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WHY IS DIABETES A PROBLEM?

90–95% of diabetes cases are type 2 diabetes.

1 in 7 US adults has diabetes.

1 in 3 US adults has prediabetes.

8 in 10 US seniors have diabetes or prediabetes.

Over 30 million people in the US have diabetes.

That’s over 3 million more than the entire population of Texas.

27 million

Over 7 million of them are undiagnosed. That’s nearly the population of NYC.

Diabetes complications in the US:

168,000

Annual hospital discharges due to diabetic ketoacidosis each year.

245,000

Annual ER visits due to hypoglycemia each year.

While much of the national diabetes data does not distinguish between type 1 and type 2 diabetes, for the purposes of this document focuses primarily on type 2 diabetes and obesity.
Despite advances in treatment, one in three patients has an A1C that is significantly above target. This applies to almost half of people with diabetes on Medicaid.\footnote{12}

Diabetes imposes huge economic burdens on the United States. We spend $327 billion a year on direct ($237 billion) and indirect ($90 billion) costs. More than half of the direct costs are due to inpatient hospitalizations and prescription medications for diabetes complications. Per capita costs have increased since 2012, and overall costs are projected to grow as more people continue to get diabetes, and as type 2 patients live longer than ever before, more people are at higher risk of costly long-term complications.\footnote{14}

Globally, the economic burden of diabetes is estimated at $1.3 trillion per year and is expected to increase to at least $2 trillion per year by 2030.\footnote{17} One in 11 adults worldwide has diabetes, with projections suggesting that one in nine will have it by 2045.

“I no longer have the funds to buy the foods I need to eat to keep my diabetes under control. I eat far too many carbs because they are cheaper & go farther. I would rather be eating more meat and fruits & vegetables.”

Each percentage point reduction in A1C correlates with a 35% reduction in microvascular complications (blindness, kidney disease, nerve damage) and a 14% reduction in cardiovascular disease.\footnote{13}
What Factors Contribute to Type 2 Diabetes Risk?

Type 2 diabetes is influenced by a host of complex factors. Genetics and lifestyle choices (namely, diet and exercise) are certainly major contributors. However, it is also impacted by a multi-factorial set of cultural, societal, and environmental factors that are less understood and often harder to address. According to Novo Nordisk’s Cities Changing Diabetes Program, the four greatest social contributors to type 2 diabetes risk include time constraints, financial constraints, geographic barriers, and resource constraints (e.g., lack of access to healthcare, medications, nutritious foods and exercise, etc.). These factors are absolutely critical to addressing and contextualizing diabetes—and why pharmaceutical therapies alone are not enough to fight this growing epidemic.

What Causes Diabetes?

At its core, diabetes is a metabolic dysfunction in which the body cannot properly process glucose. In type 1 diabetes, the body’s own immune system attacks and kills the beta cells in the pancreas that produce insulin. Behind type 2 diabetes is a disease where the body’s cells have trouble responding to insulin—this is called insulin resistance. Over time, though, the beta cells in the pancreas will fatigue and will no longer be able to produce enough insulin—this is called “beta burnout.” While type 1 diabetes has no known cause, the majority of type 2 diabetes cases are ultimately due to poor diet and a lack of exercise. This is why type 2 diabetes risk strongly correlates with obesity levels. Different people are at various levels of predisposed genetic risk for developing type 2 diabetes, which is partially why some overweight or obese individuals never develop type 2 diabetes, while others do.
“My health complications (nerve damage, pain, etc.) continue to worsen due to compounding effects of prior years of mismanagement.”

**Obesity and Type 2 Diabetes Trends Over Time**

Trends in Overweight, Obesity, and Severe Obesity Among Adults Aged 20–74 • United States 1960–2014

Over the past 26 years, diabetes has gone from being the twelfth to the eighth leading cause of premature death in the US, and from being the eighth to the third leading cause of disability and injury.

**Percentage of US Population with Diagnosed Diabetes 1958–2015**
Adult Obesity Rate by State, 1995

Percent of obese adults (Body Mass Index of 30+)

- 0–9.9%
- 10–14.9%
- 15–19.9%
- 20–24.9%
- 25–29.9%
- 30–34.9%
- 35%+
State-by-state discrepancies in life expectancy reveal the imbalanced toll of chronic disease. Life expectancy in Hawaii is 81 years and in Mississippi 75 years; diabetes contributes to over twice the number of years of life lost in West Virginia as it does in Massachusetts.³⁴
Food insecurity is the lack of consistent access to enough food for a healthy, active life. 1 in 8 Americans were food insecure in 2017.\(^4\)
What Causes the Diabetogenic Environment?

