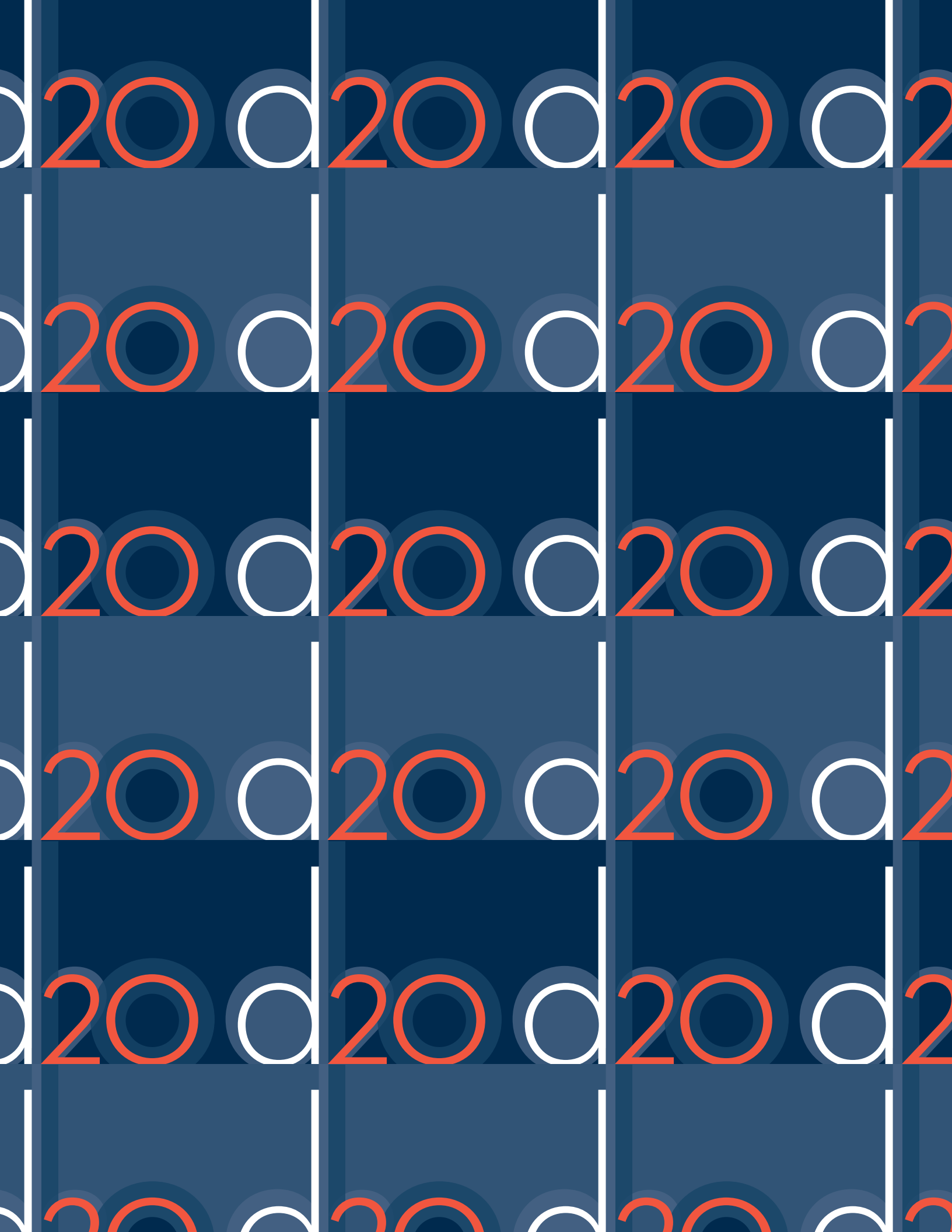




EXECUTIVE INNOVATION LAB  
IN DIABETES AND PREDIABETES

EXECUTIVE SUMMARY  
& HIGHLIGHTS



# d20 EXECUTIVE INNOVATION LAB IN DIABETES AND PREDIABETES: SUMMARY & HIGHLIGHTS

---

<b>MODULE 1   TUESDAY, OCTOBER 13</b>	<b>2</b>
Lightning Talks: Five Perspectives on Diabetes Stigma .....	2
<b>MODULE 2   WEDNESDAY, OCTOBER 14</b>	<b>8</b>
Opening Remarks .....	8
Orienting to d20 and Tackling the Stigma Beast. ....	8
Framing Basics. ....	10
Diabetes Frames for Change .....	12
Framing Workshop Breakout Session Summaries .....	14
Major Themes and Key Takeaways .....	18
Closing Remarks and Commitments to Action .....	19
<b>MODULE 3   TUESDAY, NOVEMBER 17</b>	<b>20</b>
Re-Orienting to d20 with Brooking Gatewood. ....	20
Fieldwork Insights: Breakout Session Summaries .....	20
Framing Recommendations .....	21
Ideating Solutions to Reframe Challenges with Dennis Boyle .....	22
Ideations Around Five Framing Challenges .....	23
Action Plans for Thinking About and Disseminating the New Frames .....	26
Closing Reflections and Next Steps .....	26
<b>A SPECIAL THANK YOU TO OUR SPONSORS</b>	<b>28</b>
<b>APPENDIX</b>	<b>29</b>
Changing the Narrative around Diabetes. ....	29
Module 2   Jim Carroll Closing Remarks .....	33





## MODULE 1 | TUESDAY, OCTOBER 13

### Lightning Talks: Five Perspectives on Diabetes Stigma

David Lee Strasberg, the Creative Director and CEO of the Lee Strasberg Institute, introduced five “lightning talks” focused on combatting stigma. He began by sharing his own personal story of what it means to live with diabetes and face stigma; he described it as a giant boulder that needs to be moved in order to create real, substantial change for as many people as possible. And he also shared a story of hope that things are beginning to change by talking about his son with diabetes who doesn’t shy away from the disease or let it cause him embarrassment or shame, it’s just a part of who he is. Five talks were then presented by Anthony Anderson, star and executive producer of the hit ABC sitcom, *black-ish*; Dr. Rebecca Puhl, Professor of Human Development and Family Sciences at the University of Connecticut and Deputy Director of the Rudd Center for Food Policy and Obesity; Dr. Nat Kendall-Taylor, CEO of the FrameWorks Institute; Joan Garry, Principal of Joan Garry Consulting and former Executive Director of GLAAD; and Dr. James Gavin III, Healing Our Village Chief Medical Officer and former President of the American Diabetes Association.



## ANTHONY ANDERSON

Anthony Anderson was diagnosed with type 2 diabetes almost 20 years ago and has since become an outspoken advocate for people with diabetes. In his talk, he shared his personal experiences dealing with the internal and external stigma that makes navigating life with diabetes difficult.

- Diabetes runs in Anderson’s family. His mother has type 2 diabetes and after his father died from diabetes-related complications (though his father was undiagnosed, Anderson retroactively recognized the symptoms), he experienced a serious “reality check.” He made a conscious decision to engage with his health and well-being

so that he could live a healthy life—one that diabetes was a part of, but not in control of.

- Anderson has dedicated himself to managing his health and being an advocate for others; his decision to incorporate his experiences with diabetes into his character on *black-ish* was a landmark one, enabling families all across America to see a very honest, and yet still humorous and relatable, portrayal of something that affects so many in this country.
- In association with Novo Nordisk, Anderson created the [Get Real About Diabetes](#) campaign. The goal: to “empower people with information” about managing diabetes, so that they are confident in their ability to overcome adversity and realize their diagnosis is not a death sentence. The campaign website allows people to learn about diabetes, hear Anderson’s personal story, watch fun video clips and quizzes, and share the content on social media to help spread the word.

**ANTHONY ANDERSON**

I made a decision I wasn't going to die from this disease. I'm going to live a healthy life with diabetes ... for 20 years now... I'm healthier & more fit

use it to TEACH

It is not a death sentence

**THE MYTHS**

LOSING

Fantastical Stories

BECAME MY REALITY

It can happen to ME!

**PARTNERSHIP:**

novo nordisk

**GET REAL**

ABOUT DIABETES

- information
- my transformation
- living a productive life

Hey Anthony! I lost 100 lbs!

**d20**

October 13, 2020

**LIGHTNING talks**



d20  
LIGHTNING TALK



### DR. REBECCA PUHL

Dr. Rebecca Puhl spoke to the need for scientific research in challenging the false narratives that surround diabetes. According to Dr. Puhl, disease stigma is a “social construction of illness” and often involves blaming people for their condition, which in turn worsens health outcomes.

- Dr. Puhl said that other disease stigmas have been shown to lead to [worse health outcomes](#), so it is likely true that stigma inhibits optimal diabetes management and treatment as well. What we have learned about obesity stigma, for example, can [inform](#) how we research, understand, and tackle diabetes stigma.
- Dr. Puhl said that work done on obesity stigma is relevant to diabetes stigma for several reasons, including that diabetes stigma, like

obesity stigma, hasn't received the research, attention, funding, or policy action it needs in order for it to be recognized as an enemy to public health. Obesity stigma is interwoven with diabetes stigma, given that many people with type 2 diabetes have obesity, and the two different stigmas actually share many of the same characteristics.

- Using examples from her research on obesity stigma, Dr. Puhl outlined five key ways that data can help challenge diabetes stigma. This data has the ability to:
  - Provide a necessary foundation of knowledge and scientific credibility
  - Increase public awareness
  - Mobilize the healthcare community
  - Influence policy initiatives
  - Inform effective strategies to reduce stigma
- Dr. Puhl's more recent research has shown that between 40–60% of adults with type 2 diabetes report experiencing some form of stigma; moreover, those who reported this experience and who internalized the stigma felt that they had increased challenges managing their diabetes and more severe health outcomes.

# REBECCA PUHL

Public Awareness

Mobilize Medical Community

Scientific Literature

100+ pledged support

Policy Initiatives

State legislatures

American Academy of Pediatrics

American Medical Association

Informed Strategies

Understand Causes

Need Science

Calls for Action

DECLARATIONS

Research on Diabetes Stigma

40-60% experienced Stigma internalized unhealthy behaviors

↑ distress  
↓ quality health care interactions  
↑ binge eating  
↓ physical activity

Obesity Diabetes

- FAULT
- LACK OF WILL POWER
- LAZY
- UNCOMMITTED

Obesity Weight Stigma PUBLIC HEALTH ENEMY

DISEASE STIGMA

BLAMING

WORSENS LIFE

October 13, 2020

# LIGHTNING talks



## DR. NAT KENDALL-TAYLOR

Dr. Nat Kendall-Taylor is an expert in strategic framing, which is defined as the choices we make in how we present information. To truly challenge diabetes stigma, it will require efforts to reframe the causes and experiences of living with diabetes.

