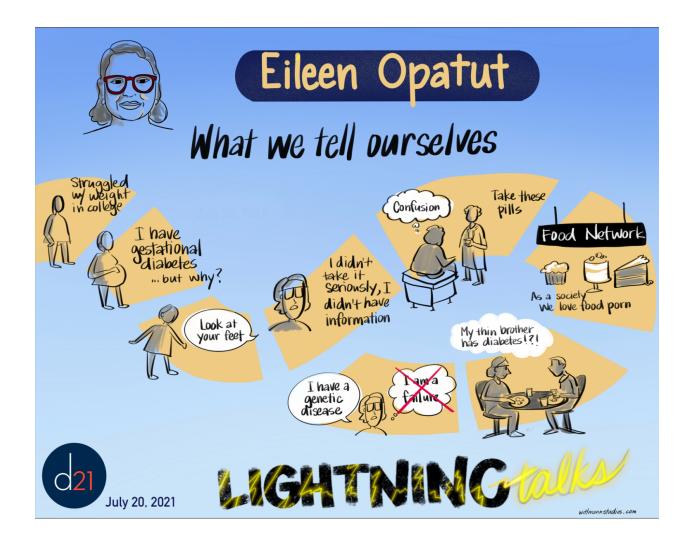
#### Media Advocacy

- Matthew Garza led the media advocacy group to also focus on identifying "small but doable actions" that will produce "high-value wins" and one big idea focused on long-term, high value and high impact projects.
- Small but doable actions that arose included conducting landscape research on social media and general media coverage of diabetes, hosting Facebook Live events to engage with people with diabetes, creating a shared media list for the dNetwork that identifies authors and publications that write about diabetes, and revisiting the Language Matters resources.
- Brainstorming produced the big idea to create a media kit (or set of media kits) that focus on a core story of diabetes.

# Lightning Talks: Stigma and the Stories We Tell

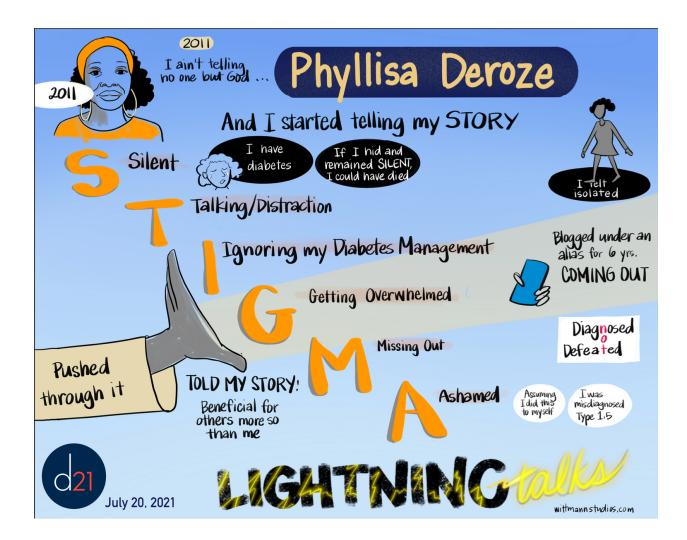
The <u>d21 Lightning Talks</u> focused on the power of storytelling – beginning with a <u>Ted Talk</u> from the author Chimamanda Ngozi Adichie, which diaTribe used as the foundation of this year's program. By listening to Adichie describe the danger of a single story, we were inspired to create a tapestry of many stories by people with diabetes. Click on each picture below to <u>watch</u> the speakers share their experiences.

