

## Spotlight on: Advocacy for MBC patients' rights

In September 2018, Adela Ayensa, General Director of [Salvati A.C.](#), visited [FEMAMA](#) in Porto Alegre, Brazil to strengthen her capacity as an advocate for patients' rights.



Salvati is an NGO in Mexico dedicated to helping cancer patients navigate a complex healthcare system and to raising awareness of cancer risks and early detection, particularly in low-income communities.

Adela was awarded a [grant](#), sponsored by the [Prevent Cancer Foundation](#) (PCF), to visit FEMAMA (Federação Brasileira de Instituições Filantrópicas de Apoio à Saúde da Mama) in Brazil, an advocacy NGO that seeks to make breast cancer a top priority for the Brazilian government through public healthcare policy. Adela aimed to learn from FEMAMA their success stories to streamline the process of positioning the rights of metastatic breast cancer (MBC) patients' treatment with accurate information in the public health agenda of Mexico.

Adela's visit included two main objectives:

1. Strengthen advocacy efforts focused on the rights of MBC patients.
2. Learn about policy-making to include MBC patients' rights (e.g. offer treatment choices paired with accurate information) in Mexico's public health agenda.

Both Mexico and Brazil have a strong voice in cancer control regionally, and this visit intended to build momentum and continuous collaboration throughout Latin America. Porto Alegre has recently been selected as a [C/Can 2025 Challenge City](#). Meanwhile, Mexico is at a crucial moment in its cancer control efforts following the [World Leaders Cancer Summit](#) (WLCS) and [Leadership in Action](#) meeting in 2017, and is currently implementing a variety of initiatives, including implementation of their National Cancer Control Plan (NCCP).

Salvati in particular is also one of the first Country Champions to sign on to UICC's [Treatment for All](#)

initiative, working across the national cancer coalition, [Juntos Contra el Cáncer](#) (JCC). This last fact had an influence in choosing FEMAMA as host organisation. Indeed, while Salvati is a founding member of JCC, FEMAMA is a founding member of [Todos Juntos Contra o Câncer](#). Both are national civil society coalitions with joint aims toward ensuring that cancer control is a priority on their respective national health agendas, calling for improved access to cancer treatment and care. This parallelism could help in building regional alliances, one of Adela's expectations.

### The visit

During Adela's visit to Porto Alegre, she:

- Participated in meetings with the different departments at FEMAMA to learn from all angles about the organisation's past and current achievements in advocacy. Particularly, during the meeting with the Communications department, she was exposed to the strategy that FEMAMA has habitually adopted, which focuses on patients, ensuring their voices were heard and testimonials were provided to influence decision makers.

Particularly, Adela learned about how to use communications in order to maximise advocacy efforts. Her skills in that area were improved by learning how to engage the general public through social media or through the website for specific short-term campaigns without financial investment.

- Visited the *Hospital Moinhos de Vento* (HMV) where she met with Dr. Maira Caleffi, FEMAMA's President and former UICC Board member. She learned how the organisation works and delivers some of their projects through other foundations, illustrating the vision of FEMAMA's President, according to which "the key to success is to learn to work together as a region to raise our voice, without seeking individual recognition".
- Visited the *Instituto da Mama do Rio Grande do Sul* (IMAMA), where she had the chance to discuss volunteers' capacity building project. IMAMA is the branch



of FEMAMA that has direct contact with patients (formed by volunteers and former patients) that runs early detection and screening campaigns, offers psychological support, and organises public events for fundraising and awareness-raising purposes.

Learning about patients' engagement is of particular importance for Salvati as their multidisciplinary model of work is patient-centric.

## Moving forward

With the launch of Treatment for All in Mexico next World Cancer Day, Adela returned to Mexico feeling inspired by discussions and looking forward to trying new ideas to put patients in the spotlight.

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*"This visit has allowed me to learn first-hand about successful experiences when patients are placed in the centre of advocacy efforts."*

Adela hopes that this exchange will help Salvati implement new collaborative advocacy projects for women battling metastatic breast cancer, not only in Mexico but throughout Latin America. More immediately, the collaboration will continue in the form of talks or courses that Salvati could offer to FEMAMA around the topics of quality of life and treatment for patients with Lymphedema symptoms.



In November 2018, the [2<sup>nd</sup> Congress of JCC along with the 1<sup>st</sup> National Congress for Patients](#) was held. Adela mentioned that this visit helped them implement social media and broadcasting campaigns to maximise advocacy reach. For instance, for the first time, sessions were broadcast via Facebook and Twitter for patients and caregivers unable to attend physically, as well as for the general public interested in knowing more about cancer and the NCCP plan for Mexico.

Learn more about Adela, Salvati and her engagement with UICC as Treatment for All focal point for Mexico from the [blog post](#) she wrote and the Treatment for All [video](#).

Learn more about UICC regional capacity building programmes [here](#).