- With the FrameWorks Institute, Dr. Kendall-Taylor works with social movements to reframe their messages and better influence the way the public thinks, feels, and acts about certain social issues.
- He used the frames that surround child mental health and COVID-19 to highlight how important language is to ultimately influence and shift behavior, medical care, and policy. It is important to implement and advocate for frames that allow

people to engage with an issue, such as diabetes stigma, in a productive way.

- Child mental health was an interesting example. Provided with two different frames, one of which was being used by over 90% of all current communications surrounding this issue, research participants overwhelmingly supported the desired policy changes when presented with the frame that was NOT being currently used. This example showed how critical the right framing message is.
- The COVID-19 pandemic also provides us with a number of clear examples that show how specific messages, such as labeling the disease as the “Chinese Virus,” can intentionally or unintentionally lead to outcomes that are undesirable.
- Dr. Kendall-Taylor ended his talk by encouraging everyone to think about what existing frames in our everyday lives contribute to diabetes stigma. How can we use new language to fight it?

# NAT KENDALL-TAYLOR

PSYCHOLOGICAL ANTHROPOLOGIST

Unlocking Change

Culture & Framing = CHOICES in how we present information

Communicate: verbs, values, metaphors

feel, think

unlock thinking

example: Child Mental Health [FRAME] (1st 10-15 words (values))

used VULNERABILITY in language

Prosperity vs Vulnerability (less positive)

Chinese virus	→ nationalism racism
Draconian measures	→ info resistance
Protect the most vulnerable	→ others zero sum stigma
People of Color infected/dying @ higher rates	→ blaming poor choices
Confront racism	→ People need to be kind & stop being ugly/hateful

OUR responsibility & opportunity

The world as we know it is built on a story. To be a change agent is, first to **DISRUPT THE EXISTING STORY** of the world and second, to tell a **NEW STORY** of the world so that people have a place to go.

- Charles Eisenstein

October 13, 2020

# LIGHTNING talks



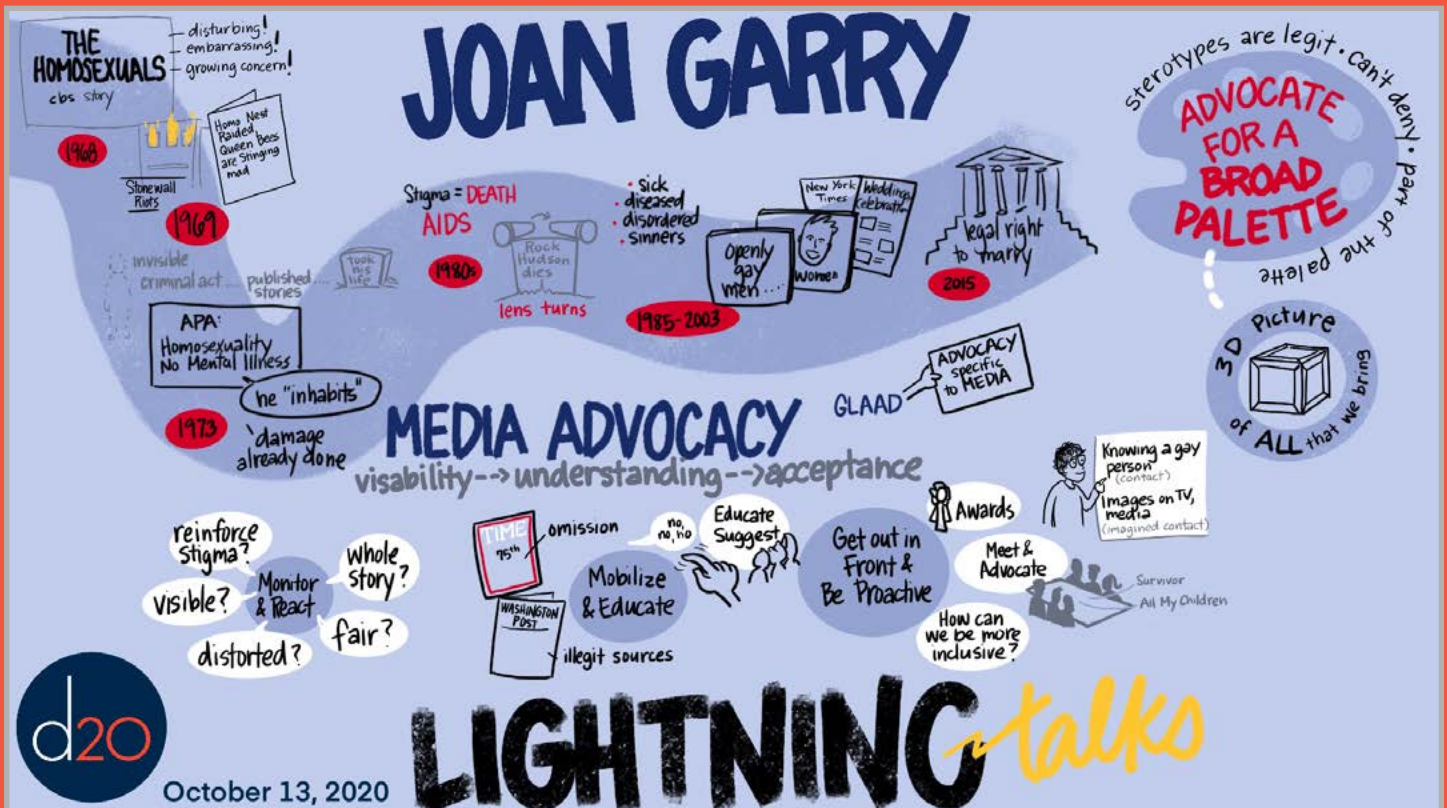
## JOAN GARRY

Joan Garry taught us about how media advocacy helped successfully reduce stigma around the LGBTQ+ community. By using the LGBTQ+ movement as an example, Garry underscored the crucial role media advocacy must play in creating a more inclusive and accurate understanding of diabetes as well.

- Garry, as a national leader in the LGBTQ+ community, explained the history of how the community was portrayed in the media dating back to 1968. Her work with GLAAD—a media advocacy organization that worked to change the

way the LGBTQ+ community was viewed by the country—helped completely shift the narrative.

- To create this understanding and acceptance of identity, Garry stressed two critical steps: (i) monitor and react; and (ii) mobilize and educate. This dual-pronged approach demonstrates that being proactive is essential to create change and emphasized that this work is not solely about eliminating stereotypes.
- She ended her talk with a controversial statement: some stereotypes can be accurate. However, instead of avoiding stereotypes, we ought to “advocate for a broad palette of images and stories” so that people understand the mixed experiences of the diabetes community.
- By connecting the journey that the LGBTQ+ community went through to the one that we are about to embark on to combat diabetes stigma, Garry offered tremendous inspiration and hope for our journey ahead.







### DR. JAMES GAVIN III

Dr. James Gavin III, a leader in diabetes medicine and research, shared his own journey to understanding stigma and the damaging role it plays in proper healthcare for his patients.

- Dr. Gavin shared a powerful story from his childhood about his first encounter with diabetes stigma. When his great-grandmother experienced severe diabetes-related complications, his family refused to discuss the condition at all. Dr. Gavin later realized this was a result of stigma, driven by fear and ignorance.

- He has seen this same stigma echoed in his practice, where he witnesses “the ability of stigma to drain energy, exterminate hope, and impose silence and reticence when there should be comfort and benefit of open exchange.”
- He noted that it is the responsibility of physicians and health care teams to help combat diabetes stigma by offering patients the space and comfort to speak freely about their concerns and know that they are not alone. This knowledge exchange will help strip away the mystery and hopelessness that too often surrounds diabetes diagnosis and management.

**DR. JAMES R. GAVIN III**

**STIGMA** Suffocating blanket

fear  
ignorance

**GOOD NEWS**  
advancements, tools, date success stories

BANK

I am a diabetes doctor

I shared secret information

I guess we all have to die of something

avoidance  
avoid weakness

Reframing the Narrative

Communicate Better  
What it is, What it is not

Good News: Data Tools

Resilient Patients Tell Their Stories

"Well controlled diabetes is the leading cause of nothing"

Avoidance  
Concealment

**STIGMA**

We can't make PROGRESS until we eliminate STIGMA

**d20** LIGHTNING talks

October 13, 2020

## MODULE 2 | WEDNESDAY, OCTOBER 14

### Opening Remarks

#### DR. ALAN MOSES



To kick off d20 Module 2: SHAPE, one of The diaTribe Foundation’s board members, former Novo Nordisk Global Chief Medical Officer Dr. Alan Moses, spoke about the need to curb

the diabetes epidemic and about the importance of our work to tackle diabetes stigma. Dr. Moses began by reminding us of our collective goal: to reduce the incidence, the prevalence, and the impact of diabetes on people who are at risk or who already live with diabetes.

He explored one of the major insights from the COVID-19 pandemic: the importance of “bending a disease curve” and what that means for individual risk and public health. While diabetes is different from COVID-19 in a number of ways—diabetes is a chronic condition and dependent on both changeable factors and factors that are extremely hard to modify—the need to bend the curve is still persistent.

The diabetes epidemic continues to grow at an alarming rate that must be addressed as soon as

possible, especially given the health disparities that have been brought to the forefront and exacerbated by the COVID-19 pandemic. Even if the diabetes field can bend the diabetes curve to 10% prevalence in 2045, we will still be devoting enormous amounts of money and resources to helping those with diabetes. Though this is not ideal, the alternative, not bending the curve and reaching almost 12% prevalence by 2045, would be astronomically worse. Therefore, we must do everything we can to keep the curve bent as low as possible. We also know that obesity is a major driver of the incidence of diabetes. If we can positively address obesity, the hope is that we can also positively affect diabetes.

Based on prior output from the dSeries, Dr. Moses said that we will concentrate on stigma at d20, as this particular lever can play a critical role in a person’s response to their risk of diabetes, on the consequences of diabetes, and on societal responses to diabetes. We will use research-based narrative framing to address diabetes stigma one message at a time.

### Orienting to d20 and Tackling the Stigma Beast

#### BROOKING GATEWOOD AND MANNY HERNANDEZ



Dr. Moses then passed the mic to Brooking Gatewood from the Emergence Collective. Gatewood is a process designer, strategist, facilitator, and collaboration coach who has worked with The diaTribe Foundation to produce the dSeries Executive Innovation Labs since d18. In her remarks, she oriented the participants to d20 by looking at the past four dSeries events and providing a road map for what we planned to accomplish moving forward.

Gatewood began by comparing stigma to Bigfoot: there have been numerous stigma sightings at each of the past dSeries events and in many places across the vast diabetes ecosystem. It appeared when we studied prevention and scenario planning at d16 and d17. It showed up in systems leadership discussions at d18. And it showed up as a key lever for change impacting many parts the diabetes ecosystem map at d19.