# Eileen Opatut – Former Senior Vice President of Programming, The Food Network



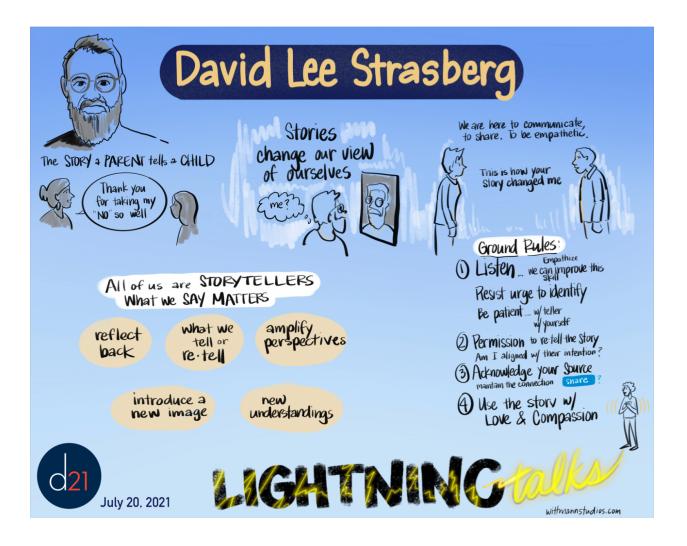


#### Phylissa Deroze – Founder, Black Diabetic Info



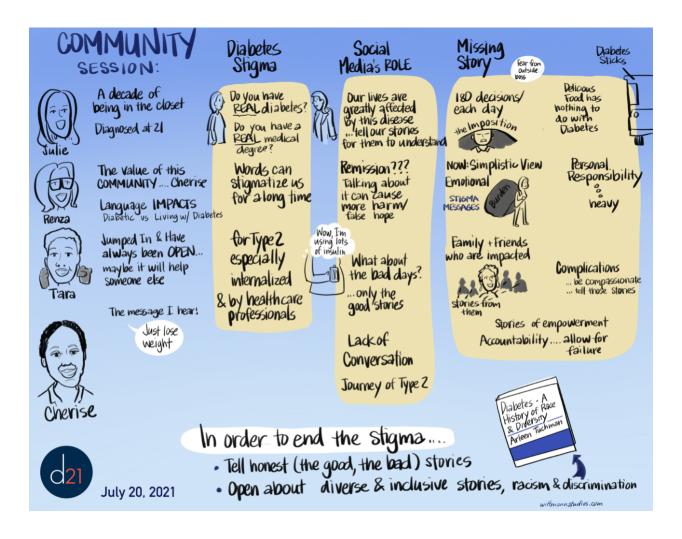


### David Lee Strasberg – CEO and Creative Director, Lee Strasberg Theatre and Film Institute





## Community Sessions – Cherise Shockley, Renza Scibilia, Julie Heverly, T'ara Smith, and Josh Kuntzman



Jump to the appendix to read Josh Kuntzman's poem on diabetes stigma, "Take It In."

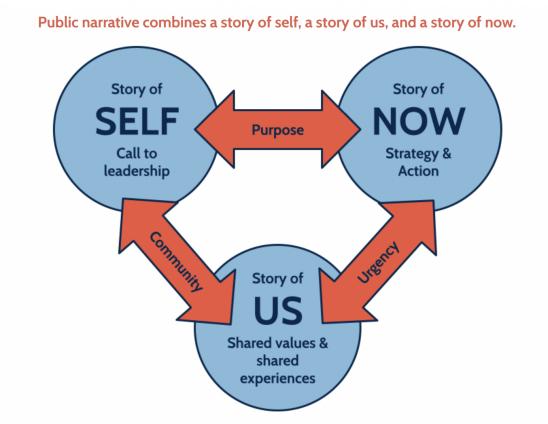


# Module 3: Shaping Stories for Change

#### Storytelling as the key to shift diabetes stigma

There is research that shows one-to-one, contact-based education strategies and storytelling can be some of the most powerful ways to shift people's behaviors on stigma. Drawing inspiration from the d21 Lightning Talks, Module 3 focused on a storytelling workshop – designed to help participants learn and practice crafting an effective story for their audiences.

Brooking Gatewood began the storytelling workshop by introducing participants to the public narrative approach developed by researchers at Harvard University, which breaks down a method to create and tell a story with the goal being to change the public narrative of an issue. This framework combines a story of self, a story of us, and a story of now.



