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Education is key—it empowers individuals to manage diabetes effectively and understand its potential benefits. Despite the difficulties, I want everyone to know there's another side to diabetes

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Gisela Ayala outlines the Mexican Diabetes Federation's focus on educating people with diabetes, healthcare providers, and the general public to dispel myths and improve diabetes management. She highlights the significant progress in diabetes management technology as well as the challenges of ensuring equitable access to these innovations, and her priorities for the organisation moving forward.

What is the Mexican Diabetes Federation and what does it aim to do?

Our principal tool is diabetes education. When you live with a long-term condition like diabetes, it’s essential to understand what is happening in your body and how various factors such as diet, exercise, and lifestyle choices affect your health. Our mission is to educate people with diabetes, their families, healthcare professionals, and society in general, addressing the numerous myths surrounding diabetes and its causes. We have a network of 21 associations across 16 states in Mexico, all of which receive patients. Here at the central office, we design and conduct courses for diabetes educators and facilitators, as well as organize our biennial Congress. The upcoming congress will be held in September in San Juan del Rio, Querétaro. Everything we do centers around the educational needs of people with diabetes and healthcare providers, ensuring that they understand the benefits of proper diabetes management.

The Congress is designed for everyone, both healthcare providers and patients. This dual focus is crucial because the information and skills needed by each group differ significantly. For healthcare providers, we focus on improving communication and teaching skills, moving away from the old, authoritarian approach where doctors would threaten patients with severe consequences. Instead, we emphasize the benefits of managing diabetes effectively through diet, exercise, and regular blood glucose monitoring.

For patients, the message is about taking ownership of their health and diabetes management. It's about self-care, understanding the impact of their actions, and being prepared for fluctuations in blood glucose levels. We aim to equip patients with the skills and knowledge to handle their condition proactively. Thus, while the core information may be similar, the approach and call to action are tailored to the unique needs of healthcare providers and patients, ensuring both groups can effectively manage and support diabetes care.

How have advancements in technology, such as new apps and devices, changed the management of diabetes over the years?

The changes have been remarkable. When the Federation was founded 41 years ago by Maria Levy and her colleagues, diabetes management was vastly different. Back then, people had to measure their glucose levels through urine, which was a cumbersome process involving multiple steps. Now, we have advanced devices that allow individuals to monitor their glucose levels using their smartphones, providing real-time data with just a simple scan.

The knowledge and understanding of diabetes have also expanded significantly. We now have a much clearer picture of the science behind diabetes. This deeper understanding has led to the development of more effective drugs and management strategies. However, the challenge remains in ensuring that these advanced treatments and technologies are accessible to everyone, as they can be quite expensive. Despite the progress, equitable access to these innovations is still a major issue.

Access to medicines is a crucial issue. What do you think can be done to improve access to diabetes medications and support for patients in Mexico, especially considering that around 50% of these medicines are purchased out-of-pocket by patients?

Over the past 30 years, the Mexican Diabetes Federation has worked hard to understand the challenges faced by families living with diabetes. One major issue we have identified is that many people are unaware that health care is a right, not a privilege or a gift from the doctor.

To improve access to medications, we need to address both awareness and systemic support. Firstly, it’s crucial to educate families about their health rights and the importance of managing their condition. This awareness helps patients understand that they are entitled to proper care and treatment, which can empower them to seek the support they need.

Additionally, our associations play a vital role in identifying gaps in treatment and advocating for change. For example, we work to address issues like insulin shortages in hospitals by bringing these problems to the attention of health authorities through letters and other advocacy efforts.

Moreover, improving laws and policies to ensure comprehensive treatment, which includes not only insulin but also necessary supplies like syringes and glucometers, is essential. If the government can allocate funds for more advanced tools, such as glucose sensors, it would greatly enhance the quality of care for patients.

Ultimately, improving access requires a combination of better education for patients about their rights, proactive problem-solving by health organizations, and effective policy changes to ensure that essential diabetes management tools are available and affordable for everyone.

You mentioned that one of your main objectives is education for both patients and healthcare providers. How do you achieve this, especially in a large country like Mexico, where some states, such as Chiapas and Oaxaca, are more vulnerable and harder to reach?

Our network is formed by people directly affected by diabetes, with more than 60-70% of the leaders in our associations being mothers of children with diabetes. These mothers are incredibly strong and dedicated. However, it’s important to note that the founders and board members of our associations are volunteers, which can be quite challenging in a country like Mexico.

In states like Veracruz, Oaxaca, and Chiapas, we currently don’t have established associations due to the difficulties volunteers face there. About five or eight years ago, we started working with smaller groups of people instead of formal associations. These groups receive training to improve how they communicate their needs to stakeholders.

In Mexico City, we have extensive training and advocacy programs available for everyone, including NGOs. We prepare training sessions for our associations, and in turn, these associations organize their own training for their beneficiaries.

For states without an established association, we face more challenges. For instance, three years ago, we visited Oaxaca and established a good relationship with a local doctor and a mother of a diabetic child. This led to discussions with the health minister of Oaxaca. However, we discovered that the state lacks the infrastructure to provide comprehensive treatment for children with type 1 diabetes, highlighting the ongoing difficulties in ensuring access and support across all regions.

Can you tell us more about what you do for children with type 1 diabetes?

We focus significantly on this issue. It’s important to understand that type 1 diabetes, which accounts for less than 10% of diabetes cases, is different from type 2 diabetes, which is the most common form.

