



# The Big Sunflower Project 2019

## About the project

The Big Sunflower Project aims to raise awareness of the rare neuromuscular conditions 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 about and raised awareness of the conditions since 2001.

## Why a sunflower

Sunflowers have appeared on the Information Point website for many years 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.

Since 2011 The Information Point has given away sunflower seeds in return for photos. The photos raise awareness of centronuclear and myotubular myopathy in two ways, firstly by sending seeds to people who have never heard of centronuclear and myotubular myopathy and secondly by displaying photos of the sunflowers on The Information Point website, in newsletters and on social media.

## Taking part

300 packets of seeds containing 50 seeds will be distributed during 2019 (one packet of seeds per applicant). Additional packets can be supplied in return for small donation.

Anyone is welcome to apply for seeds but priority will be given to families affected by centronuclear and myotubular myopathy, community groups, educational establishments and good causes. If you are chosen to receive seeds, you will receive an email with further information about taking part and it will be announced on the project social media pages when your seeds go in the post.

**Please note, the project is not associated with any freebie websites and project seeds are not freebies or free samples as has been promoted by many of these organisations in previous years. Please do not share information about the project with these organisations. The project does not have the capacity to deal with the number of requests generated by being advertised on these websites and if featured, it will force seed distribution to stop.**

Seeds can only be sent to the UK and Europe due to import and export rules but the project wholeheartedly welcomes participation from anyone who wants to raise awareness of centronuclear and myotubular myopathy by growing a sunflower and people who buy their own seeds are welcome to join in (if you would like to do this, please get in touch advising where you will be growing your sunflowers, so you can be included on the project map).

Seeds are generally sent out in batches and are sent by second class post, so please allow time for delivery. Unfortunately we are unable to send seeds outside of Europe at this time but we welcome participants from around the world if they can source their own seeds.

### **Take photos and share**

All we ask in return for our seeds is that people share their photos - these can be photos of you planting your seeds, photos of your flowers as they grow or when they have flowered. Sharing the photos helps The Information Point raise awareness of centronuclear and myotubular myopathy, as well as allowing participants the opportunity to see the sunflowers being grown by others taking part in the project. Photos may be displayed on the project website, in the Information Point newsletter and on Facebook, Twitter, Flickr and Instagram. The photos also help evidence the achievements of the project when funding is required and successful funding applications mean the project can continue each year.

### **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. 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.

### **Donate to The Information Point**

The Big Sunflower Project is only possible through donations and funding, we do, however, welcome donations to assist with the running cost of the project and to ensure the future of the project.

### **Donate to the Myotubular Trust**

Alternatively, you can make a donation to the Myotubular Trust. 100% of all funds raised by the Trust goes directly towards research, to help find a cure or treatment for centronuclear and myotubular myopathy.

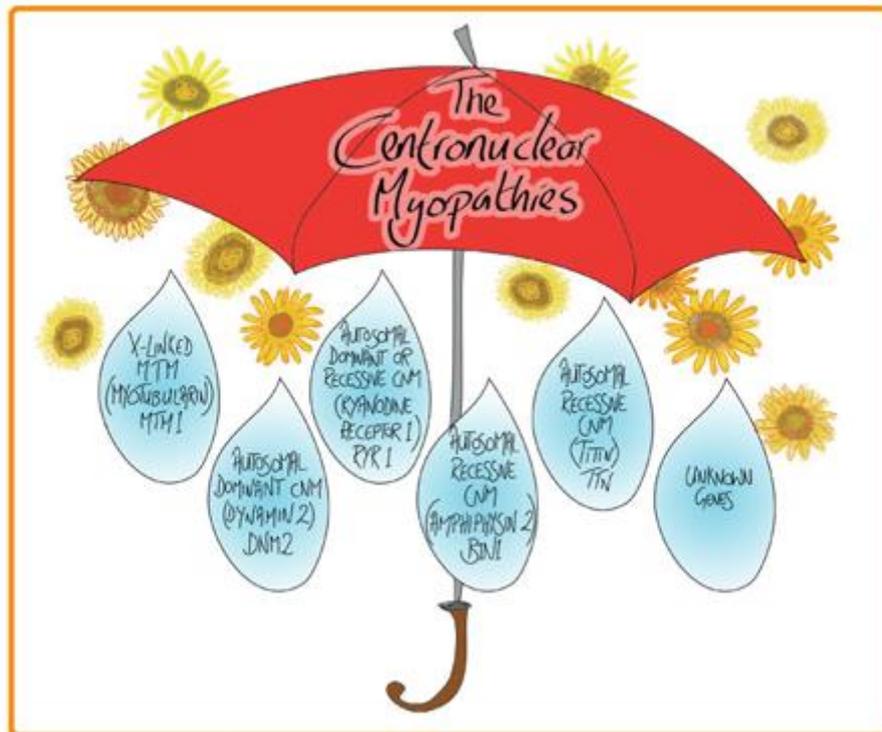
**Sunflower seeds for The Big Sunflower Project 2019 have been obtained from Kings Seeds at a large discounted price, with money donated to the project in 2018. Seeds have also been donated by Katrin Wurmitsch-Hohenwarter and her friends and family in Austria and Mike Rogers in the UK, who grew sunflowers during the 2018 project and harvested the seeds.**

**For further information visit The Big Sunflower Project website at <https://thebigsunflowerproject.wordpress.com/>.**

## 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](http://www.centronuclear.org.uk) or email [centronuclear.org@btoopenworld.com](mailto:centronuclear.org@btoopenworld.com).**