The workshop then focused on clarifying our audiences. Gatewood asked participants to think about where they have the highest leverage opportunity to influence others. These key audiences may be people with diabetes, healthcare providers, journalists and the media, medical school students, industry leaders, or others.

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Next, participants fleshed out the key ideas they wanted to convey in their story. Part of this task means focusing less on the facts themselves, but rather on the messaging and how the facts are crafted for a specific audience. There is a difference between telling a narrative and a story: telling a narrative is about stringing together a series of ideas with a logical connection, while a story has a greater personal element that elicits an emotional response from people.

Finally, participants were given time to work on crafting their story – whatever that may look like. They were divided into breakout groups of three to practice sharing their stories aloud and receive feedback from group members. These sessions allowed participants to refine their stories and identify ways to maximize their impact on the listener.

#### The storytelling workshop can be found in the appendix.

### Integrating storytelling into each action area

Participants explored in their action area groups how storytelling insights could be integrated into both a collective plan and individual influencer actions over the next year.

# Research: Setting an agenda for academic research to better understand diabetes stigma

- Jim Carroll led the research group through a brainstorming session to determine the first steps needed to create a research agenda.
- They also discussed ways to engage with diverse audiences from people with diabetes to healthcare providers to better understand how stigma exists within the general public.
- When considering sources of funding for a research agenda, the group talked about the framing of stigma and the importance of adopting separate frames such as health equity when presenting the problem of diabetes stigma.

# Healthcare Provider Engagement: Reducing stigmatizing information and interactions in healthcare settings

- Brooking Gatewood led the healthcare professional group through a discussion on the importance of language and communication in different interactions involving healthcare providers: between diabetes communicators and HCPs, between HCPs themselves, and between HCPs and people with diabetes.
- The group agreed that scientific and medical progress is limited by stigmatizing language, and they felt that addressing harmful language is a crucial effort that needs to involve all HCPs, not only those who already recognize stigma as an issue.



• Group members suggested looking to the LGBTQ+ rights movement as a model for how to integrate respect and inclusivity into the clinical space and apply it to caring for people with diabetes.

#### Media Advocacy: Advocating for accuracy and empathy in media

- Matthew Garza facilitated this group's discussion on the value of representing the stories of people with diabetes in the media, leveraging the influence of popular media personalities with diabetes, and shifting the way we talk about diabetes stigma in the media.
- Participants agreed that less focus should be on the split between people with type 1 and type 2 diabetes and instead there could be benefits to joining forces by generating more buzz about diabetes as a whole.
- The group concluded with a brainstorming session around what a stigma media campaign would look like including: speaking to the impact of bringing together coalitions for public service announcements, harnessing the power of celebrity voices, and expanding campaign messaging to mediums outside of digital media such as print and public messaging at bus stops.

# dNetwork Development and Stigma Information Hub: Growing a cultural movement to address diabetes in the US

- Chris Barnes facilitated this group's discussion of what to include and prioritize in the creation of an online stigma-busting resource agreeing to make language guidance a significant focus of the website.
- Group members brought up the issue of stigmatizing language used among HCPs and industry professionals and how this language can pass down from generation to generation highlighting the need for both a grass-roots and grass-tops approach to create change.
- The group also identified smaller website ideas including short written or video stories to represent the complexity of stigma and a pledge to indicate an active commitment to combating stigma.

All of the action area groups concluded by revisiting their written action commitments from the end of d20 – making collective and individual commitments to reframe the narrative of diabetes stigma through their personal and professional conversations, organizational decisions, and project ideas.



#### Onward to d22: What comes next for stigma?

"I've gotten to work on a lot of cool, interesting efforts in my time, but none with the potency and potential of what you all are doing here with this dNetwork effort," said Gatewood, as she closed out Module 3 of d21. "I feel like we're just at the beginning. I'm just reflecting on when I started at d17; we didn't have a dNetwork, we didn't have a systems map, and we didn't have a steering committee. Since then we have done so much shared learning and growing to really understand this space and I know at times it can seem slow but from a movement perspective, we're moving at a pretty quick pace. I am really excited to keep watching and supporting as this grows and evolves."

