

## Overcoming the gap in ophthalmological evaluation and treatment in children with microcephaly and Congenital Zika Syndrome.



*Left: DM and his mother arriving at FUDEM. Right: DM with his glasses, provided with support from the ASSIST-Zika Project/FUDEM*

Ensuring the multidisciplinary approach of children with microcephaly and Congenital Zika Syndrome (CSaZ) can be challenging for governments and cooperating agencies. The Project Applying Science to Strengthen and Improve Health Services in the context of Zika (ASSIST Zika), funded by USAID, has been working in El Salvador since 2016. Among its goals, it aims that, by 2019, at least 80% of all children affected by Zika have received 80% of the recommended actions of care according to age.

Advances in scientific knowledge have shown that microcephaly is not the only marker for CSaZ, and that ocular anomalies, such as chorioretinal atrophy and focal pigment mottling, are characteristic of congenital infection due to this virus. The international consensus agrees that, in the case of babies with microcephaly, at least one ophthalmological evaluation is required. Many of these children, when presenting macular lesions, require vision therapy and optical aids.

In the country, the ophthalmological evaluation for children with microcephaly and CSaZ is only performed in third-level and second-level hospitals that have a specialist, which results in long waiting periods for the evaluation. Likewise, when there is evidence of the need for optical aids and low-vision therapy for these cases, there is no institutional response capacity to provide this benefit. In this context, the ASSIST Zika project sought the support of FUDEM<sup>1</sup> for the evaluation of the cases identified, joined the proposal, and requested the training of its own resources. Subsequently, an agreement between SAVE THE CHILDREN (STC) and FUDEM was identified as providing eyeglasses to

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<sup>1</sup> FUDEM: A non-governmental organization engaged in the provision of ophthalmological evaluation, rehabilitation, and optical aids to visually-impaired children and adults.

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schoolchildren from the STC intervention areas, which the ASSIST Zika project requested the additional evaluation of children less than 4 years of age that have been diagnosed with microcephaly and CSaZ, which was approved on November 12, 2018.

This initiative has benefited children like DM who, through his mother MGYC, shares his story with us:

In 2016, MGYC became pregnant with her third baby. She was worried about news and TV reports which warned about a new disease “Zika”, which caused something called “microcephaly” in children, but prayed to God that that was not the case with the child she was expecting. At 20 weeks, she sought care because both herself and 10-year-old son had a fever and a rash; however, there was only one appointment left with the doctor, and she decided to have her son seen. The impact that this disease could have on her baby was not explained to her.

At 34 weeks of pregnancy, she went to the hospital for her follow-up ultrasound, during which they detected an abnormality in the baby and, for that reason, they decided to refer her the next day to the third-level hospital. It was there that she was evaluated, and the prenatal ultrasound found multiple congenital anomalies, in addition to other metabolic alterations. She was admitted for more testing and evaluations by specialists. After discharge, she was still unable to understand what her baby had and why this was happening to her.

At 37 weeks, she started labor and went to the third-level hospital, where DM was born; a newborn with low weight, who also had microcephaly and arthrogyriposis. The doctors at the hospital told her that the illness she suffered during her pregnancy was probably Zika, and that the anomalies her baby presented were related to the CSaZ. At first, this devastating news for her and her family, but they felt blessed because their son was alive. They were affected by the uncertainty of his condition but, despite all this, they became hopeful. DM had daily convulsions despite the use of medications, and his psychomotor development presented lower limb spasticity with scissor gait, dorsal kyphosis, and difficulty in following objects with his eyes.

The ASSIST Zika project met DM and his family at the National Women’s Hospital, when his case was proposed to be presented at the third ECHO Zika teleclinic session. MGYC shared her story, and the difficulties her family was having to be able to have access to the care required by the child. Her family thought that DM could not see, but during the evaluation performed at 2 years and 3 months, the physiotherapists found that he fixed his gaze on some objects and colors. DM needed a new ophthalmological evaluation, because the first time he had been prescribed eyeglasses, and with great effort the family was able to buy them; however, they found no improvement.

DM was called by FUEDEM to be evaluated and new eyeglasses would be provided, if required. His transportation was coordinated with the Metropolitan Region of the Ministry of Health.

Today, DM is 2 years and 9 months old and, although he still has significant difficulties in his motor skills, with the help of his eyeglasses and physical and vision therapy he has improved his quality of life and plays and smiles during his early stimulation exercises. His family is very grateful and reassured with the care of their son, “the darling of everyone at home” as his mother tells us. As a result of this experience, two more children from the department of Cabañas have already benefited, also with the support of SIBASI to ensure their transportation, and the strategy has been extended to more cases identified with this need.