



The Information Point is a website based in the UK. It was established in 2001 with the aim of providing information and raising awareness of the rare neuromuscular conditions known as centronuclear and myotubular myopathy, as well as bringing those with the conditions together, whatever their age, whatever form of the condition they have, wherever they may be in the world.

The Information Point was set up by Toni who is diagnosed with autosomal dominant centronuclear myopathy, as is her father Mike. Toni says 'When dad and I were diagnosed, we struggled to find any information that specifically related to CNM/MTM - that is how I came to set up the Information Point, so that other people didn't have the same problems that we had - so there was a place that was dedicated specifically to CNM/MTM where people could visit to find all the information they needed in one place in the early days of diagnosis and beyond and also to provide help to those whose work may bring them into contact with affected individuals'.

The Information Point can be found at <http://centronuclear.org.uk/>, on Facebook at <https://www.facebook.com/CentronuclearAndMyotubularMyopathyInformationPoint> and Twitter at https://twitter.com/The_Info_Point.



The Big Sunflower Project aims to raise awareness of the rare neuromuscular conditions known as centronuclear and myotubular myopathy by asking people to grow a sunflower. Since 2011 the project has given away sunflower seeds in return for photos of the sunflowers, which are displayed on The Information Point website, in newsletters and on social media.

Seeds are now sent to schools and nurseries, community groups, groups who work with disadvantaged people, hospices and youth groups to name a few, so as well as raising awareness of centronuclear and myotubular myopathy, the project supports the activities of these groups too.

Further information about The Big Sunflower Project and how to join in can be found at http://centronuclear.org.uk/theinformationpoint/pages/the_big_sunflower_project.html and on Facebook at <https://www.facebook.com/groups/406061643077357/permalink/509983536018500/>.