Looking to the future, we shared the name and vision for the stigma hub website: <u>dStigmatize.org</u>. With <u>dStigmatize.org</u>, diaTribe aims to synthesize the learnings from d2O and d21 and expand on the dNetwork's mission to address stigma by creating an online resource. The website will consolidate information about diabetes stigma into a curated, easily-accessible, and easily-shareable resource.

The goal of <u>dStigmatize.org</u> is to be a "one-stop shop," for people (from diabetes communicators to HCPs to loved ones of those with diabetes, and many more) to visit and learn about the kinds of stigma that affect people with diabetes, including tips and guidance on how to combat stigma.

dStigmatize.org is set to be launched in 2022.





# Appendix

### **Storytelling Worksheet**

GOAL: Craft a two to three minute story to inspire others to become part of our stigma-busting movement!



Solo reflection & refinement time	<ol> <li>Clarify key audience(s).</li> <li>Identify the key idea(s) you want to convey.</li> <li>Craft a story to shift mindsets and inspire action.</li> </ol>
Practice and test	4) Practice the story and receive feedback from peers. Iterate and refine.
Implement	5) Integrate into your personal action plan! How will you spread the message and enroll others in our shared work of stigma-busting?

#### 1) CLARIFY YOUR AUDIENCE

Think about where you have the highest leverage opportunity to influence others, shift mindsets, enroll key players, and inspire action to reduce stigma. You might focus on one representative individual, or a group of individuals in the diabetes ecosystem. Once you have these people in mind, consider these questions to help craft an effective story for them:

Who is this audience?	Why them?
What's unique about them?	What are your instincts about how to engage them effectively? <i>(tone, style, timing, context, etc.)</i>



#### 2) IDENTIFY KEY IDEAS

Review our <u>Core Ideas list</u> and select a handful of messages that seem essential for this audience to achieve the desired result:

Insert core messages here	

#### 3) CRAFT YOUR STORY

The worksheet below offers starter questions to help you think about elements of your experience that might inform your story.

- This is an invitation for those who like prompts, but feel free also to skip to the blank story-writing page first to work on your story. You may want to come back to these questions after as a sort of check-list (we all have different creative processes).
- Remember you can draw on your personal *why* (why are you working to eliminate diabetes stigma?), even if you don't have a personal story about diabetes stigma.
- You can also choose to incorporate or amplify other people's stories as well as intersectional topics where it might help you inspire and engage your audience.
- If you feel stuck, just start writing! Get started on what Anne Lamotte calls the Sh\*&ty First Draft! As the great storyteller Truman Capote once said: *"Failure is the condiment that gives success its flavor."* All good stories get polished through the practice of telling them.

STORY OF NOW WHAT is the change you want to make in the world?	STORY OF SELF WHY are you called to make that change? What specific experiences have shaped your story of self?



#### STORY OF US

WHAT personal story can you tell (yours or someone else's that has impacted you and you have permission to share) that will help others understand why you want to be part of that change?

Challenge Why did you feel it was a challenge? What was challenging about it? Why was it your challenge?	Choice Why did you make the choice you did? Where did you find the courage (or not)? Where did you get the hope (or not)? How did it feel?	Outcome How did the outcome feel? Why did it feel that way? What did it teach you? What does it make you wonder?	
What do you want to teach us? (What's the moral?)	How do you want us to feel?	What action are you wanting those feelings to inspire?	
What question might you ask us to invite us into the story and/or your sense-making?	THINKING AHEAD: How might you use other media – visual art, music, advertisements, events, etc. – to help tell this story?		

#### WRITE OUT YOUR STORY HERE



#### **4) PRACTICE SESSIONS**

Run through a few sessions with family, friends, and colleagues to help you practice telling your story and receiving feedback. Be sure to get their opinions on:

- What was the emotional impact of the story?
- When were they the most engaged?
- What worked well?
- What questions came up?
- What did they want to know more or less about?