She also reiterated the specific goal of the dNetwork—by 2030, reduce the trend of type 2 diabetes and obesity for the 40% of those at risk in the US—as well as the goal of d20: “Flattening the curve, one message at a time.”

Gatewood outlined the roadmap for d20, which began with **learning** about stigma and the tools to help reduce it, **shaping** new narrative frames we can align our messaging around, **acting** to change

the story and reduce diabetes stigma, and then finally **connecting** leaders committed to doing their part to help flatten the curve.

Gatewood then introduced Manny Hernandez, who spoke about his experience being a key member of the d19 working group that focused on stigma as a major lever in the diabetes ecosystem.

Manny’s group began the process of tackling stigma at d19. Their working title was “We want to ADD to the conversation,” and the group set the goal of “changing the public perception of diabetes from ‘it’s their own fault’ to ‘it’s a serious disease and we all need to help’ by 25% in five years as measured by public opinion polls and surveys.” They also outlined a strategy to achieve their goal through the creation of the Alliance for Diabetes Dignity (ADD), focused on changing the language around diabetes.

# Bending the Curve

**Impact of STIGMA**

Change the public perception of diabetes from "It's their own fault, so we don't care." to "It is a serious disease, and we need to help."

by 25% in 5 years

as measured by public opinion polls & surveys

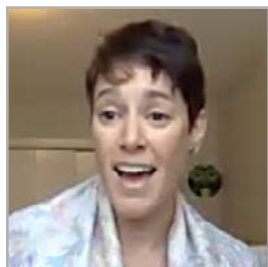
**STRATEGY**

Create A.D.D. Alliance for Diabetes Dignity

- Social Media Campaign
- a new lexicon/script
- "ACT UP" equivalents
- Media outreach for representation & visibility in corporate environment

## Framing Basics

### MARISA GERSTEIN PINEAU



#### Why Framing?

Marisa Gerstein Pineau of The FrameWorks Institute opened the workshop with an explanation and background on framing. Frames are sets of choices

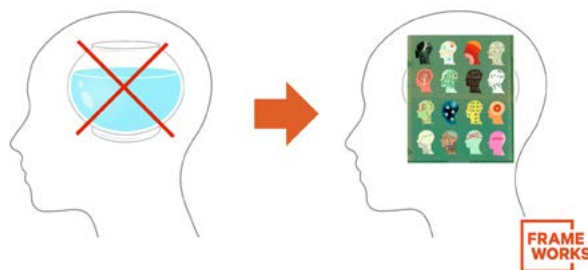
about how information is presented: what to emphasize, how to explain it, and what to leave unsaid. In turn, these choices affect how people think, act, and feel about a particular issue. For example, certain frames may prime people to support programs and policies that help people with diabetes, while others may not.

In order to successfully amplify a message, it is important to engage in a shared framing strategy, which requires a degree of cooperation among organizations to use the same basis for messaging. Otherwise, many groups giving different messages makes it difficult for people to know what to think and dilutes or confuses the message.

For example, the Reframing Aging Project was sponsored by several organizations, including AARP, The American Geriatrics Society, and the National Council on Aging, all of whom had the challenge of talking about aging in order to dispel stigma and create a world where people can age well. By aligning their messaging and choosing the right frames, they were able to significantly shift the discourse through articles, media outlets, and more.

#### What You Are Up Against

Every person holds cultural models, which are assumptions and beliefs created through years of experience, that are often embedded in the structures we live in. People rely on these preconceived assumptions and ideas that they hold to automatically process and make sense of information.



When people hear different messages, they are not “empty fishbowls” ready to intake and believe information; rather, they are working the new information into any cultural models they already possess and forming opinions based on that. Thus, knowing what assumptions and beliefs that people hold before you start communicating is essential.

#### Communications Traps

Pineau then outlined three common communications traps that can make our messaging counterproductive.

##### 1. Myth Busting

While it is a common tactic for communications strategies to use a “Myth vs. Truth” format, this tactic often backfires. Studies on the myth-fact structure found an ordering problem: people usually remembered what they read first, the myth, rather than the whole message. Moreover, the misremembering got worse over time, as more people remembered the myth to be the true statement. To make matters worse, people also attribute the false information to the messenger, which may lead to the reputation of being a false information spreader or uncredible source.

##### 2. Unframed Data

People often think that the more data and evidence that they provide, the more people will understand and agree with their message. However, it turns out that the data does NOT speak for itself. Without framing the data and giving an explanation either before or at the same time as presenting the data,

people will immediately begin forming their own opinions about the evidence presented to them.



Take this message, for example: *The COVID pandemic is having more serious effects on Black Americans than whites. Thirty-three percent of hospitalized patients are Black even though Black people only make up eighteen percent of the population.*

While the intent of the message is to bring awareness to the health inequity between Black and white Americans, simply providing this data without that frame can mislead people. Two unintended responses to this message included:

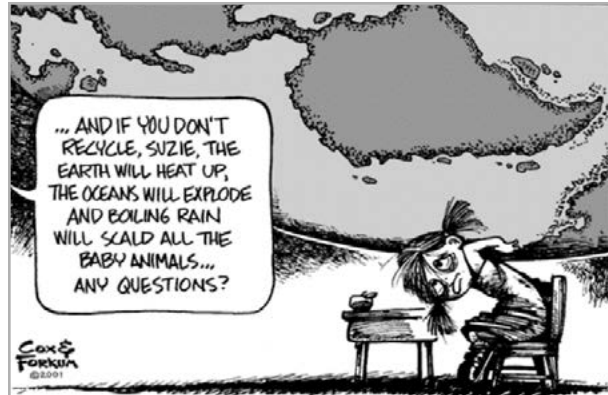
- I'm part African American; most people I know are healthy... [but] I would say parents do not sign their children up for healthcare. They sign up for welfare but not healthcare. That's probably in a more urban area where its widespread.
- They could be more smokers or other things that they do differently.

Thus, rather than convincing people about the importance of health equity, the data had the opposite effect: it reinforced prejudices against Black Americans and beliefs that the actions of Black people caused their plight during the pandemic.

### Crisis Messaging

Crisis messaging is usually employed to signal urgency and the need for support and attention, but it is often counterproductive because it faces a "finite pool of worry." Often, crisis messaging will actually overshoot urgency and lead to a sense of

fatalism, or a feeling that the problem is inevitable and nothing can be done. In addition, while crisis messaging may prompt immediate attention, that focus wanes quickly due to people’s limited capacity for the kind of worry that motivates action. Moreover, because we live in a world where there seem to be crises everywhere, one risk tends to reduce concerns about another, leading to an essentially “zero sum” game.



## Diabetes Frames for Change

In preparation for d20, The FrameWorks Institute created a framing brief, [Changing the Narrative Around Diabetes](#). These research-informed reframes give people new ways of understanding and perceiving people with diabetes, which in turn can help change attitudes and reduce diabetes stigma.

Marisa Gerstein Pineau walked through the following five frames with d20 participants. The purpose of these frames was to begin giving participants the tools to craft their own narratives, using the reframing strategies that seem most effective in their personal spheres of influence.

### 1. Talk about what we all need to be healthy.

People generally believe that we are all solely responsible for our own health. This thinking emphasizes personal failure when someone is unhealthy, and it can lead to shaming and blaming people with diabetes for their condition.

Instead, communicators should emphasize what we all need to be healthy, including access to preventive healthcare, safe outdoor areas to exercise, and affordable, healthy foods. By diverting thinking away from individual blame and toward our common needs and experiences, we can stop the “othering” of people with diabetes and focus on our shared community.

### Stigma-Reducing Reframe:

*“We all need things to help us stay healthy. We need high quality healthcare. We need safe places to exercise. We need affordable, healthy food. We need those same things if we have diabetes, along with targeted treatments and care. Making sure we all have what we need to stay healthy means people with diabetes have what they need—not just to control their weight but to live well.”*

### 2. Show—don’t tell—what stigma is, and explain implicit bias.

Implicit bias is our unconscious way of thinking that affect our understanding, actions, and decisions. Instead of telling people that stigma, prejudice, and implicit bias exists, it is important that we explain, not assert, what they are, where they come from, and how they are harmful to people with diabetes. By explaining these patterns, we can prime people to recognize their bias and think about solutions more effectively.

### Stigma-Reducing Reframe:

*“We are constantly exposed to images of people with diabetes as people who won’t control their bad habits. This affects our attitudes and behaviors, often in ways that we don’t realize. As a result, people with diabetes may feel a sense of fear and shame that prevents them from talking about their diagnosis and even avoid seeking treatment. If we*

want to reduce stigma, we need to change the narrative and our thinking about diabetes.”

### 3. Start with what we want people to know about diabetes instead of repeating damaging myths.

Presenting and refuting myths is often counterproductive. The first thing we read or hear is what stays with us, so the myth-fact structure can often backfire. Instead, communicators should start with the facts and only repeat myths if they must.

#### Stigma-Reducing Reframe:

“Many different factors can increase people’s risk of developing type 2 diabetes. Age, race, and genetics all play a large role, and mothers who have gestational diabetes caused by pregnancy hormones also have a bigger chance of developing the disease. Diet, physical activity, and weight are just part of the story.”

### 4. Explain equity and always link it to clear solutions.

Health inequities are differences in health outcomes that are caused by prejudice and discrimination. While inequities play a massive role in diabetes, most people misunderstand what inequity means or how inequities work, and they often conflate equity with equality. In turn, because people don’t understand the significance of inequity, they often also don’t support equitable solutions. Thus, communicators must explain equity and inequities clearly in order to address the root problems.