On a broad scale, economic growth in the US coupled with our increasingly Westernized, modern lifestyle have led to a significant increase in type 2 diabetes over recent decades. While the problem is complex and the list below is by no means exhaustive, certain key areas of influence include:

**Food Culture** On a national scale, calorie-dense foods with low-nutritional value are often the cheapest, most readily available option. Moreover, foods of all kind come in larger portion sizes than ever before. While intake of specific foods, such as sugar, has increased over time, so has our intake of food overall.

**Urban Planning and Physical Activity** The built environment can encourage or deter physical activity. For instance, a lack of green space and urban violence can pose barriers to exercise, especially in low-income neighborhoods where residents may not be able to afford gym memberships.

**Healthcare Coverage** Healthcare coverage is associated with type 2 diabetes diagnosis rates and glycemic control. Even with the Affordable Care Act, 14 states have not expanded Medicaid, leaving some of the most vulnerable individuals uninsured.

**Food Deserts** Food deserts are areas without ready access to fresh, healthy, and affordable food. These environments often foster poor dietary habits, especially in children, that can contribute to the onset of type 2 diabetes.

**Geographical Barriers** Distance from healthcare can influence how often patients seek healthcare. This is particularly a problem in rural areas, as the US is facing a shortage of primary care providers and endocrinologists. In 2011, there was an estimated shortage of 1,500 endocrinologists based on patient demand. Moreover, an estimated shortage of up to 45,000 primary care providers (who provide 85% of diabetes care) is expected by 2020. As a result, patients often have to travel long distances while facing transportation barriers in order to receive care.

**Time Constraints** Type 2 diabetes prevention and management is time consuming, often requiring more time than people have in their daily lives. One study found that if people with type 2 diabetes followed every recommendation by the American Diabetes Association, it would add two hours to their daily routines. When conflicted between jobs, caring for children and family, and other life priorities—diabetes prevention and management can fall to the side.

**Lack of Peer Support** Studies have shown that social isolation can be as lethal as cigarette smoking. For people with diabetes—a disease that comes with a great deal of social stigma—peer support can often be challenging to attain.

**Cultural Attitudes** How people perceive diabetes can play a significant role in our ability to prevent and treat it. From how people prioritize diabetes in their own lives (is diabetes management a top priority?), to societal perceptions of “normal” body weight, to public perception of the severity of diabetes compared to other diseases, these cultural attitudes influence behavior and ultimately health outcomes.

**Limited Health Literacy** In the US, only 12% of US adults have proficient health literacy, and over one third have issues with common medical tasks such as following prescription directions. Moreover, health literacy disproportionately affects different groups of people: 28% of white adults have “basic or below basic” health literacy, compared to 65% of Hispanic adults. Of course, limited health literacy influences many other factors that contribute to type 2 diabetes risk.

For more background on diabetes prevention, healthcare systems, behavior change, stigma and The Anthology Bright Spots, visit the online appendix at diatribe.org/foundation/appendix.
Food as Medicine: Background and Primer

Overweight and obesity are significantly associated with type 2 diabetes, along with a host of other conditions. By encouraging loss of excess weight, we can tackle one of the most addressable contributors to diabetes and poor health more broadly.

Poor diet quality plays a major role in overweight and obesity, in addition to being linked to cardiovascular disease and certain cancers. Research suggests it’s the number one risk factor for death in America, above smoking and high blood pressure. By thinking of food as medicine, we can begin to tackle obesity and diabetes alongside other diet-related conditions.

What Are Some of the Barriers to Healthy Eating?

“Like a yoyo, I lose weight, I gain weight. I eat healthy, and then I go and mess up… The problem is consistency.”

Energy-dense foods like refined grains, added sugars, and fats tend to be cheaper than nutrient-dense foods. The cheapest shopping plan meeting USDA nutrition guidelines costs $649.90 per month for a family of four, which equates to over 30% of the post-tax income of a family just above the poverty line and ineligible for the Supplemental Nutrition Assistance Program (SNAP). Though individuals on SNAP receive financial support to purchase food, they are still three times more likely to die from diabetes complications than non-participants.

