Interview: Marlene Oliveira – Founder and President, Instituto Lado a Lado Pela Vida, Brazil



"Pharmaceutical companies have made tremendous progress in terms of patient engagement, and the same actually goes for their relationships with NGOs and patient organizations."

24.10.2017

Tags: Brazil, Instituto Lado a Lado, Institute, Healthcare, Men's Health, Awareness, Patient Education

Marlene Oliveira, founder and president of the Instituto Lado a Lado Pela Vida (Side by Side for Life) documents the main objectives and achievements of this Brazilian institution of reference, which tirelessly strives to help Brazilians live longer and healthier lives and access better healthcare outcomes through targeted prevention and advocacy campaigns as well as high-level roundtables that include all stakeholders among the country's healthcare ecosystem.

The history of the Institute began in 2008 with a focus on men's health and prostate cancer prevention, which actually led to the creation of the very popular "Blue November" campaign in 2011. Where does the Institute stand in 2017 and what are its main missions?

In the grand scheme of things, one of the fundamental missions of the Institute is to encourage and help Brazilians take better care of their health. In this regard, we focus on three critical stages throughout the overall healthcare pathway: prevention, treatment, and access.

In Brazil like in almost all countries around the world, the number of deaths caused by cancer and cardiovascular diseases remain dramatically elevated despite the efforts of the government and the medical community to tackle these diseases. We then decided to concentrate our actions on these two critical therapeutic areas through patient-oriented campaigns that aim to educate and

help Brazilian people preventing these diseases, as well as raise awareness about the medical options available and patients' rights. In Brazil, informing patients about their rights probably takes on a heightened importance than in many developed countries, as the population unfortunately does not have an equal access to healthcare services. This situation has prompted us to advocate for the implementation of a more personalized approach to healthcare, marking a sharp difference with the "one-size-fits-all" vision that still prevails within the country's public healthcare system.

What has been the impact of the recent economic crisis on the country's healthcare delivery?

[Featured_in]

It is rather difficult to gauge, especially given that Brazil's healthcare capacity has historically evolved by small steps rather than through disruptive changes. Nevertheless, one cannot deny that our country's health system still holds substantial rooms for improvement while displaying specificities that render it difficult to be directly compared with developed countries' health models. In this vein, it is impossible to approach Brazil as a homogenous country, as strong disparities in terms of healthcare needs, access, and delivery emerge across its huge territory – and even among the population itself.

For example, Brazilian women are historically more health-conscious than men, as the latter typically start worrying when the disease symptoms would appear. Nevertheless, we see that this dynamic has recently changed and Brazilian men are more and more receptive to prevention campaigns, which also means that the government has to be ready to handle an increasing healthcare demand. Three years after the beginning of our "Blue November" campaign for prostate cancer prevention, awareness started to pick up and the demand for related for healthcare services was soaring accordingly. As a result, the Ministry of Health told us that our prevention campaigns and the increasing healthcare needs that they generated were disrupting the public health system!

Let me give you another example: in Brazil, an absurd number of women still die of neck of the womb cancer, especially in comparison to the results obtained by developed countries. This dramatic situation notably takes its roots in the fact that a substantial share of our population lives in areas where the access to information, diagnostic capacity, and treatments is extremely low or inexistent. These discrepancies affect our country's capacity to optimally diagnose and treat patients, and also prevent us from depicting a precise and comprehensive healthcare picture: in Brazil, it is extremely challenging to obtain up-to-date, nation-wide data, while the information we have is not consistent from one state to another.

How do you adapt your campaigns to the multifaceted reality of the country's healthcare needs?

[related_story]

The communication medium and even the content of our campaigns change according to the targeted population. When focusing on more "educated" social classes, we really try to build comprehensive campaigns that would target all individuals at once. However, in regions like the rural areas, where life expectancy is seven to ten years lower than in the big cities and people do not have access to the same infrastructure as in large urban centers, we elaborate more visual, simple, and straight to the point campaigns.

Nevertheless, we are in 2017 and everyone in Brazil has a smartphone, even in the most isolated regions of the country, which tremendously helps us to launch large-scale prevention campaigns across all parts of the country – through text messages for instance.

Is there any upcoming prevention campaign that you would like to highlight?

We noticed that a worrying share of the Brazilian population does not know that environmental pollution and asbestos increase the risk of lung cancer, hence we would like to raise awareness around the causes of lung cancer other than tobacco. In this regard, we see that asbestos is still widely used in Brazil despite its proven correlation with various kinds of cancer, while most exposed workers do not wear appropriate protection either, which explains why they display a significantly higher prevalence of cancer than the rest of the population.

The Institute is concerned about the number of deaths from people with lung cancer who never smoked. We have to do something about it.

For skin and melanoma cancer, we want to showcase how pollution and sun exposure ages the skin and raises the risk for skin cancer. In this regard, the Brazilian Dermatology Society recently released a schedule that aims to tell people at what time they can sunbathe without any risks. In most regions of the country, it is between 8 and 10 AM, but, in the North of Brazil, even early morning exposure is dangerous for the skin.

As part of your commitment to help patients better know their rights for health-related matters, what is your assessment of the growing phenomenon of "judicialization of health", where patients sue the Ministry of Health to freely access the treatments they need, leveraging the fact that this right is enshrined in the Brazilian constitution?

This phenomenon is gaining in importance because our public health system is evolving toward a direction that leaves Brazilian patients with no choice but to rely on legal actions to access the medicines they need.

As per Lado a Lado, our mission is to empower patients with all the information they need on diseases prevention, treatment and healthcare access – but we do not consider that the judicialization of health stands as the way forward for our country's health system.

I agree that judicialization is a big complicator, it disorganizes the whole system, will always prioritize one over the other. Those who have more clarification and money to support the legal process will have more chance than those who depend on SUS exclusively. On the other hand, the inclusion of new drugs does not happen efficiently in our country.

There are drugs that took approximately 15 years to incorporate. The solution is not easy but everyone should think about the patients first and not always that happens.

To summarize, we do not support the *judicialization of health*, but we do believe that all Brazilian patients should have access to the drugs that were approved for use in the country.

We will meet with a large number of pharmaceutical companies operating in the country for this *Brazil Healthcare & Life Sciences Review 2017*. What is your perception of these companies' commitment to the healthcare ecosystem?

Pharmaceutical companies have made tremendous progress in terms of patient engagement, and the same actually goes for their relationships with NGOs and patient organizations. They invested substantial resources to build impactful initiatives that aim to raise awareness around critical diseases and work very closely with all kinds of research, medical, clinical institutions.

From my point of view, I believe pharmaceutical companies in Brazil are now starting to move from a transactional approach to embrace a more patient-oriented and human vision, where they fully acknowledge the game changing importance of educating patients. Our institution is already working alongside pharmaceutical companies on specific initiatives and projects, and our overall thinking is to connect with all stakeholders operating across the country's healthcare ecosystem – and not only the pharma side.

What is your final message to our international readers?

I deeply believe that Brazil has developed a very interesting healthcare model, although the coverage of some basic needs still need to be tremendously improved across the country's territory. We also need to evolve its management model and favor a more transparent, predictable

approach in this regard. Fulfilling this objective will help moving toward personalized healthcare, where the objective is not only to treat patients' symptoms but rather to consider the patient as the center of a holistic continuum of care, with a strengthened link uniting the patient to the physician and the way around.

See more interviews