#### Stigma-Reducing Reframe:

“The COVID-19 pandemic and glaring examples of racial injustice are casting a bright light on an old problem in America. Health inequities are differences in health outcomes rooted in prejudice and discrimination. In the U.S., these inequities harm people of color in a variety of ways: through limited access to quality healthcare, racist interactions, and higher rates of exposure to air

# CHANGING THE NARRATIVE

**1** Talk about what we **all** need to be healthy, while still discussing specific needs

We are all **solely responsible** for our own health

Emphasize what we all need to have good health

**BECAUSE** Diverts thinking away from individual blame → our common needs & experience

## SHIFTING THINKING

<ol style="list-style-type: none"> <li>1 Those People</li> <li>2 Describing Stigma</li> <li>3 Mythbusting</li> <li>4 Stating inequity</li> <li>5 Crisis messaging</li> </ol>		<p>All of us</p> <p>Implicit bias</p> <p>Facts first</p> <p>Explaining equity</p> <p>Collective solutions</p>
--	--	---

**5** **Avoid Crisis:** instead talk about **how** we can tackle diabetes **together**

Crisis should be quickly solved, or can't be solved at all

Offer solutions we can accomplish **together**

**BECAUSE** People need to **see how we solve important social problems** and how they can be **part of the solution**

**2** **SHOW - don't tell - what stigma is and explain implicit bias**

Explain, don't just assert

Stigma doesn't exist or isn't that much of a problem

Explain implicit or unconscious bias & where it comes from

**BECAUSE** Helps people recognize the problems stigma poses and how we can address them together.

**3** **Start** with what you want people to know about diabetes instead of **MYTHS**

The myth is true

**Start** with the facts & don't repeat myths unless you must

**BECAUSE** The **1st** thing we read or hear is what stays with us

**4** **Explain equity and always link to clear solutions**

Equity is equality

Explain equity and inequities clearly

**BECAUSE** People don't support equitable solutions if they don't understand the problem

October 14, 2020

*pollutants and other environmental toxins like lead, among others. It contributes to worse outcomes and higher risk for diabetes and many other diseases. And it undermines the well-being of our most underserved communities.”*

## 5. Avoid crisis: instead talk about how we can tackle diabetes, together.

Talking about diabetes as a public health crisis may be accurate, but it is often counterproductive. People generally think that problems should be solved quickly, or they cannot be solved at all. Crisis messaging often presents problems as so overwhelming and difficult to solve that it leads to a sense of fatalism, or a feeling that the problem is

inevitable and nothing can be done. Communicators should instead offer solutions at the beginning of their message, emphasizing our collective ability to solve the problem, so people can understand how they can play a part in those solutions.


### Stigma-Reducing Reframe:

*“Diabetes is a serious but solvable public health problem. Finding ways to treat diabetes and to support people with diabetes is more important than ever as we face the COVID-19 pandemic. Find solutions and resources by visiting our website. We can tackle this problem—together.”*

## Framing Workshop Breakout Session Summaries




After Pineau’s Framing Workshop, the d20 participants broke out into small groups to discuss several questions about what excited them about the frames presented, what they were questioning,

and ideas on how to customize the frames in order to test them in their individual spheres of influence. Summaries of their discussions are below.

GROUP	PARTICIPANTS	DISCUSSION SUMMARY
<b>Artichoke</b> 	Kelly Close, Jim Carroll, Laura Feinberg, Thom Scher, Joe Nadglowski, Phil Sutherland	This group focused primarily on the “crisis frame.” There is talk about crisis in diabetes all the time, even when it is probably more effective to “minimize the crisis framing and push people to the general principles of what it’s going to take to be healthy.” On language, the framing of the word “solvable” garnered interest, and there was support around the idea of setting an aspiration instead of focusing on having the biggest crisis. In another vein, it is important to understand where we are and where others are in the conversation, and to bring people to where we, at d20, are through good communication strategies. Participants also discussed who the audience is for the frames and how the message can be shared with the audience in an inclusive manner, while still acknowledging inherent differences (e.g., the differences between type 1 and type 2 diabetes.)



GROUP	PARTICIPANTS	DISCUSSION SUMMARY
<p><b>Asparagus</b></p> 	<p>Orville Kolterman, Francine Kaufman, Robert Gabbay, Genevieve Fadayomi, James Gavin, Emily Fitts</p>	<p>The frames this group found most helpful were avoiding crisis and talking about what we all need to be healthy. Many of the people in this group were key opinion leaders who often give presentations—they mentioned that they frequently use the crisis framing as the first part of their presentations, but they agreed to change the framing of their presentations to start with the solutions and then emphasize the “burning platform” at the end. There was also discussion around the importance of reframing the conversation about what we all need to be healthy, rather than presenting people with diabetes as people with “special needs.” The group talked about ways in which providers can reframe the way they think and talk about “responsibility” and “control.” They discussed that people with diabetes have direct control of only 5–10% of the factors that contribute to their diabetes (like diet and exercise), but most of healthcare and public attitudes are entirely focused on those aspects instead of systemic problems like health inequity.</p>
<p><b>Broccoli</b></p> 	<p>Alan Moses, Divya Gopisetty, Karmeen Kulkarni, Virginia Valentine</p>	<p>This group explored the ideas around the cultural barriers and biases in healthcare specific to food and diabetes and the important role language and framing play in combatting those barriers and biases in the treatment of patients. The discussion of language then shifted to a reflection on how specific word choice, such as the title “diabetic,” might harmfully restructure one’s relationship with their disease or how the inclusion of questions such as “do you exercise” or “what kind of food do you eat” and the exclusion of questions such as “do you have access to healthy food,” contribute to personal responsibility and blame. They agreed that stigma and implicit bias should be better represented in scientific literature and at conferences and that implicit bias lacks a clear definition, and this phenomenon could most clearly be elucidated by example.</p>

GROUP	PARTICIPANTS	DISCUSSION SUMMARY
<p><b>Cauliflower</b></p> 	<p>Kelly Brownell, Nicholas Cuttriss, Shreela Sharma, Matthew Garza, Eliza Skoler</p>	<p>This group agreed that there is a need for data and research to support the narratives that we are propagating. As we build frames for different situations, being able to test them and to come up with academic data that supports their success is key to helping everyone understand what works, and also garner support so there isn't complete reliance on instinct alone. This also ties into another major conversation on the building and customization of these frames; it's important that leaders in the diabetes community have ownership over the solutions we all hope to implement.</p>
<p><b>Celery</b></p> 	<p>David Lee Strasberg, Judith Vecchione, Carl Rashad Jaeger, Mila Clarke Buckley, Chris Barnes, Kyle Jacques Rose</p>	<p>This group discussed the power of “show don't tell.” Many members of the group had a wide array of storytelling backgrounds that have allowed them to understand the power of a narrative and of sharing an experience with an audience. In this way, people with diabetes can be normalized, especially in the media, where it is often greatly dramatized. Most, if not all, humans care about their health, some just have greater barriers than others preventing them from reaching their goal. Thus, rather than focusing on the division between people with type 1 diabetes, people with type 2 diabetes, and people without diabetes, we should focus on commonalities. The group agreed that many problems with stigma are rooted in cultural ties to individualism, and that combatting that ideology may lead to decreased stigmatization and increased collaboration within the overall system.</p>
<p><b>Green Beans</b></p> 	<p>Caroline Pappajohn, Alijah Marquez, Shannon Faught, Kristen Williams, Jennifer Tepper, Alex Engel</p>	<p>The participants in this group resonated with the idea of avoiding crisis communication and, instead, infusing our work with what we want people to know. The first steps toward carrying out this framing decision is, as stakeholders, to determine what we want people to know. Additionally, we want to use frames to create an inclusive attitude—moving away from “them” toward “we”—and emphasize empowerment and activation. We want to use the “solutions exist” frame and then tailor the message according to the audience.</p>

GROUP	PARTICIPANTS	DISCUSSION SUMMARY
<p><b>Lettuce</b></p> 	<p>Paul Sytsma, Jennifer Hahamian, Stefanie Cousins, Angela Moskow, Dennis Boyle</p>	<p>This group is heavily involved in marketing and communications, and thus participants emphasized the power of words and recognized the unfortunate prevalence of the “crisis frame.” The conversation also touched on who the target audiences are that may hold stigmatizing views and the importance of trying to avoid sounding complacent if the framing language emphasizes uncontrollable factors too much. The group began to build example campaign strategies, agreeing on language that focused on a “continuum of people’s health” and “impacting your personal health through tailored lifestyle choices.”</p>
<p><b>Peppers</b></p> 	<p>Cherise Shockley, Phyllisa Deroze, Brian Ballard, Deana Zabaldo, Larry Soler, Karena Yan, Frida Velcani</p>	<p>This group found the “start with what you want people to know” and “avoid crisis language” frames to be the most helpful in challenging stigma and prioritizing the take-away message that you want people to remember and internalize before attempting to dispel myths. Other things that came up were the importance of providing culturally relevant frames for different audiences and the importance of telling more than one story to represent the diversity of people with diabetes. We also discussed how current systems, from healthcare to addictive technology, are set up to be reactive rather than proactive. How can we reframe issues to address the root cause and avoid placing total responsibility on the individual?</p>
<p><b>Spinach</b></p> 	<p>Richard Wood, Scott Johnson, Manny Hernandez, Conrod Kelly, Mallory Erickson, Julia Kenney</p>	<p>In this group, participants stated that they likely used, and were most impacted by, the crisis and myth-busting “Communication Traps.” When talking about the “show, don’t tell” frame, the group commented on the lack of heterogeneity in the media and diabetes-related ads when it comes to images of people with diabetes. The group also discussed the “othering” that people with diabetes experience and the way they are blamed for their disease. This othering was described as an emotional defense mechanism, because people don’t want to believe that this disease can impact them. When thinking of the challenges of better representing the real diabetes community, group members talked about time, balance, finding the right level of detail, and systemic discrimination.</p>

GROUP	PARTICIPANTS	DISCUSSION SUMMARY
<b>Tomatoes</b> 	James Corbett, Ruey Tu, John Close, Marjorie Sennett, Tom Cirillo	And finally, this group’s participants analyzed the presented frames and examined their uses. Some key points were made about the process of framing itself, such as the fact that the context, the type of stigma, and the audience intended for the frame must be considered as well. The discussion group found the frame—“talk about what we all need”—to be particularly helpful. Several participants emphasized that in America especially, a culture of individualism can often lead to the othering of people with diabetes and contributes to stigma. Another recurring theme was the importance of personal stories. Although this is an individualistic component, discussion participants concluded that these stories can show similarities in experiences within society and can help to contribute to the ‘we’ narrative.

## Major Themes and Key Takeaways

Through the Zoom chat box comments, participants’ verbal comments, and breakout group presentations, several major themes and insights arose.

- **The power of “we”:** we are all affected by diabetes, whether we have it or not. Emphasizing togetherness and deconstructing our individualistic cultural frames can help reduce stigma. We all care and work hard to be healthy, and we all deserve the tools and resources to achieve that goal.
- We need to use our energy to reduce stigma around diabetes in general, which includes type 1, type 2, and gestational diabetes. **Solidarity** among all people with diabetes is important to affect stigma.
- **Myth busting is counterproductive**, especially when the myth is presented before the truth, because people remember the myths, not the facts.
- **Finite pool of worry:** while it may prompt initial engagement, crisis messaging causes fatalism and crisis fatigue, causing people to quickly lose energy and interest in an issue. Instead, present people with action items and solutions—people get excited when they feel they can actively help an urgent problem.
- **The data does NOT speak for itself:** presenting people with unframed data is ineffective. Instead, give people the tools to understand the data before or while you are presenting it.
- **Language matters**, and we should use people-first language. Rather than “diabetic” or “obese person,” try “person with diabetes” and “person with obesity.”
- Frames and messages must be **tailored for different audiences**. For example, the conversation of health equity and social determinants of health may move some audiences but not others.
- **COVID-19 presents an opportunity** to engage with the non-diabetes community, as the entire population is now faced with uncertainty and threats to their health much like people with diabetes are on a daily basis. However, simultaneously, COVID-19 runs the risk of sucking all the oxygen out of the room and of further stigmatizing diabetes because of the constant discussion around the increased risks of diabetes and the virus.