#### 5) PREPARE TO SHARE YOUR STORY MORE WIDELY!

Now that you've practiced and dialed in your story a few times, keep sharing it! The next time you have a chance to influence those core audiences you identified in step 2 — you'll now have a new tool at your disposal to help you!



# "Take It In"

### By Josh Kuntzman (2021 July 20)

Listen to the poem here.

I wouldn't say lazy. I'd say angry. "Seeing red." "My blood boils." I'd say angry, if I had to pick A feeling, an outlook, a way of life At the top of my emotion/spirit list. Of course, I went through the other steps of grieving: Saying "no way" and disbelieving Because I didn't even feel the disease-Just a little bit dizzy and a lil bit thirsty— And of course that turned to "Please. Don't let this be real." But it was, and it is. And it seems like it always will be: Stomach, pancreas, liver, blood, Misaligned dominoes of flesh-thud, thud, thud-Falling inside of me. "You have diabetes." Okay, then I was angry: Where was my sin? The rot in my soul. Because I know diabetes: it's fat, lazy, unaware, Balloon-people whose legs fall off because They have no self-control. But I? — okay, maybe the occasional Arby's, And big bones run in my family— But can we make a deal? A barter, a bargain, A trade-off? Don't take this from me. And that was the start of my life as a number; My skin full of pinholes, my blood full of math: My CGM, my A1C? No DKA, take TZDs. Shit, I'm at 200... now 153.

Is this just at random? God's playing with me? I Hate it. And it's work: Constant hunger, excessive thirst. I miss buffets. (Heh) miss Taco Bell... If that doesn't make you depressed, how's this: I'm so Tired, that my version of peace Is a cool-quiet place to poke a needle in my skin, Without someone making the same goddam joke About me doing heroin. And these are the people who'd say "I'm his friend"; Who don't even listen, before saying, again, "You just need to do X, and then you'll be okay" Repeating false-hopes, like a Gut-punch replayed: Chromium & Cinnamon, Hydrogen Peroxide & Magnet Shoes, Glymetrol & Exotic Herbs-"100% effective!" It's Facebook-true. But-God grant me serenity-I accept that I'm not alone in this flood; That for every 10 men I see checking their watch, ... one of them's checking his blood. That for every pregnant woman (who's obese, non-white, or over 25) There's a chance, while she's busy growing that life, ... that her glucose is on the rise. That my roommate's first boyfriend in the schoolyard ... always carried an orange juice, just in case. That my partner's dad Couldn't feel his foot bleeding, then stopped breathing ... had his heart-valve and carotid replaced. That the father of the bride had two metal legs. That the baseball coach now avoids broccoli. That my neighbor had a block in his infusion tubes ... and was over 400 before he got some insulin. That my student pulled through 5 all-nighters, Trying to get an A ... knowing that she'd take a hit When her lab results came in. So here I go, getting all angry again, When it attacks my blood while you attack my pride: As I fail to control unstoppable pumps,

And forego comforts like a monk, While you say "Why don't you just (pfft)— Be different inside?" Because it's easy: Exercise & Diet fixes Fat & Lazy. Pearls? Meet Swine. That's your view. But in reality? YOU Want an easy pivot from seeing this reality of mine. Take it in. The pricks and needles, Doctors, drugs, blood every morning. Every hour. Every meal. Ketones, glucose, ... are You absorbing? Take it in: this is not simple choices. Take it in: this is not moral failing. Take it in. What I control, what I don't; The dangers, and the stressors That compound my ailing: All that I love, that I've let go and miss. The normal excesses that make life... lived. All that I fear-drugs, tools, insurance, ... my own body-that I must accept and forgive. All those around me, who I need to love me, Who head-shake at tired eyes and discolored skin. All those who judge me, as I try to live While my blood boils inside me; my life. Take it in.

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**POWERED BY** 

THE diaTribe

WRITTEN BY

MATTHEW GARZA, DEVANSHI GUPTA, ARVIND SOMMI, CHRIS BARNES, AND JIM CARROLL

www.diaTribe.org