

## Best practice case study: the UK

### NP-C in the UK

There are approximately 86 people with NP-C currently living in the UK. As in other countries, the journey to diagnosis for patients and their families can often be long and frustrating.

### Think Again. Think NP-C activities 2014-2015



In September 2014, the UK team (Niemann-Pick UK [NP-UK] working with Jackie Imrie, NP-C expert and global advisory committee member for the campaign), undertook a tour of UK hospitals and key clinical conferences to raise awareness of the disease among healthcare professionals who may see patients with NP-C in their practice.

Various campaign materials were adapted and tailored for UK clinicians, including specialty-specific posters, infographics and an educational slide-deck. Venues visited include Milton Keynes Hospital and the European Society of Human Genetics conference in June in Glasgow, as well as other venues in London, Birmingham and Sheffield.

The team has also achieved media exposure for the campaign. In December 2014, the Daily Mail published the campaign show-reel on their website with a reach of nearly 200 million monthly users. On Rare Disease Day in February 2015, the campaign also featured on BBC News.

In addition, social media platforms for local audiences have also helped the team reach as wide an audience as possible, with dedicated campaign pages created on Facebook, LinkedIn and Twitter.

### Looking ahead

The UK team is continuing to plan activities to raise awareness of NP-C. These include attending relevant national conferences and regional roadshows to help reach a broader range of healthcare professionals who may come into contact with NP-C patients, such as school nurses.

This year, the UK has seen a 10% rise in diagnosis of NP-C since the launch of the Think Again. Think NP-C Campaign which shows that the key messages of the Campaign, underlined by the team's on-going targeted activities, are being heard and acted upon.