## Closing Remarks and Commitments to Action

Jim Carroll gave inspiring closing remarks that spoke to how frame shifts, collective action, and unbounded determination can transform social issues, such as the marriage equality movement. To read his full remarks, please see the [Appendix](#).

d20 was concluded with each participant writing down their specific commitment to sharing and testing their new narratives between Module 2 and Module 3.

Below are some examples of participant commitments:

Your FRAME-TESTING commitments:	What I learned testing the frame:
One key place I plan to test some new frames in the coming weeks is _____.	
At work during team meetings as we work to build out future topic areas	Some communication styles that I thought could be helpful can actually have the opposite effect
I will be speaking with our IDF Youth Leaders from around the world and will discuss/exchange with them how, together, we can use framing in advocacy projects and their communities back home.	My conversations reinforced the importance of culture as it relates to discussing stigma, particularly when there are many different nationalities/backgrounds in the room. Framing is still an effective tool, even with this varied of an audience, when respective cultural 'norms' are addressed. A great example is the recent adaptation of "Language Matter" in France that has been adapted and localized for France: <a href="https://www.diabetopole.com/le-pouvoir-du-langage">https://www.diabetopole.com/le-pouvoir-du-langage</a>
A/B test some frames on Beyond Type 2 platforms (after a brainstorm and meeting with the team on how inspiring today was!)	(1) Harder than it looks for an editorial team; it's a deeper level of thought on content, and (2) When we did it in beaten-over-the-head ways, it was notably well received

**KEY INSIGHTS**

- Stigma a BIG ISSUE** in the medical profession more effectively
  - Clincias dont know they have BIAS
  - not on their radar
  - help them understand & connect w/ patients
  - multiple ways to reach them
- Living a Problem vs Not Being A Problem**
- Diabetes is the **VILLIAN** Everything is a **BATTLE** vs It impacts us all
- SHOW** requires a machine
- We **ALL** care
- We **ALL** care about each other
- We are all **HEROES** beating the odds
- Together individual messaging
- NEED:** Something to **BLAME**
- CHOICES:** personal tailored options
- "WE"** → people "like us"
- "CARE"**
- "TOGETHER"**
- DIFFERENT AUDIENCES**
- keep the core msg.
- Framing For General Public
- MEDICAL PROFESSIONALS**
  - Avoid Crisis
  - "What do **WE** ALL need to be healthy?"
- COVID ENVIRONMENT**
  - Now Media is only interested in COVID, not other medical messages
  - use this time to gain visibility?

d20 October 14, 2020

# MODULE 3 | TUESDAY, NOVEMBER 17

---

## Re-Orienting to d20 with Brooking Gatewood

Gatewood began Module 3 by re-orienting participants to the things they learned in Modules 1 and 2 and by introducing the work that lay ahead of them on the third day of d20.

She first reiterated the goals of **learning, shaping,** and **acting** throughout d20 and beyond, and noted that Module 3 would focus especially on the third.

Gatewood then reemphasized that the work of d20 was grounded in the larger systems mapping work that was established at d19. Stigma affects many different parts of the systems map; and by working to address stigma, that can open the door for even greater change in areas like:

- Moving decision makers and scaling the movement
- Improving the quality of and access to medical care
- Reaching those at risk for and those most impacted by diabetes
- Reducing risk factors from social determinants of health

Gatewood also explained that Module 3 would consist of gathering insights from the fieldwork that participants had done since Module 2, developing solutions to framing challenges with Dennis Boyle from IDEO, and designing personal action plans for each participant.

## Fieldwork Insights: Breakout Session Summaries

Shortly after Gatewood laid out the agenda for Module 3, the d20 participants broke out into small groups to discuss what they learned from their fieldwork during the month between Module 2 and 3. They discussed the challenges they faced, the successful interactions they had, and what additional resources might help with shifting the narrative around stigma. Major insights from these breakout sessions included:

- There are many opportunities to have meaningful discussions about stigma and reframing in both personal and professional settings—more than many participants anticipated.
- Shifting the current narratives, and moving away from stigmatizing language, is not an easy task, even for those who work in communications.
- Many participants stressed the importance of having a set of guidelines and talking points—when initiating conversations around language and reframing, there is a need for a tool that can be quickly and easily referenced.
- There is a great opportunity to partner with industry to ensure advertisements support reframing diabetes for the general public.
- Healthcare providers, and especially primary care physicians, are a key demographic that needs to be targeted for education on reframing to avoid diabetes-related stigma.
- Language that encourages shared responsibility, such as “we,” “us,” and “our,” is usually well received and allows people to shift away from blame and toward an understanding that everyone should be working toward better health.
- Myth-busting is a common frame that people recognized, but they often found it hard to shift away from this method in particular because of how ingrained it is in current communication strategies.
- Crisis messaging was a particularly challenging obstacle that many people, especially those in industry, faced. Participants found it difficult



to convey the scale and urgency of the problem without turning the situation into a catastrophe.

- Frames around health equity are very important, but they are hard for many people to grasp. Stigma plays directly into conversations about equity—for people who face additional systemic

disadvantages, personal responsibility is often overemphasized. For example, Black, Indigenous, and people of color face additional challenges in the healthcare system due to systemic racism, and these inequities can exacerbate the negative effects of diabetes stigma.

## Framing Recommendations

### MARISA GERSTEIN PINEAU



To follow up on her Framing Workshop from Module 2, Pineau shared some additional tips when it comes to shifting narratives.

#### Bridge and pivot

This is a nonconfrontational technique to move a conversation in a different direction without reinforcing something the other person is saying (i.e., something stigmatizing). Try phrases like:

- It's interesting that you should say that, but actually we know \_\_\_\_\_.
- You could also think about it this way...
- Actually, the science tells us \_\_\_\_\_.
- Although it is important to understand...
- On the other hand, the data tells us...

### Humanizing stories

Personal stories are effective, but don't forget to frame them. Contextualize the stories before, during, and after telling them, and be sure that the story can connect to other people's experiences. Take the opportunity to talk about the circumstances and systems that unite our shared experiences, and think about alternate protagonists, such as groups, institutions, and places.

### Unexpected messengers

Narrative change does not necessarily have to come from influencers and large organizations; having messengers on the ground can be a really effective strategy.

- For example, Pineau shared a five-year evaluation done by the National Network for Ocean and Climate Change Interpretation (NNOCCI) group. By training zoo docents to talk about climate change while they walked people around zoos and aquariums across the country, NNOCCI found that people who visited NNOCCI sites were more knowledgeable and more activated on climate change than other Americans.

## A rigorous, five-year evaluation of NNOCCI showed the impact



Observations of NNOCCI training participants and other measures demonstrated that the “Study Circle” training model changed communications practices.



By interviewing the professional and personal networks of interpreters, researchers found that FrameWorks frame elements travel effectively through “social radiation.”



By intercepting visitors, researchers found that NNOCCI zoos and aquariums were sharing more information about climate change, that visitors recalled the frame elements, and were more likely to take civic action.



A national survey found that people who visited a NNOCCI institution were more knowledgeable and more activated on climate change than other Americans.

## Ideating Solutions to Reframe Challenges with Dennis Boyle

After breakout groups shared their major insights and challenges from their frame-testing experiences, five major challenges emerged:

1. **Keeping the conversation focused on diabetes, not obesity.** Participants found that once diabetes was brought up in conversations, people often shifted the conversation to obesity and weight stigma. How might we refocus conversations on diabetes, specifically?
2. **Combatting the blame and shame ‘individual responsibility’ frame.** In America, individualism is a core value, and many people believe that poor choices and lack of willpower are the primary causes of diabetes. How might we pivot/reframe when people come back to blaming ‘bad behavior’?
3. **Introducing the health equity frame where it’s not already understood/ believed among the audience.** The health equity frame presented two challenges for frame-testers: (i) the difficulties around explaining health equity to audiences for

whom the concept does not resonate, and (ii) the phenomenon where the concept of health equity often triggered thoughts around race and gender only, but not diabetes. How might we bridge the gap in people’s understanding of the link between equity and health?

4. **Inspiring healthy habits without shaming.** People are often told to ‘make healthy choices,’ but the dichotomy of ‘unhealthy’ versus ‘healthy’ is often oversimplified and even stigmatizing. How might we inspire behavior change without being stigmatizing in the process?
5. **Getting attention for diabetes without crisis messaging.** Frame-testers found difficulty in communicating urgency around diabetes without sparking fatalism. How might we get attention to this issue without adding to our society’s crisis-driven media?

In order to tackle these challenges in small groups, IDEO’s Dennis Boyle first shared some relevant principles of design thinking for our work tackling stigma: Design thinking is a fundamentally



human-centered process that starts with what people need, desire, or want, and then balancing between the people, business, and technical factors. It starts with gaining empathy by connecting with patients, users, and customers. What we want here is clear—to reduce stigma—and this session will focus on addressing some of the key factors we'll need to address to get there. We'll also want to think about 'extremes' cases—if we can solve a problem for these cases, the solution likely applies well to most situations.

Boyle also offered several concrete brainstorming rules to guide participants in the ideating process:

- **Defer judgment**—wait until the end of the brainstorming session to judge ideas.
- **Encourage wild ideas**—cultivate an attitude of playfulness and humor in ideation.
- **Build on ideas of others**—use teammates and principals of collaboration to your advantage.

- **Stay focused on the topic**—while it is easy to go on tangents, remember the specific problem that needs solving.
- **Only one conversation at a time**—when one person is talking, listen to them.
- **Be visual**—use physical or virtual post-its, or some other visual device, to keep ideas flowing.
- **Go for quantity**—aim for a lot of ideas that you can select from later.

Employing IDEO's design thinking approach, participants then broke into five smaller groups to focus on generating solutions for each of the major challenge areas. They individually recorded their ideas on virtual post-it notes, and then as a group, selected one 'practical' idea and one 'wild' idea to share back with the group.

## Ideations Around Five Framing Challenges

*At the end of the collaborative working session, teams presented their initial ideas for strategies to address each of the five core challenges.*

### Challenge #1: Keeping the conversation focused on diabetes, not obesity.

#### Ideas and solutions:

- Find a "poster child" who is innocent and blameless to help people see diabetes in a different light. For example, the poster child who significantly changed the stigma surrounding HIV/AIDS was Ryan White, an American teenager who turned into an advocate for AIDS research and public education after contracting the disease through a blood transfusion.
- Educate people that we have less personal control to prevent diabetes than commonly acknowledged. Diabetes cannot be controlled or prevented through willpower and behavior alone, yet the world still believes that people

have the ability to control it themselves without medical intervention.