Type 2 diabetes typically affects individuals over 35 and is often linked to obesity, lack of physical activity, and family history. In contrast, type 1 diabetes is an autoimmune condition, where the body attacks its own pancreas, and it usually appears without any family history in about 80% of cases. Unlike type 2, type 1 diabetes cannot be prevented because we still don’t know why it occurs.

We work hard to support children with type 1 diabetes because, with proper treatment, blood glucose monitoring, and physical and mental guidance, a child diagnosed today can grow up to lead a normal, productive life. However, without adequate care, their life expectancy can be reduced by up to 10 years. That’s why our efforts are so crucial in providing these children with the resources and support they need to thrive.

How difficult is it to diagnose type 1 diabetes in children, and what are the common signs that families should look out for?

Diagnosing type 1 diabetes in children can be quite challenging, primarily because it often appears without any family history, so families don’t expect it. Children with type 1 diabetes may exhibit symptoms such as feeling very tired, losing a significant amount of weight quickly, and experiencing frequent infections. Additionally, their breath may have a fruity smell, similar to

apples, which is a sign of ketoacidosis, a common symptom in type 1 diabetes.

The difficulty lies in the fact that these symptoms can be easily overlooked or attributed to other causes. For instance, parents might think their child is tired from playing or may try to increase their food intake when they notice weight loss. This is why more training for doctors is essential. Simply measuring a child's blood glucose level can quickly identify the condition, but this step is often missed due to a lack of awareness.

Moreover, children diagnosed with type 1 diabetes need proper education and support to manage their condition. We work hard to provide this support and ensure they can lead happy, healthy lives despite the challenges.

We understand that the Federation has a 'seal' program. Could you explain what this project is about and its purpose?

We have three different seals aimed at guiding people with diabetes in making informed choices. The idea behind these seals is to help individuals understand nutritional labels better and make decisions based on that information. About 15 years ago, we noticed that not all nutritional labels accurately reflected the product's reality. For example, a product might be labeled as "light," but it's only light in fat, not in carbohydrates or sugars. Our seals are designed to identify products that are genuinely friendly for people with diabetes.

We have seals for various food products. The aim is to provide a clear and trustworthy guide for those living with diabetes. Additionally, we distribute a magazine quarterly that offers valuable information and updates. This magazine used to be bi-monthly, but due to high printing costs, it is now every four months. We also have a digital edition, which is free and accessible to everyone. We distribute the magazine through our associations and many hospitals across Mexico City and other locations.

How does the Federation collaborate with the pharmaceutical industry and the government?

We believe in working collaboratively with all stakeholders because everyone plays a role in finding solutions, not just identifying problems. Together, we develop campaigns and tools for people with diabetes and healthcare providers through workshops, forums, and seminars. We receive

sponsorship from the pharmaceutical industry for many of these initiatives, which helps support our efforts significantly.

We also collaborate with the food industry. While this collaboration can be controversial, we believe it’s essential. The food industry needs to understand what people with diabetes consume and why, and people with diabetes deserve higher-quality products. This collaboration aims to improve the availability of healthier options tailored to the needs of those managing diabetes.

There is a misconception that making nutritious choices for diabetes is expensive, but with nutrition knowledge, people can create healthy meals affordably. In Mexico, we have a rich variety of fruits and vegetables available, providing ample opportunity to make healthier food choices, even within traditional meals like tacos.

Ultimately, our goal is to empower individuals to make informed choices that support their health.

You’ve been with the Federation for 20 years, what have been your most important challenges, and where would you like to see the Federation in the next three years?

I believe our most significant challenge has been educating decision-makers about the importance of diabetes education and dispelling prevalent myths. Many government officials lack accurate information about diabetes, especially regarding type 1 diabetes in children. When advocating for these children’s needs—whether it’s at school, on buses, or in other areas—it can be incredibly challenging to ensure they receive everything essential for their health and well-being.

I am convinced that decision-makers need a thorough understanding of what children with type 1 diabetes require to thrive and contribute productively to society. It’s an investment in their future productivity and well-being. If we fail to support these children adequately, the costs to both their health and the healthcare system can be substantial. This, I believe, is our most pressing challenge.

Looking ahead, over the next three years, I envision the Federation continuing to expand its educational efforts, strengthen partnerships with industry and government, and advocate even more effectively for the needs of people with diabetes across Mexico.

You mentioned working with the government and legislators. Could you explain how the Federation collaborates with them?

We engage with anyone who wants to understand more about diabetes and the needs of people living with diabetes. Whether it's with federal legislators or state officials, we actively seek opportunities to advocate for better policies and support systems. States like Jalisco, Guanajuato, Chihuahua, and Tamaulipas have shown strong commitment to diabetes legislation. Tamaulipas, in particular, has made remarkable strides in state laws pertaining to diabetes management and care.

Last year, for example, our advocacy efforts contributed to an amendment in the National Health Law that mandates all healthcare systems to identify the type of diabetes affecting patients, regardless of their age or location.

Looking ahead, I envision the Mexican Diabetes Federation playing a pivotal role in shaping national diabetes policies. In five years, I hope to see us recognized as a consultative body for government programs, much like national cancer programs. Our goal is to be seen not just as critics but as constructive partners, offering solutions and advocating for comprehensive diabetes management nationwide.

What message would you like to leave with our readers worldwide?

I believe Mexico's healthcare system faces numerous challenges, but families affected by type 1 diabetes demonstrate incredible resilience and dedication to their children's health. Education is key—it empowers individuals to manage diabetes effectively and understand its potential benefits. Despite the difficulties, I want everyone to know there's another side to diabetes. I am 32 years old and living well with diabetes. While diabetes can bring complications and hardships, there's also strength and hope in managing it together. With enough support, people with diabetes can be unstoppable.

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