

Best practice case study: Argentina

NP-C in Argentina

The vast size of Argentina poses a challenge to raising national awareness of the campaign amongst healthcare professionals. However, founder of Niemann-Pick Argentina, Marcelo Minotti, has used social media to bridge these distances to great effect since launching the campaign in September 2014.

Think Again. Think NP-C activities 2014-2015

The group developed their own webpage about the local campaign in Spanish and opened Facebook, Twitter and Instagram pages, accruing around 600 followers/likes by the end of 2015. They were creative in their approach to raising awareness, beginning by taking the Spanish campaign logo to hospitals around the country for healthcare professionals to pose with and share the photos on their own social media pages, as well as the campaign channels.



Following the digital launch of the campaign in September 2014, the group organized presentations about NP-C at hospitals, to share information with current healthcare professionals who may come across a patient with NP-C, as well as at medical schools, to target future generations of medics.



In addition, Niemann-Pick Argentina utilized awareness days as an opportunity to share information about the campaign; for Rare Disease Day 2015 the group developed a Spanish version of the global campaign infographic and also translated a BBC Health article from the UK, which major Argentinian news network, La Nación, subsequently published on its website.



Given the size of the country, the group approached national celebrities to support the campaign to ensure that the word was spread as far as possible. Celebrity supporters include premier football club 'Racing' and star footballer Diego Milito.

Marcelo Minotti and expert neurologist Dr Marcelo Kauffman were also interviewed for national TV programme 'Network Health' to discuss the campaign and the symptoms of NP-C.

Argentina has truly demonstrated how much a patient group can achieve using social media as the main tool. Well done Argentina for your continued efforts in raising awareness of NP-C!



Looking Ahead

As part of its campaign, Niemann-Pick Argentina plans to continue sharing medical supplies with underprivileged patients and raising awareness of NP-C in schools, targeting teachers whose observations can be key in the early detection of NP-C in children and adolescents.

The team is also developing a new smartphone application called SUSSI (Sistema Unificado de Seguimiento de



Sintomas). SUSSI allows patients with neurodegenerative conditions, including NP-C, to track common symptoms of their disease in real-time. A healthcare professional can then use the app to monitor and evaluate a patient's clinical status, allowing them to respond immediately if treatment is required. Visit the website [here](#) to learn more.