### Challenge #2: Combatting the blame and shame 'individual responsibility' frame.

#### Top solutions:

- Create a national campaign that normalizes diabetes by underscoring the fact that people with diabetes are people we know and love. For example:
  - "I am a surgeon, a mother of two, a marathoner, AND I am a person with diabetes."
  - "I am an architect, a father of two, a sailor, a skier, AND I am a person with diabetes."
- Organize a sitcom, drama, or a game show where almost all the characters are people



with diabetes, and people without diabetes are the “abnormal” ones. Such a show can set up situations, conversations, and comedy to combat stigma.

### **Challenge #3: Introducing the health equity frame where it’s not already understood/believed among the audience.**

#### **Top solutions:**

- Amplify the voices of those with lived experiences to explain equity and develop empowering messages around equity. While celebrities are eye-catching, they are often not relatable—make them part of the story, but not the whole story.
- Start by framing equity within your own organizations and communities, paying close attention to being reflexive and creating concrete definitions and goals.

### **Challenge #4: Inspiring healthy habits without shaming.**

#### **Top solutions:**

- Find a more empowering term or menu of terms to describe health. Even the phrase “make healthy food choices” can sound stigmatizing, and the issue of health is more complex than the dichotomy of “unhealthy” versus “healthy” makes it seem.
- Use motivational interview to determine what matters to people, and guide them toward behavior change that aligns with their values and achieves their personal goals.

### **Challenge #5: Getting attention for diabetes without crisis messaging.**

#### **Top solutions:**

- Instigate a “story corps” vehicle that showcases the diverse stories and backgrounds of people with diabetes, such as “Everyone knows someone with diabetes” or “30 under 30 most influential people with diabetes.” By showing that young, fit people can have diabetes too, a campaign can show that diabetes often doesn’t align with the stereotypes and stigmas.
- Create fact sheets and more detailed messaging resources that:
  - Address why this is important now, without crisis messaging
  - Highlight terms to use and not to use
  - Give tips for getting journalists to refrain from myth/crisis headlines and help dispel stigma
  - Provide specific and tailored ways to connect with different key audiences, including both people with diabetes and the general public

# CHALLENGES

Keep the Conversation focused on...

...not Obesity

Combating the **BLAME** and **SHAME**

INDIVIDUAL

RESPONSIBILITY Frame

Introducing the **HEALTH EQUITY**

frame where it's not already understood/believed among the audience

Inspiring **HEALTHY HABITS**

without shaming

Getting Attention for **DIABETES** without crisis messaging

# SOLUTIONS

**Poster Child**

**NATIONAL CAMPAIGN**

I am a surgeon, a mother of two, a marathoner, AND I am a person with diabetes.

I'm an architect, a father of two, a sailor, a skier, AND I am a person with diabetes.

We have **less** personal control to prevent diabetes than we previously believed

**EDUCATE**

**sitcom, DRAMA - GAME SHOW**

**AMPLIFY the VOICES** of those with lived experiences to explain EQUITY

**START** by framing EQUITY within your own organizations and communities

More Empowering **PEJMA TERMS**

What matters to you

To achieve **YOUR** Personal Goals

**VALUES**

30 under 30 Most influential people with diabetes

Everyone knows somebody with diabetes

**STORY CORPS**

**FACT SHEETS**

important info! tips for journalists

terms to use! not to use! specific & tailored ways to connect

## Action Plans for Thinking About and Disseminating the New Frames

Module 3 concluded with participants creating personal action plans to continue dismantling stigma in their personal and professional lives. Through small co-working sessions, each person identified two or three focus areas in their life where they believed they could make an impact on stigma. Below is an example of an action plan that participants created.

<b>WHERE</b> can I leverage my influence to help reframe the narrative?	<b>HOW</b> specifically can I influence a shift of framing in this area to reduce stigma? <b>WHO</b> will I engage?	<b>WHAT</b> reframes/talking points will I focus on?	<b>By WHEN?</b> WHAT specific actions can I commit to in next 3 months?
In the media	I will practice these reframes when interviewed, and where possible pitch stories/angles/headlines that can help offset stigma!	<ul style="list-style-type: none"> <li>• Avoiding crisis messaging</li> <li>• Leading with facts + explanation, not myth-busting</li> <li>• Integrate equity &amp; 'beyond just behavior' frames</li> </ul>	I expect I will be able to practice this in 3–4 media interactions in the next 3 months.
Amongst academic colleagues	I can encourage graduate students and researchers to study impacts of implicit/explicit diabetes stigma in health care, media, and other relevant settings	Diabetes is a serious but solvable problem and as researchers we have a powerful role to play in bringing more dignity to PWD by providing data on impacts of stigma and other social determinants of health	I will be speaking at an academic conference in January and will integrate these learnings and a pitch for research into my talk.
Through my drug and/or device sales team	Share d20 learnings and work with Bob the sales team manager to develop a plan to integrate some of these reframes into our regular HCP sales pitches <i>and</i> KPIs.	Stigma and shame reduce adherence to diabetes self-care protocols. We can help spread the messaging to HCP to see themselves as part of the solution addressing the serious but solvable problem of diabetes and sharing tips for engaging patients in non-stigmatizing way.	Planning meeting by end of year; Plan set by end of Q1 2021; Quarterly check in with Bob on progress

## Closing Reflections and Next Steps

At the end of Module 3, participants gathered as a full group to present their commitments and share their closing reflections, which are summarized below.

- You do not need a significant audience or a large platform to participate in spreading these new narratives and dismantling stigma. Conversations with our friends, families, and close communities are worthwhile and impactful.
- In order to make lasting change, our message needs to get beyond the usual audience, especially in the online space. Besides talking to each other about stigma, we need to reach people who are outside the diabetes world so they can also understand it and share it with their communities.
- Personal experience can differ so drastically that relying on a universal message or a one-size-fits-all narrative may not be sufficient. In some areas, a shared narrative is effective; however, with other audiences, a more targeted and nuanced message is more useful.



**normalization** moving forward  
 conversations with friends **online**  
 lasting change **degrees of stigma** **presence**  
**shared** **targeted message**  
**narrative** **beyond usual audience**  
**high impact** **intersecting stigmas**  
**diversity and universality**  
**avoid assumptions** **aligning our communities**

However, while we must recognize diversity and find universality where possible, we cannot wait for the perfect message before moving forward.

- We must be mindful of intersecting stigmas and how they may influence the perception of diabetes stigma. For example, people who have varying degrees of stigma from other sources, such as race, ethnicity, poverty, education level, or gender, may perceive the impact of diabetes stigma as relatively less significant.
- Part of the narrative should normalize diabetes management because much of it can benefit all people, not just people with diabetes. For example, almost everyone can benefit from limiting sugar intake—it is not a matter of “this is what I do and this is what you do,” but rather “this is what we all can do.”
- We cannot assume that we know what people in the general population think about diabetes. In order to get clearer and more specific messaging, we need objective research to understand general beliefs.

Nearly all of the participants expressed interest in continuing to practice this framing work and staying involved in a future stigma campaign or initiative.

To conclude, Gatewood gave an overview of the next steps:

- diaTribe will share a summary of d20 insights via the [Stigma Primer webpage](#).
- Participants will consider joining a Stigma Strategy Group, which will serve as the workgroup for our work around future stigma initiatives.
- With input from this group, diaTribe will spearhead additional communications tools to build on our framing insights, including talking points and a social media toolkit.
- Participants will continue serving as influencers in their personal and professional lives, testing frames and advocating for frame-shifts, and sharing insights and progress with diaTribe ([stigma@diatribe.org](mailto:stigma@diatribe.org)).
- d21 will be a continuation of this diabetes stigma work, with diaTribe working with Brooking Gatewood to create a program that builds upon the stigma insights of d20 and of the Stigma Strategy Group for longer-term opportunities.



# A SPECIAL THANK YOU TO OUR SPONSORS

---

We are grateful for the financial and other support by the following generous sponsors.



# APPENDIX

---

## Changing the Narrative around Diabetes

A FrameWorks Framing Brief in partnership with the diaTribe Foundation  
October 2020

**Diabetes** is a chronic disease. But people with diabetes also experience an equally chronic problem: stigma.

Underlying this stigma against diabetes are shared, deeply held assumptions about health that are embedded in American culture. **The most common and problematic assumption is that health is primarily a matter of individual responsibility.** In other words, health is shaped by personal choices about diet and lifestyle, and the primacy of these individual choices prevents people from thinking about other critical factors like access to healthcare and healthy environments. When people hear and think about health and illness the assumption that health is simply a matter of individual choice is usually the first to come to mind.

This focus on personal responsibility leads to a stigmatizing narrative that blames people with diabetes for making bad choices and for increasing healthcare costs. This narrative sets up “us vs. them” thinking and the assumption that people with diabetes are using more than their fair share of limited healthcare resources. Diabetes is also tightly linked to obesity, which is similarly stigmatized, meaning people with diabetes are doubly othered and shamed. As a result, people may feel a strong sense of fatalism about addressing this disease because they assume people with diabetes won’t make the right choices. Health equity, meanwhile, is almost entirely absent from the conversation.

If we are going to tackle stigma against diabetes we need to frame effectively. Framing means making choices about how we explain an issue or

problem, what we emphasize, what we say—and what we don’t say. We’ve seen the power of framing in our own work on [aging](#), [addiction](#), [childhood development](#), and [obesity](#) (in the UK). And we’ve all seen the power of framing in shifting the narrative in the [civil rights movement](#), [marriage equality](#), and [teenage smoking](#).

Reframing diabetes means making careful, strategic, and evidence-based decisions about how we talk about diabetes that avoid the traps posed by individualism and fatalism. Instead we can use effective framing to direct people’s thinking along more positive, productive channels. We can create messages that avoid othering and instead recognize our universal experience; that don’t just assert but explain how stigma happens and why it is so damaging; and that pre-empt fatalism by demonstrating that solutions are possible, and we can achieve them together.

This brief contains five reframing recommendations that will help us change the narrative around diabetes. Each recommendation includes text drawn directly from influential, diabetes-focused websites, and a reframed version rooted in research that shows how to easily and effectively reframe it for greater success in shifting mindsets. Here’s just one of the five examples of the kinds of shifts we can make to impact diabetes stigma with the way we talk about it:

**Talk about what we *all* need to be healthy, while still discussing people’s specific needs.**



## COMMON FRAME

All you have to do is decide. Decide to stay at a healthy weight. Decide to eat well. Decide to be active. If you're at-risk, paying attention to living a healthy lifestyle or getting early treatment can, for some diabetics, actually return blood sugar levels to a normal range. Make the right decisions—and take control of your diabetes.