The presence of food deserts means that people in certain geographic areas do not have physical access to nutritious foods. Food swamps that overwhelm healthy choices with unhealthy ones tend to be associated with even higher obesity rates.

Healthcare providers are not typically given the nutrition education tools to help their patients. Over a third of surveyed medical schools provided less than 12 hours of nutrition education in 2014; the recommended minimum is 25 hours. Fewer than half of medical schools report teaching any nutrition in a clinical setting.

Further, there are numerous unanswered and evolving questions in our understanding of what constitutes “healthy” food. Nutrition research is often misrepresented or oversimplified in the media, leading to distrust of the establishment.

What Efforts Are Underway to Improve Nutrition?

A number of community programs are expanding access to fruits and vegetables and offering nutrition education. Brighter Bites provides donated fruits, vegetables, and recipes to families at local schools where 80% or more of the students receive free or reduced lunch. Cooking Matters offers free cooking and nutrition classes to families in underserved communities. Food pharmacies at Geisinger and Zuckerberg San Francisco General enable healthcare providers to write prescriptions for fruits and vegetables for low-income patients.

There are national efforts to reduce consumption of sugar-sweetened beverages, which contribute the largest amount of sugar to the American diet and account for 6.5% of daily calories. Eight localities across the US have instituted soda taxes, and the UCSF medical system has ended the sale of sugary beverages on its campuses, in addition to adding clear nutrition labelling to foods prepared on-site and a Smart Choice designation on healthy foods.

Digital health programs like Omada, Virta, and Noom provide coaching and personalized support for making dietary changes, often leading to greater weight loss than traditional programs.

For further exploration, here are some resources we’ve found helpful:

- Food Prescription Programs: Food as medicine: Doctors are prescribing broccoli and bananas alongside beta blockers
- Nutrition Science and Research: Global Dietary Database
- Food Policy: Food-PRICE, Healthy Food America, and Duke World Food Policy Center
How Might Food as Medicine Interventions Save Lives and Dollars?

The costs of diet-related disease are immense, but fortunately, strategic policies and novel research have the potential to dramatically improve health outcomes and garner tremendous savings.

Worksite Wellness—investing in health is a smart business decision

Reducing employee health risks such as high glucose and blood pressure by just 1 percent could save employers $83 to $103 per person annually.

Every dollar that employees spend on wellness programs generates about $3.27 in lower medical costs and $2.73 in less absenteeism.

Strengthening the 'N' in SNAP

Making nutrition a core SNAP objective would improve the lives of millions of low income families, while lowering health care costs and reducing disparities.

30% fruit and vegetable (F&V) incentive to all SNAP participants is estimated to save...

$6.77 Billion in healthcare costs over a lifetime!

$39.16 Billion: amount of healthcare savings over a lifetime that would be produced by a combined incentive/disincentive program within SNAP

Nutrition research is advancing quickly, but there’s still so much left to learn. Areas of research that warrant funding include:

The cardiometabolic effects of phenolics, dairy fat, probiotics, fermentation, coffee, tea, cocoa, eggs, specific vegetable and tropical oils, vitamin D, individual fatty acids, diet-microbiome interactions.

Healthcare—the number one cause of poor health should be the number one priority of the healthcare system

Providing a 20 percent incentive for fruit and vegetable purchases to Medicaid and Medicare beneficiaries is estimated to prevent 1.95 million cardiovascular disease events and to save $40.9 billion in healthcare costs.

Providing free fresh food as a treatment for diabetes yields a more than 40% decrease in the risk of death or serious complications.

A broader 20 percent incentive including whole grains, nuts, fish, and plant-based oils would prevent 3.31 million cardiovascular disease events save $102.4 billion in healthcare costs.

This infographic is adapted from The Friedman School at Tufts University. Visit https://nutrition.tufts.edu/sites/default/files/documents/FIM%20Infographic-Web.pdf to see source material.
How Much Public Research Funding Goes To Diabetes?

