

## Best practice case study: Canada

### NP-C in Canada

Canada currently has 28 patients diagnosed with NP-C. Prior to rolling out the campaign, the Canadian team (the Canadian Chapter of the National Niemann-Pick Disease Foundation [CCNNPDF] in collaboration with Actelion) identified the challenge of engaging local clinicians on the subject of NP-C, as it is such a rare disease.

### Think Again. Think NP-C activities

A live webex was hosted to launch the campaign in March 2015. The webex featured Dr Julian Raiman, a metabolic disease specialist from Sick Kids Hospital Toronto and medical advisor for the CCNNPDF. Dr Raiman spoke about the importance of increasing awareness of NP-C through initiatives such as the Think Again. Think NP-C campaign.

A campaign website was created providing detailed disease information along with a list of local referral centres. Facebook and Twitter pages were created, providing information in both English and French to ensure the content was easy to access for audiences across the country.

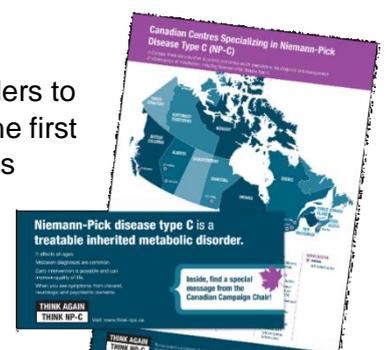


The campaign featured in a symposium on inborn errors of metabolism, hosted at the Garrod Association's annual meeting in Vancouver in May 2015. Chaired by Dr Clara van Karnebeek, paediatrician and biochemical geneticist, the symposium was attended by 60 healthcare professionals. A summary report from the symposium was shared with 5,000 Canadian psychiatrists, neurologists and geneticists in June with a clear call-to-action driving for earlier diagnosis for patients with NP-C.

Since launch, the team has seen a significant increase in requests for information on NP-C from healthcare professionals and the number of patients being referred for testing.

### Encouraging screening through a series of mailers

To encourage screening, the team in Canada distributed a series of mailers to 1,000 physicians including neurologists, geneticists and psychiatrists. The first mailer was shared in April 2015 and presented various genetic conditions which can be confused with NP-C and therefore lead to misdiagnosis. The second mailer was distributed in February 2016 and aimed to increase awareness of NP-C; it also included information and contact details for local NP-C expert centres.



### Looking ahead: leveraging [www.think-npc.ca](http://www.think-npc.ca)

The team are continuing to work with physicians and KOL speakers to raise awareness of NP-C and leverage the Canadian campaign website, [www.think-npc.ca](http://www.think-npc.ca) during upcoming CME events.



Congratulations to everyone involved in supporting and driving the Think Again. Think NP-C campaign in Canada!