## STIGMA-REDUCING REFRAME

We all need things to help us stay healthy. We need high quality healthcare. We need safe places to exercise. We need affordable healthy food. We need those same things if we have diabetes, along with targeted treatments and care. **Making sure we all have what we need to stay healthy means people with diabetes have what they need—not just to control their weight but to live well.**

Read on for more examples and context on research-informed reframes, and consider where reframing may be helpful in your diabetes work. Giving people new ways of understanding this health issue and different ways of perceiving people with diabetes can change attitudes and help end stigma. And this is change we can accomplish together through our communications by amplifying consistent, well-framed messages.

### 1. Show—don't tell—what stigma is and explain implicit bias.

Stigma against people with diabetes is pervasive. Our research has shown simply saying that certain groups are stigmatized does little to help combat stigma and can even backfire.

When we are exposed to negative images and representations of different “types” or groups of people, we develop patterned, unconscious ways of thinking called implicit bias. These are thoughts and feelings about social categories that fall outside of our conscious awareness. Explaining what implicit bias is and how it is harmful helps people understand that diabetes and the stigma around it is a challenge we need to address together. Instead of telling people to change their attitudes, we pinpoint the underlying problem and prime them to think about solutions that work.

## INSTEAD OF THIS...

Few other diseases carry the social stigma of diabetes. Fat, lazy, slothful, couch potato, over-eater and glutton—these are a few of the negative stereotypes associated with people with diabetes. This stigma takes its toll. Stigma-induced shame prevents them from talking about their diagnosis and even avoiding seeking treatment. We need to reduce stigma today.

## TRY THIS:

We are constantly exposed to images of people with diabetes as people who won't control their bad habits. This affects our attitudes and behaviours, often in ways that we don't realize. As a result, people with diabetes may feel a sense of fear and shame that prevents them from talking about their diagnosis and even avoid seeking treatment. **If we want to reduce stigma, we need to change the narrative and our thinking about diabetes.**

### 2. Start with what you want people to know about diabetes instead of repeating damaging myths.

A common method of communication in health and beyond is to present audiences with a “myth” and then refute the false information with the real facts. But this myth-fact structure actually backfires. We tend to remember the thing we hear or read first, so we are more likely to remember the myth as true. Not only that, but this backfire effect can get worse over time as people's memories begin to fade, and even lead people to attribute the myth to the people trying to refute it. Always try to avoid repeating false information about diabetes, and if you have to refute false information, start with the facts.





### INSTEAD OF THIS...

**MYTH:** People with Type 2 Diabetes Caused Their Disease

People with Type 2 diabetes wished it upon themselves and willingly gave themselves the disease.

**FACT:** While lifestyle factors such as physical activity and weight may increase the risk of developing Type 2 diabetes, age, race and genetics also play a large role. Mothers who have gestational diabetes caused by pregnancy hormones also have a bigger chance of developing the disease.

### TRY THIS:

**Many different factors can increase people's risk of developing Type 2 diabetes.** Age, race, and genetics all play a large role, and mothers who have gestational diabetes caused by pregnancy hormones also have a bigger chance of developing the disease. Diet, physical activity, and weight are just part of the story.

## 3. Explain equity and always link it to clear solutions.

Racial inequities affect every aspect of our lives, including our health outcomes. Diabetes is no exception. Black, Latinx, and Indigenous Peoples are at higher risk of developing diabetes and less likely to receive the healthcare they need. But most people don't understand what inequity means, or how inequities work. Instead they misunderstand the term or conflate equity with equality and have trouble linking the solutions you are advocating for to the underlying problem. Communications that lack a clear explanation of equity miss a critical opportunity to build understanding and support for equitable solutions.

### INSTEAD OF THIS...

Inequity systemically harms people of color. The COVID-19 pandemic and glaring examples of racial injustice are casting a bright light on an old problem in America. Health inequity is obvious and widespread. It contributes to worse outcomes and higher risk for diabetes and many other diseases. And it undermines the wellbeing of our most underserved communities.

### TRY THIS:

**The COVID-19 pandemic and glaring examples of racial injustice are casting a bright light on an old problem in America.** Health inequities are differences in health outcomes rooted in prejudice and discrimination. In the U.S., these inequities harm people of color in a variety of ways: through limited access to quality healthcare, racist interactions, and higher rates of exposure to air pollutants and other environmental toxins like lead, among others. It contributes to worse outcomes and higher risk for diabetes and many other diseases. And it undermines the wellbeing of our most underserved communities.

## 4. Avoid crisis: instead talk about how we can tackle diabetes, together.

COVID-19 poses an acute threat to the health and wellbeing of people with diabetes. Raising support for development of new treatments and effective supports is therefore more important than ever. Talking about diabetes as a public health crisis makes sense—but may also be deeply problematic. “Crisis messaging” is often ineffective and counterproductive for several reasons. First, talking about social problems as crises, particularly in our current environment, leads to a sense of fatalism about addressing the problem. Crisis messaging often present problems as so big and overwhelming, they are just too difficult to solve. Second, when everything appears to be a crisis—and this is particularly the case now—crisis fatigue begins to set in. Rather than engage, people tune out. And third, crisis messaging may raise support in the short term, but the salience of the issue may quickly fade. If we want sustained attention and support for treating this diabetes, we need to keep people engaged over the long term.

The cure for fatalism and short-term support is conveying urgency while offering people concrete solutions that they see themselves, their communities, and our country as a whole as having a stake in. When people



see clear and concrete solutions that have collective benefits they can recognize, it raises their support and increases their sense that addressing a problem is possible.

INSTEAD OF THIS...	TRY THIS:
Diabetes may be the most serious public health crisis of our time. The economic burden of diabetes is massive, and the COVID-19 pandemic has only exacerbated these costs as people with diabetes are hit particularly hard by the disease. We need to solve this crisis today.	Diabetes is a serious but solvable public health problem. Finding ways to treat diabetes and support people with diabetes is more important than ever as we face the COVID-19 pandemic. Find solutions and resources by visiting our website. We can tackle this problem—together.

## 5. Talk about what we all need to be healthy, while still discussing people’s specific needs.

### Circling back to the example we started with at the beginning of this brief:

People with diabetes face significant challenges when it comes to health and wellbeing. Their challenges stem from not just to the diagnosis itself, but also because they are blamed for their own condition. In our society, people are thought to be solely responsible for our own health. If you are unhealthy, it must be because you failed. Failed to eat well, failed to exercise, failed to control the impulses that made you unhealthy. People living with diabetes are “othered,” blamed, and shamed as people with diabetes, even within the healthcare system. This in turn discourages people with diabetes from seeking health assistance that could help them treat and control the condition.

When we use messages that begin by emphasizing what we all need to have good health—like high quality preventative healthcare, access to safe and exercise-friendly outdoor spaces, and healthy affordable food choice—we divert thinking away from individual blame and toward our common experiences. This creates space for more productive conversations about how to treat diabetes by fixing systems, not just individuals.

INSTEAD OF THIS...	TRY THIS:
All you have to do is decide. Decide to stay at a healthy weight. Decide to eat well. Decide to be active. If you’re at-risk, paying attention to living a healthy lifestyle or getting early treatment can, for some diabetics, actually return blood sugar levels to a normal range. Make the right decisions - and take control of your diabetes.	We all need things to help us stay healthy. We need high quality healthcare. We need safe places to exercise. We need affordable healthy food. We need those same things if we have diabetes, along with targeted treatments and care. <b>Making sure we all have what we need to stay healthy means people with diabetes have what they need—not just to control their weight but to live well.</b>

## About FrameWorks

The FrameWorks Institute is a non-profit think tank that advances the mission-driven sector’s capacity to frame the public discourse about social and scientific issues. The organization’s signature approach, Strategic Frame Analysis®, offers empirical guidance on what to say, how to say it, and what to leave unsaid. FrameWorks designs, conducts, and publishes multi-method, multi-disciplinary framing research to prepare experts and advocates to expand their constituencies, to build public will, and to further public understanding. To make sure this research drives social change, FrameWorks supports partners in reframing, through strategic consultation, campaign design, FrameChecks®, toolkits, online courses, and in-depth learning engagements known as FrameLabs. In 2015, FrameWorks was named one of nine organizations worldwide to receive the MacArthur Award for Creative and Effective Institutions. Learn more at [www.frameworksinstitute.org](http://www.frameworksinstitute.org)

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, electronic, mechanical, photocopying, recording, or otherwise, without the prior permission of the FrameWorks Institute. Please follow standard APA rules for citation, with the FrameWorks Institute as publisher. FrameWorks Institute. (2020). Education is at a Crossroads. Washington, DC: FrameWorks Institute. © FrameWorks Institute 2020



## Module 2 | Jim Carroll Closing Remarks

### JIM CARROLL



At the end of d20 Module 2: Shape, Jim Carroll, COO/CFO of The diaTribe Foundation gave a powerful and emotional closing speech that helped ignite the

d20 participants to go out into the world and begin the work to dismantle diabetes stigma:

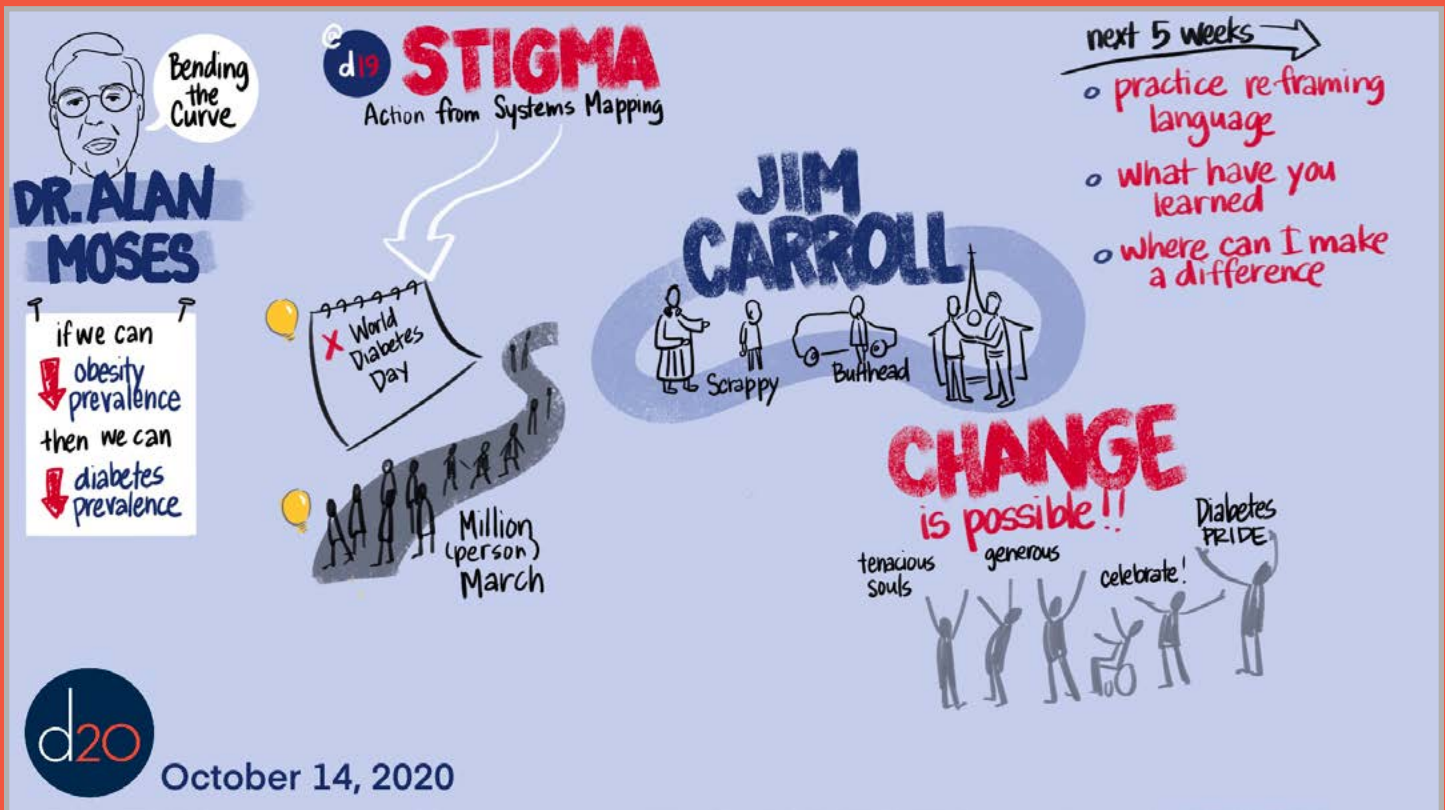
Fifty years ago, before some of you were even born, before some of your parents were even born—yikes!—a scrappy young man got into a fight with a raging [expletive] (let's call him Bevis) at the local Catholic church.

