

'We've been forgotten': Brazil's Zika generation

December 18 2018



Transmission electron microscope image of negative-stained, Fortaleza-strain Zika virus (red), isolated from a microcephaly case in Brazil. The virus is associated with cellular membranes in the center. Credit: NIAID

When doctors told her that the six-month-old fetus she was carrying had severe brain damage caused by the Zika virus, Thamires Ferreira da Silva tried to commit suicide by jumping in front of a bus in Rio de Janeiro.

"I just wanted to finish it," said the 29-year-old Brazilian, crying.

But the bus driver braked in time and more than two years later, she is raising her son Miguel with the help of her husband Wallace, their families and medical specialists.

Miguel was the first child in Brazil to be diagnosed with the mosquito-borne illness, which at the time was an unremarked phenomenon but which soon grew to be the focus of a global health alert.

"I feel that we've been totally forgotten," Ferreira da Silva said.

Her son, aged two years and four months, suffers from microcephaly—a condition in which the brain does not develop properly and results in a smaller than normal head.

He also has lissencephaly, where parts of the brain appear smooth, the rare Dandy-Walker syndrome that is characterized by deformation of the part of the brain that controls movement, kidney problems and epilepsy.

Despite being cross-eyed, the toddler can see, and he reacts to [family](#) voices. But he is unable to walk, sit or lift his head.

His parents follow a strict and costly regime that involves giving him six medicines every 12 hours and regular hospitalizations.

"It's difficult and it costs a lot. Families hide their child so society doesn't see it. But us, we want to be part of society," Wallace said.

He works at night as a computer technician to help pay the countless bills racked up for Miguel's care, including for his pediatrician, kidney doctor, physiotherapist and psychomotor specialist, spread across three different hospitals.

Absent parents

The Zika epidemic in Brazil that started in 2015 caused an exponential increase in the number of babies with microcephaly and other neurological defects, particularly in the northeast, the country's poorest region.

Between November 2015 and May 2018, the [health ministry](#) registered more than 3,000 cases linked to Zika infections during pregnancy.

The government has taken several measures to assist mothers raising Zika-affected children, such as priority access to [public housing](#) and minimum-wage payments for the poorest families.

But often they still face difficulties getting access to municipal services because of a lack of information or the complicated bureaucracy.

"They do everything so you don't come back. There is a lot of bureaucracy so you just give up because you are overwhelmed with so many things," Ferreira da Silva said.

Initially, she and her husband contacted other families in the same situation to swap information and lobby authorities to make sure their rights were respected, such as the house they have just moved into in Rio.

But their standard of living and the attention they have managed to provide for Miguel is not the rule, they say—and especially not for

single mothers who have been abandoned by their partners.

"Miguel makes us fight, not only for him but also for the families. Because we know how difficult it is. We know that many families have an absent father," said Wallace.

Paradoxically, the biggest difficulty they faced was not receiving complex medical treatments but basic pediatric attention.

"In the public health system, doctors generally don't know the congenital syndrome (of Zika). So they don't manage to give basic pediatric care," Wallace said.

"Yet this same baby who has a congenital syndrome, who has microcephaly and other illnesses too will have, for instance, tooth pain and all those other normal problems other babies have."

'Live for today'

The parents say they would like to have more children. But they are all too aware of the constant attention and resources Miguel requires. So they are putting that off until Thamires completes a nursing course she had to give up and is able to work again.

For now, Miguel is their sole focus. When they can, they take him to children's parties, and to the beach. For his last birthday, they invited other mothers with infants with microcephaly.

But there are many low moments. In Miguel's short life so far, he has already been admitted into intensive care eight times.

They find succor in the advice they first received from doctors: never give up.

"Live for today. Miguel could live for 10, 20 years—or two or three. But if you don't live, you will feel frustrated in the future for all you didn't experience, they told me," Thamires said.

"So I will bathe him, kiss him, take in his smell. Because at any moment they could put him in hospital."

© 2018 AFP

Citation: 'We've been forgotten': Brazil's Zika generation (2018, December 18) retrieved 3 May 2024 from <https://medicalxpress.com/news/2018-12-weve-forgotten-brazil-zika.html>

<p>This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.</p>
--