

## Spotlight on: Advocate for a legislative forum on cancer

In April 2018, Alexandra Núñez, founder and President of the [Asociación Tour Rosa de Costa Rica](#) visited [Instituto Desiderata](#) in Brazil, to strengthen her advocacy and policy-related skills.



Alexandra Núñez is a cancer survivor, having first been diagnosed in 2006. She has survived four different cancer diagnoses, and her experiences led her to create Tour Rosa to advocate for early diagnosis of breast cancer and provide a support

network to women battling cancer.

Alexandra was awarded a [grant](#) sponsored by the [Prevent Cancer Foundation \(PCF\)](#), to [learn how to maximise her organisation's ability to influence public policy](#) by visiting another organisation that has already made strides in that area. Alexandra learned about Instituto Desiderata - an advocacy NGO focused on strengthening the public health system in order to promote early diagnosis and treatment for children and adolescents with cancer in Rio de Janeiro, Brazil – during the Leadership in Action meeting in Mexico in 2017. The Executive Director of Instituto Desiderata, Roberta Costa Marques, a [2017 UICC Young Leader](#), attended the same meeting.

The visit had two primary goals:

1. Strengthen advocacy efforts to create a national roundtable bringing in all key stakeholders, with the ultimate goal to develop public policies that will promote early detection and access to treatment for all.
2. Improve Tour Rosa's educational programme on early detection.

As a cancer survivor, Alexandra brings a unique perspective to her work and she hoped to gain further experience in a professional context to advance her organisation's goals. In particular, Tour Rosa, with a network of other Costa Rican NGOs are working towards the establishment of a national roundtable formed by different stakeholders and decision makers

to discuss issues such as access and management of biological and biosimilar medicines, the strengthening of pharmacovigilance systems, and on the patient's right to informed consent.

Instituto Desiderata has established a similar forum previously in Brazil and Alexandra was keen to learn how they organised, fundraised, and increased their forum's visibility.



## The visit

The team at Instituto Desiderata shared their experiences and successes with advocacy campaigns, such as [Unidos pela Cura](#) (a multi-stakeholder program designed to promote the early diagnosis of childhood cancer through education, an organised referral flow, and an information system) and in working with the Paediatric Oncology Forum and Brazilian national parliament.

Alexandra's visit included:

- Shadowing staff members to understand multiple viewpoints and engage in in-depth discussions about Instituto Desiderata's activities
- Meetings and interviews with various departments of Instituto Desiderata
- Presentations of Tour Rosa's work to facilitate knowledge exchange and feedback
- Visits to hospitals and three other local organisations to gain a broader view of cancer related advocacy campaigns in Brazil. These organisations were the [Instituto Nacional de Câncer \(INCA\)](#), [Instituto Ronald McDonald](#), and [ACT Promoção da Saúde](#).

These visits and the meetings with Instituto Desiderata were an opportunity to share best practices, reflections, and lessons learned around various public policy advocacy campaigns and public

policy monitoring efforts that were undertaken in Brazil.

## Moving forward

Alexandra and Roberta are continuing to foster their collaboration to maximise benefits of the visit. Alexandra hopes that Roberta will in turn visit Costa Rica to discuss her experiences in advocacy with other Costa Rican cancer NGOs.

One of the positive outcomes of this visit was the exchange of patient and technical perspectives. Roberta said that Alexandra's patient viewpoint **“brought another perspective and greatly enriched the conversations we had, as well as gave us the opportunity to talk about common aspects of a cancer organisation that, in this case, does not work with children.”** Alexandra shared some of the different challenges that patients face in navigating the health system in Latin America, such as financing their treatment. **The visit proved to be educational not only for Alexandra, but also for the host organisation, and fostered a valuable exchange of ideas and perspectives.**



Alexandra learned not only how to affect change in public policy but also how to ensure that new policies are implemented, which she feels poses problems in Latin America.

**She gained practical ideas about how best to monitor policy implementation**, such as technical secretariats, educational programmes for primary care doctors, and maintaining a participatory model that includes citizens and experts. Alexandra **enhanced her technical skills for advocacy programmes**, such as monitoring and evaluation, creating mapping documents, and constructing strong partnerships.



*“I have become empowered, with a clear vision that will be part of my leadership growth. This has had a very big impact for us, an organisation from such a tiny country. We have felt that we matter.”*

The visit has put two inspirational Latin American advocacy NGOs in contact and created a professional, long-term relationship that will continue to foster learning throughout the region. Roberta spoke highly of Alexandra as an **“incredible leader”**, and likewise, Alexandra felt that **“Roberta was always attentive and shared her knowledge and her teams”**; helping me to fulfil the objectives I had with the grant”.

Alexandra's visit exemplifies [Treatment for All's](#) efforts to improve access to cancer services, with an emphasis on early detection and treatment.

Learn more about Alexandra and Tour Rosa from various news articles [here](#) and [here](#), and learn more about UICC's regional capacity building programmes [here](#).