The parish priest took it upon himself to break up the fight. He sat Scrappy and Bevis down and

discovered the cause of the fight was because Bevis repeatedly called Scrappy a “big [expletive]”. This led, unfortunately, to an extremely long lecture—I think it was a form of penance.

At the conclusion of the long lecture, the holy man took Scrappy aside and let him know that if it were true that he was a homosexual, that God didn't love him and that he would die alone and burn in hell and never be with his family in heaven.

A few years later, our hero, Scrappy, was part of a carpool that took turns driving to school with his neighbor and friend, let's call him Butthead. One warm winter day (this was in Florida), Scrappy was told that he wasn't welcome in the car anymore because being seen with a [expletive] was cramping Butthead's dating prospects. So, even though they had pretty much spoken to each other every day



**DR. ALAN MOSES**  
Bending the Curve

if we can ↓ obesity prevalence then we can ↓ diabetes prevalence

**d19 STIGMA**  
Action from Systems Mapping

**JIM CARROLL**

next 5 weeks →

- practice re-framing language
- what have you learned
- where can I make a difference

**CHANGE is possible!!**  
Diabetes PRIDE  
celebrate!  
generous  
tenacious souls

**d20**  
October 14, 2020

for the previous five years, they lived on the same street, they had the same friends, they never spoke again. Ever.

The wonderful and amazing adventures of Scrappy eventually led, decades later, to his getting married to a man in front of 100 friends and family members and politicians and even the media. In front of a Catholic church! Who would have thought that over a 50-year period that the world could be so different?

### Well, it can.

It wasn't overnight, despite how fast it feels now. And it wasn't millions of people all pulling in the same direction. It was the result of a dogged group of tenacious souls who kept at it until they got it right.

I remember in 2005 when the Mayor of San Francisco began marrying same sex couples at City Hall. At that time the nonprofit group, Equality California, (the organization that was spearheading the marriage equality effort in California) had something like ten staff and maybe 4,000 donors in total. That same year the attendance at the Gay Pride celebration in SF was estimated to be 850,000. The point being is that the work of a few (and the generosity of a few more) resulted in a seismic shift in the way that the society viewed people like Scrappy and, even more to the point, that very change was celebrated by nearly a million people.

With your help and commitment, I am convinced we can create the same kind of change for people with diabetes and the people who love them. Our own version of Diabetes Pride.

One day my doctor told me that for the last three years in a row my blood glucose had gotten increasingly higher to the point that I was now prediabetic, and I needed to start taking a drug called Metformin. I'm not sure I heard anything else he said that day, but I did look up diabetes when I got home on the net. Because apparently Google knows and sees all, my search directed me to a diabetes nonprofit eight blocks from my house.

That serendipitous search resulted in my meeting an amazing force of nature, Kelly Close, who ended up offering me a job at The diaTribe Foundation.

Because I was making such a big job change, I called my stock broker to make changes in my investments. He asked me why I was moving money, and I told him about my new job that was related to my prediabetes diagnosis. His response was: "Wow, I don't think of you as fat and lazy." For those of you who haven't met me in person, I'm about 5'10" and weigh about 145 pounds.

My response was: "What the [expletive] did you just say to me?" For those of you haven't met me yet, I have no filter between my brain and my mouth. The stock broker, who is pretty much a good guy, said, "Oh no, I didn't mean anything by it, my mother is a diabetic, and she's fat and lazy." That was my first experience with diabetic stigma. That was the moment that changed the way I now think about how stigma affects people with diabetes.

So, for you "scrappy" few who are here today and have committed to tackling this problem together, thank you! I have been so lucky to have been a tiny, tiny part of the stigma busting efforts for LGBTQ people and for marriage equality, for people with HIV/AIDS and breast cancer. The efforts by the "scrappy" few people I have been blessed to work with have been life changing for countless millions of people. Just think of what all of us at d20 right here today can do that will change the lives for even more millions of human beings.

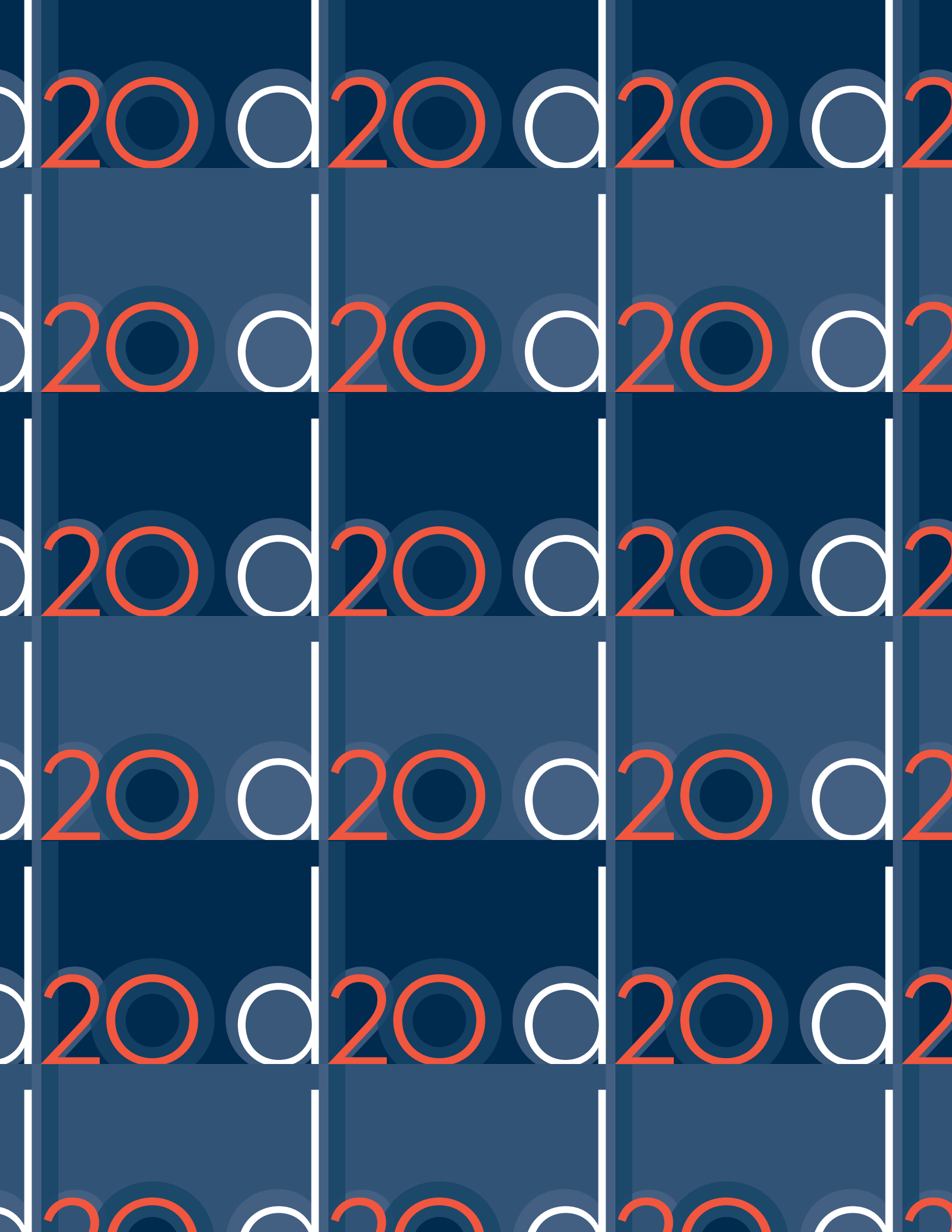
For the diaTribe Board of Directors and the dSeries Steering Committee, for the Lightning talk speakers and David Lee Strasberg and Alan Moses and Marisa Gerstein Pineau and for the amazing Brooking Gatewood and of course for the diaTribe Staff, especially Karena and Matthew, and for the support of Tom and our fearless leader Kelly, thank you. This Innovation Lab would have been impossible without you. I especially want to thank Manny Hernandez and Karen Talmadge and Virginia Valentine for being the proverbial sparks at d19 that set this stigma blaze afire.



For the support of Abbott and Sanofi and AstraZeneca and Novo Nordisk and Merck and Pfizer and Boehringer Ingelheim, thank you. It is so hard to raise money so that people can come together and learn to do things better; therefore, your continued commitment toward our efforts at diaTribe to help patients everywhere live happier and healthier lives is amazing and much appreciated.

For now, thank you all for your thoughtful and generous participation in d20. Thank you for indulging me and Scrappy.







EXECUTIVE INNOVATION LAB  
IN DIABETES AND PREDIABETES

POWERED BY

THE **diaTribe**  
FOUNDATION

WRITTEN BY

KARENA YAN, MATTHEW GARZA,  
TOM CIRILLO, JIM CARROLL, AND KELLY CLOSE

[www.diaTribe.org/foundation](http://www.diaTribe.org/foundation)  
[@diaTribeNews](https://twitter.com/diaTribeNews)