



The Big Sunflower Project

Now in its fifth year, The Big Sunflower Project aims to raise awareness of centronuclear and myotubular myopathy by growing sunflowers. The project is an initiative of the Information Point for Centronuclear and Myotubular Myopathy which has provided information and raised awareness of the conditions since 2001.

Why a sunflower?

Sunflowers have appeared on the Information Point website for some time now – they were chosen for the cheery and positive outlook they convey, growing to such dizzy heights, as if they are on a mission to touch the sky and nothing can hold them back. Every year since 2011 The Information Point has given away sunflower seeds in return for photos of the sunflowers, which are displayed on our website, in our newsletters and on social media. Taking part is easy - keep reading to find out how.

How the project works

Sunflower seeds are free of charge to anyone in the UK and Europe wanting to take part. Sadly we are unable to send seeds outside of Europe but people in these countries are welcome to buy their own seeds and take part too - our aim in time is to have sunflowers growing in somewhere in the world all year round.

All we ask in return for our seeds is that people send photos of their sunflowers, so they can be included in online photo galleries on Facebook and Flickr and in The Information Point newsletters to raise awareness of centronuclear and myotubular myopathy. Don't forget when sending your photos to tell us how you heard about The Big Sunflower Project, where in the world you grew your sunflower, why you decided to take part, how tall your sunflower grew and anything else interesting that happened when you were growing your sunflower.

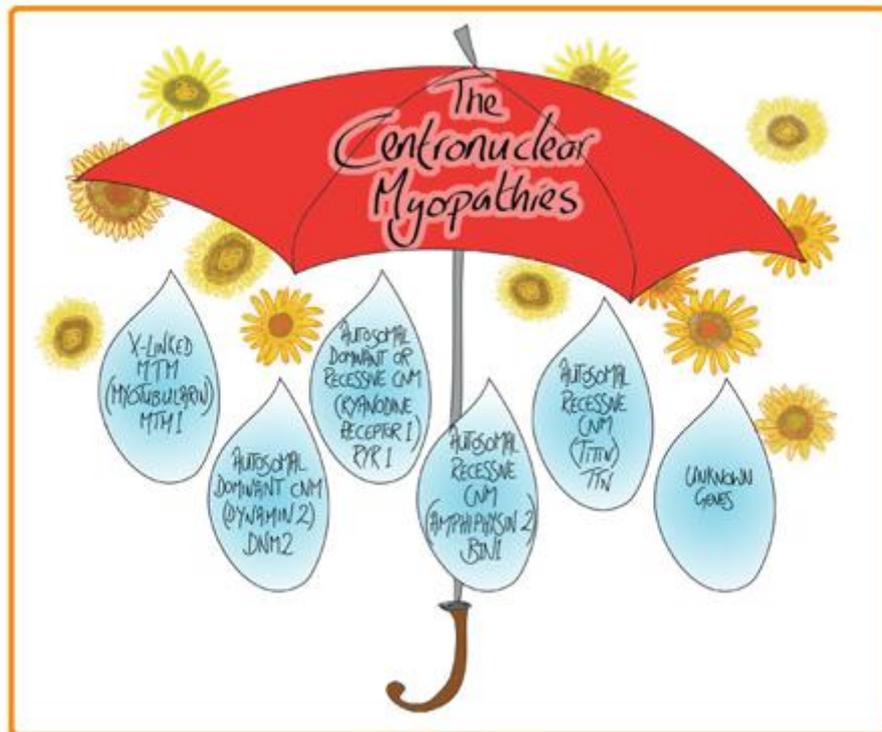
Get others involved to raise awareness of CNM / MTM

We are keen for as many people as possible to get involved in The Big Sunflower Project, so please feel free to share your seeds with family, friends and neighbours. Groups such as charities, community groups and gardening groups are welcome to join in too. In this way it is hoped that the project will educate people about centronuclear and myotubular myopathy - both those who grow the sunflowers and those who see the photos, as well as being a bit of fun.

A note about the Information Point for Centronuclear and Myotubular Myopathy

The Information Point was established in 2001 to help those with the rare neuromuscular conditions known as centronuclear and myotubular myopathy which are inherited muscle disorders from birth.

Manifesting as a defect in the cell structure of voluntary muscles and causing low muscle tone the conditions affect children and adults. The term myotubular myopathy is currently used to describe the x linked form of the condition while centronuclear myopathy is used to refer to the autosomal forms. Collectively, the three forms are known by the umbrella term of the 'centronuclear myopathies'.



The conditions affect the muscles in a range of ways, depending on the form of the condition. Symptoms include muscle weakness; mobility issues requiring some users to require a wheelchair; respiratory problems with some sufferers being partially or totally ventilator dependent; and problems with feeding requiring the use of a g-tube.

The conditions are so rare, there are no exact incidence figures. The Information Point aims to bring those with the condition together, whatever their age, whatever form of the condition they have and wherever they may be in the world; and to create awareness of these rare conditions. The hope, to create a one stop shop where people can visit to find all the information they will need at their fingertips 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.

For further information about centronuclear and myotubular myopathy and to learn more about the work of the Information Point, please visit our website at www.centronuclear.org.uk or email centronuclear.org@btoopenworld.com.