In 2017, cancer accounted for $6.0 billion of total NIH funding, HIV/AIDS accounted for $3.0 billion of total NIH funding, and diabetes accounted for $1.1 billion of NIH funding (chart 1). There were roughly 15.3 million people living with cancer and 1.1 million people in the US with HIV/AIDS, compared to over 30 million living with diabetes (chart 2). By that comparison, the NIH spends about $2,727 per person with HIV/AIDS, $392 each year per person with cancer, and only $37 per person with diabetes (chart 3). These disease areas have benefited tremendously from this amount of funding—and rightfully so—serving as a point of reflection on how funding dollars can impact outcomes.

Moreover, funding for innovation in health services and delivery, which examines access, care quality, and population health, amounts to just 0.3% of total healthcare expenditures and roughly one-twentieth the sum that goes into science research. Federal spending on nutrition research is $1.5 billion per year. For comparison, the Farm Bill’s budget is almost twice the combined budgets of the NIH, CDC, and FDA. These areas could move the needle on many aspects of diabetes management, yet they continue to be underfunded.
“My numbers are high and climbing. Can’t seem to get them to go down and also cannot get any weight to come off. Frustrated!”

The Challenge of Type 2 Diabetes

In Summary

Type 2 diabetes is not an easy disease to live with. While public perceptions of diabetes tend to paint it as simply a “touch of sugar” that is easily managed, that is not the case. Not only can it lead to devastating complications, it causes a significant amount of emotional and financial stress for patients and their families.

What Do People With Type 2 Diabetes Think About?

STIGMA
FINANCES
Burnout
Complications
MEDICATIONS
Depression
Hypoglycemia
Physical Activity

Patient Perspectives

Diabetes is a complex condition that affects almost every part of day-to-day life. Everyone with diabetes has a different experience, but for most it represents a significant source of physical, emotional, and mental distress.

• Every bad glucose reading, high A1c, unhealthy meal choice, and day without physical activity represents a new failure, leading to feelings of helplessness, fear, and frustration.

• People with diabetes are twice as likely as the average person to have depression, and are also at risk for experiencing burnout (exhaustion from the endless attention diabetes care requires).

• The majority of people with diabetes feel stigma surrounding their disease. This can make people feel that they are a burden on friends, family, or society at large, and may ultimately hide their disease from others.

• For many, diabetes can feel like a full-time job, and there simply aren’t enough hours in the day to give it the attention it requires.

• Living with complications drastically impairs one’s daily life, impacting all aspects of social, professional, and personal life.
“The endocrinologist told me to ‘starve’ myself because I am obese. I wanted to cry, but I did not.”

Social Stigma: What Messages Do People with Type 2 Diabetes Hear from Society?

Just eat less sugar. You have no self-control. You don’t care about your health. My grandpa died from diabetes. You’re going to go blind. Diabetes is preventable. It’s your fault that you are sick. Diabetes is easy to manage.

Personal Expense of Diabetes
Diabetes is also expensive for individuals. People with diagnosed diabetes incur annual average medical costs of about $16,500, more than two times higher than those without diabetes. The majority of these costs is attributed to the treatment of hypoglycemia and diabetes complications. Each American adult spends more than $900 per year to pay for diabetes healthcare costs, whether that adult has diabetes or not.
d19: Where Do We Come In?

The dSeries aims to become the hub for high impact aligned collaborative action to address diabetes in America through:

• **Connectivity** Cultivate a unique approach to learning, leadership development, and relationship building among diabetes and other health leaders in the US.

• **Strategy** Build a strategic, robust, ecosystem-level plan for interest-aligned action to address type 2 diabetes in the US in the next decade.

• **Action** Innovate and amplify high-impact solutions that reduce the societal burden of type 2 diabetes.

Since 2016, the dSeries has offered a unique forum for executive leadership and learning in the field of diabetes prevention and care. These highly selective gatherings bring together top minds in science, medicine, policy, business, education, technology, community service, and philanthropy to explore how to activate meaningful change in the US diabetes landscape. For the last four years, dSeries participants have worked together to cultivate a deeper understanding of bright spots in diabetes prevention and care while advancing promising initiatives. Each year, dSeries participants grapple with some of the most challenging social change issues we face in diabetes today—and have acquired innovation tools to identify new ways to address the problem at scale.

