

The Big Sunflower Project



The Big Sunflower Project raises awareness of the rare neuromuscular conditions known as centronuclear and myotubular myopathy by sending sunflower seeds to people who have never heard of the conditions and by asking project participants to share photos of their sunflowers which are displayed online. 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.

Join in

- **Follow and share**
Find us on social media and share your photos, stories and growing tips
- **Get on the map**
Tell us where you are growing your sunflowers to be included on the project map
- **Share**
Share your seeds with family, friends, neighbours and colleagues
- **Raise awareness**
Put a notice at the place where you are growing your sunflowers to raise awareness of the project and of centronuclear and myotubular myopathy
- **Fundraise**
Hold a fundraising event and donate the proceeds to The Big Sunflower Project
- **Make a donation**
Seeds for the project are free but we welcome donations to ensure the future of the project
- **Learn**
Learn more about centronuclear and myotubular myopathy at <http://centronuclear.org.uk/>.

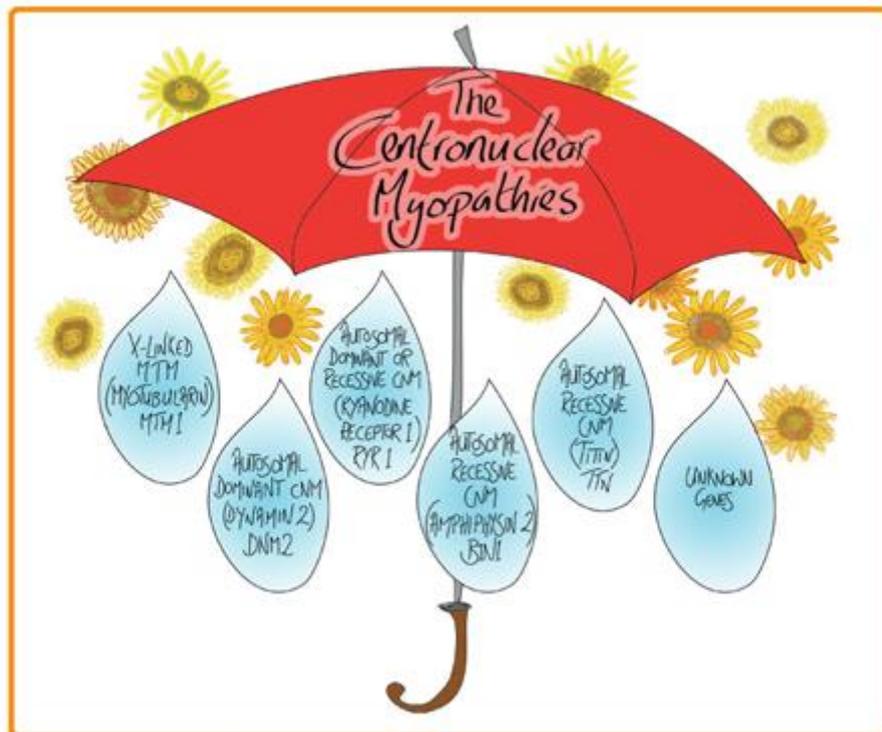
Further information

- **Website:** <https://thebigsunflowerproject.wordpress.com/>
- **By email:** centronuclear.org@btopenworld.com
- **Facebook:** <https://www.facebook.com/groups/406061643077357/>
- **Twitter:** @The_Info_Point (share using #TheBigSunflowerProject)
- **Instagram:** <https://www.instagram.com/thebigsunflowerproject/>
(share using #TheBigSunflowerProject)
- **Donate:** <https://thebigsunflowerproject.wordpress.com/donate/>

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.