

## We need to speak louder and act for diabetes & other NCDs

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Diabetes testing in Brazil

**Sheila Vasconcellos is a journalist living with type 1 diabetes in Brazil. Here she writes of how both challenges and opportunities - like being a Bakken Invitation Honoree - have inspired her to be a powerful voice of change for NCDs.**

In a country where resources are lacking and where there are few diabetes education initiatives, people who live with diabetes face a difficult situation. In Brazil, we must overcome several barriers when living with this "silent disease". Silent because diabetes complications build up for years without any symptoms. Silent also because people prefer not to speak about diabetes. Young people, and even adults, who have not accepted their condition start developing early diseases on their heart, kidneys, feet, eyes, brain and other organs. All this could be avoided if we started to speak more about diabetes and barriers to better manage this serious health condition.

### Leveraging moments that define our lives

As a journalist, speaking has never been my problem. Taking care of diabetes has been complicated for most of my life. However, there are moments that define our life. During a severe hypoglycemia with no symptoms I fell and broke my ankle in 3 parts. To prevent this situation from recurring, I found in medical technology the safety needed. I learned how to count carbohydrates and started using an insulin pump connected to a glucose sensor. With it, alerting me at every glucose variation, I have come to live better and manage diabetes better.

I figured out, then, that it was time to give back to the community, retributing a little of the extra life I had gained. Since I was invited to participate in the Bakken Invitation in September 2015, I began volunteering for diabetes, advocating for the reduction between diagnosis and appropriate treatment time, and to ensure a full life horizon for patients and their caregivers.

### Learning from with others living with diabetes

I got closer to people whose lives are the same as for me and our families. Many still do not accept diabetes and its

treatment. In addition, due to lack of resources, access or knowledge they continue to suffer hospitalisations caused by scary severe hypo and hyperglycemias. I realised that I could help them - and myself too - by elevating our voice. I'm currently looking for spaces for us to share experiences, strengths and do more for diabetes in Rio de Janeiro and in Brazil as a whole. I started volunteering as a member of the Association of Diabetics of Lagoa in June 2016. A few months later, I was elected Vice-President of this same association, when I started to advocate for the design of public policies and use of social networks for diabetes education. I participated in congresses, seminars, conferences, forums, meetings, and public hearings in Brazil. In 2017, we opened the year increasing our presence in the media (TV, Internet and print newspapers) with various stories about the lack of supplies and insulin analogues for the treatment of people with diabetes in Rio de Janeiro.

### Becoming a political advocate for change

I never thought I would be involved in politics, but I began to attend meetings with deputies, councilors, senators, leaders of patients and professionals entities, physicians, digital influencers, caregivers, lawyers, and anyone who could somehow contribute to change the situation in a way that would allow those with diabetes, from young children to elderly, to access quality health care. However, the silence of the authorities is deafening. I see children regressing in treatment, disconnecting and putting away their insulin pumps, patients washing to reuse single-time-use supplies or rationing tests to try to manage diabetes during a serious state of financial crisis. It was a very difficult year.

This did not prevent us from taking action: we organised protests in the streets and through social media networks and events to provide blood glucose tests, lectures, recreational activities, carbohydrate counting workshops, psychological support, lawyers' guidance, and meetings with social workers and podiatrists. We rescued a diabetes association that was about to close its doors. Now, in the middle of 2018, the fight continues. We still haven't been able to offer the right treatment to everyone through our public Universal Health Coverage system, called SUS. Many to go to court against the State to receive their treatment, while some Brazilian states already have regulations to treat children, teenagers and adults who live with diabetes with the best available medical therapy.

### Taking responsibility for speaking louder about epidemic diseases

I believe we are responsible for our choices, all of us. I have chosen to fight so that children like Gustavo are entitled today to treatment that allows for the best possible management of diabetes. Those who live with diabetes know the care we need 24 hours a day. And life is not just about diabetes. We need to study, work, love, have fun and we cannot continue to accept outdated, poor quality or lacking treatments. We need to speak more and louder about diabetes and what is needed to prevent and properly treat a disease that is already a global epidemic. This year I attended the IAPO Global Patient Congress and an International Volunteer Conference and I continue to learn more about how we should speak, act and fight for life, health and for a bright future for all! We can change the health system to stop it. We can do whatever we want. Nothing or nobody will stop us. We just cannot be silent.

#### **About the Author**

**Sheila Vasconcellos** ([@Sheila1970](#) [1]) has had type 1 diabetes for 30 years. In January 2014, she began using an insulin pump. Determined to give back, Sheila started volunteering at Casa de Apoio, where she helps children diagnosed with cancer and serious blood conditions. Sheila believes that the insulin pump has given her an extra life, and hopes to live another 45 years loving and supporting others. In 2015 she became a [Bakken Invitation Honoree](#) [2]. Learn more about Sheila and the Bakken Invitation here, and read her ENOUGH Voice of Change submission [here](#) [3].

#### **Interested in applying for the Bakken Invitation?**

If you are advocating to improve health outcomes for others, and / or contributing to innovation that improves the lives of people, and / or taking actions to make your dreams for a better world, a reality – we look forward to receiving your application for the Bakken Invitation. Applications for 2018 honorees close on July 18, 2018. [MORE HERE](#) [4]

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### Links

[1] <http://twitter.com/sheila1970>

[2] <http://www.medtronic.com/us-en/about/foundation/bakken-invitation.html>

[3] <https://enoughncds.com/voices-of-change/>

[4] <http://www.medtronic.com/us-en/about/foundation/bakken-invitation/program-guidelines-and-application.html>

[5] <https://old.ncdalliance.org/category/tags/diabetes>

[6] <https://old.ncdalliance.org/taxonomy/term/756>