In 2019, we will drive this work even further through the launch of a coordinated “dNetwork” for change. In the wake of d18’s call for greater aligned action, the dSeries is becoming more than an annual meeting. The diaTribe team has been working with experts and critical players in the field to develop a type 2 diabetes ecosystem map to prioritize key levers for changing the status quo, and we have launched a cross-sector steering committee to drive the direction of the movement-level strategic action through the dNetwork. The results of these preparations will be shared at d19, and will help us raise the bar for what we can accomplish together in the years to come.

At d19, we will:

• **Align** on dNetwork strategic action priorities.

• **Learn** about promising new trends with a focus on Food as Medicine.

• **Catalyze** strategic projects in priority impact areas.

• **Strengthen connections** across the diabetes ecosystem and the growing dNetwork.
dNetwork Tools and Terms

**The dSeries**
The annual Executive Innovation Lab event hosted by the diaTribe Foundation.

**The dNetwork**
The proposed name for the growing community of leaders that has been cultivated through the dSeries events. Through the dNetwork, dSeries participants engage in ongoing, high-impact aligned action to address type 2 diabetes in America.

**The dSeries Steering Committee**
The inaugural Steering Committee for the dSeries. The primary charge of this committee is to help prepare and plan for the transition from the dSeries to a dNetwork, to support the ecosystem map development process, and to support the establishment of a roadmap for the dNetwork to become the hub for high-impact aligned action to address type 2 diabetes in America.

**Diabetes Ecosystem**
This is the term we will use for the field of actors, organizations, interconnected systems and flows of information, resources, behaviors and mindsets that together make up the context for understanding diabetes in America. History, current state, emerging trends affecting prevention, prevalence, treatment, and the role of the disease in media, culture, and policy are all relevant for understanding the diabetes ecosystem. We use the term ecosystem because it is an excellent metaphor that makes room for nested and overlapping systems, and because in healthcare the term “system” has many meanings and uses already.

**Aligned Action**
This is the term we tend to use to refer to projects and activities that are coordinated across groups with shared interests in order to enhance impact for systems change. Aligned action requires slowing down to understand others’ goals and incentives, to build trust and find win-win areas of shared interest, to co-create strategies and action plans, to coordinate and share information and amplify each other’s efforts, and to learn and reflect together on progress. There are many synonyms for this approach, including collective action, collective impact, collaborative action, and network activities.

**Systems Change**
Actions that address root causes of systemic dynamics/problems over time and in turn shift the set-points and behavior patterns within a system. Systems change does not have to be intentional; climate change is an example of a change happening on our global atmospheric climate regulatory system based on the unintended consequence of fossil fuel emissions. Social movements like women’s suffrage and gay rights represent intentional and successful systems change efforts, as do effective treatment interventions for diabetes.

**Scenario Planning**
Scenario Planning is a tool that helps us design and manage for an uncertain future not by asking ‘What will happen’ or ‘What should happen’?, but rather ‘What might happen?’ This question acknowledges that the future is uncertain and often outside our control. By asking this question in a structured and creative way, scenario thinking can help groups identify new opportunities and challenges and begin to find a path toward a better future. Scenario planning lets us tell stories about the unknown future based on known uncertainties, and these emerging stories help us see different ways the world might play out in the future. For more on what we learned from applying this tool to the diabetes landscape at d18, see our d18 summary report, available at diatribe.org/foundation/dseries.

**Systems Thinking**
Systems thinking helps us address root causes of problems rather than providing band-aid solutions. It also helps us avoid unintended consequences that actually make the problem worse due to lack of understanding of core systems dynamics (like feedback loops and time delays). Perhaps most useful for understanding systems thinking in brief is comparing it to more conventional thinking mindsets:
**dNetwork Tools and Terms (cont.)**

<table>
<thead>
<tr>
<th>Strategic Question</th>
<th>Conventional Thinking Response</th>
<th>Systems Thinking Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>How are problems and causes connected?</td>
<td>Obvious, easy to trace</td>
<td>Indirect, <strong>not obvious</strong> (remember: systems problems are ‘wicked’)</td>
</tr>
<tr>
<td>What creates problems?</td>
<td>Others create them and so must be the source of the change</td>
<td><strong>We unwittingly co-create problems</strong> and so can influence solving them through our own behavior change</td>
</tr>
<tr>
<td>Are Quick Fixes Useful?</td>
<td>Yes. Short-term success assures long-term success</td>
<td>Often not. They can have (<strong>unintended consequences</strong>) and can have neutral to negative long-term impacts</td>
</tr>
<tr>
<td>How can we optimize the whole?</td>
<td>Optimize the parts (separately)</td>
<td>Improve <strong>relationships</strong> among parts</td>
</tr>
<tr>
<td>How should we approach initiatives/projects?</td>
<td>Take on many independent initiatives simultaneously</td>
<td>Focus on advancing <strong>a few key coordinated change initiatives</strong> sustained over time</td>
</tr>
</tbody>
</table>

**Levers for Change/Leverage Points**
These are places within a complex system where a small shift in one thing can produce big changes in everything. A useful reference here is Donella Meadow’s famous short list of classic types of leverage points, in increasing order of effectiveness:

1. **The mindset or paradigm out of which the system—its goals, power structure, rules, its culture—arises.**

Levers for change are best determined by seeking input from many stakeholders across different parts of the system to determine areas where incentives and interests align with potential for impact. The work we have done at past events in combination with the additional interviews and research for the systems mapping process we are engaged with at d19 serve to help identify top levers for change. A lever has the potential for impact if it deeply impacts the system, is feasible, has a positive cost/benefit ratio, is sustainable over time, and is systemically viable.

2. The goals of the system.
3. The distribution of power over the rules of the system.
4. The rules of the system (incentives, punishments, constraints).
5. Information flows.
6. Material flows and nodes of material intersection.
7. Driving positive feedback loops.
8. Regulating negative feedback loops.
9. Constants, parameters, numbers (subsidies, taxes, standards).
**Systems Leadership**

Systems leadership is about how we behave in the face of complexity. It is a commitment to resist the temptation to oversimplify reality and instead increase the complexity of our own perspective to meet the challenges we face. It is about how we act both as individuals and together as leaders in service of long-term visions and goals for systems change. Systems leadership starts with a willingness to slow down to understand the whole of—in our case—the diabetes ecosystem in order to better achieve a desired purpose of reducing the incidence of type 2 diabetes in America. Systems leaders are also cross-sector leaders as all systems problems require reaching across the usual silos we operate in to enact powerful change. While systems leadership takes many forms, they are often called upon to serve as diplomats, connectors, visionaries, influencers, innovators, and strategists. Perhaps most importantly, systems leaders recognize that systems are perfectly designed to achieve the results they are achieving right now, and so they lead with curiosity and courage to ask and answer difficult questions, such as:

- Why have we been unable to solve this problem despite our best efforts?
- How might we be partly responsible, albeit unwittingly, for the problem?
- What are the payoffs to us of the current system?
- What might we have to give up for the whole to succeed?
- What might be unintended consequences of our previous and proposed solutions?
- How might we cultivate shared understanding, shared interests, shared ownership, shared action?
- Whose voices are we missing to truly sense into the whole?
- How and where can we model making explicit choices in service of our highest aspirations, in the face of many competing interests?

- How might we foster these systems leadership capacities in others?

**Design Thinking/Human-Centered Design**

Design thinking brings together what is desirable from a human point of view with what is technologically feasible and economically viable. It also allows people who aren’t trained as designers to use creative activities to foster collaboration and solve problems in human-centered ways. As IDEO reminds us, there’s really no single definition for design thinking—it’s at once an idea, a strategy, a method, and a way of seeing the world. Generally, the approach involves framing a ‘How might we’ design question, gathering inspiration through a human-centered discover process of what people really need, brainstorming, prototyping and refining, and then crafting a story that inspires further action. Some highlights and principles that undergird design thinking include:

- Adopt a “beginner’s mind,” with the intent to remain open and curious, to assume nothing, and to see ambiguity as an opportunity.
- Dream up wild ideas, take time to tinker and test, and be willing to fail early and often.
- Embrace empathy, optimism, iteration, creativity, and ambiguity.
- Listen to and stay focused on the people you’re designing for to arrive at optimal solutions that truly meet their needs.

We have engaged with design thinking to build shared understanding of challenges in diabetes in past dSeries events, and will use it again on day 2 at d19 to help advance the top high leverage strategies we develop on day 1. We think of the core design question for d19 itself as: How might we work together to curb the type 2 diabetes and prediabetes epidemic in America?
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