



Wolfram Syndrome UK Caregiver Wellbeing Pilot Project

A recent Wolfram Syndrome UK (WSUK) survey identified a strong support need for WS carers. Most carers stated they struggled with their wellbeing, believing that caring for a WS affected person negatively impacts on their own mental and/or physical health. In addition, many stated their caring duties put pressure on their relationships, family life and finances, while half experience social isolation.

Pilot objectives

In response to these needs, WSUK has recently received a grant from the National Lottery Community Fund to launch a new pilot project. The objective of the pilot is to improve the wellbeing and reduce the isolation of WS parent/carers.

Pilot Project – wellbeing plan and activities

The pilot project will include a maximum of 20 parent/carers, who with a member of the WSUK team, will develop a wellbeing plan, identifying specific activities that will help to improve their emotional and physical wellbeing. Funding is available for WSUK to purchase wellbeing activities for each parent/ carer (up to a maximum amount). Parent/carers will provide feedback on how their wellbeing activities are supporting them. Parent/carers will be asked to record their experiences through photos/video to highlight how these activities have helped to improve their wellbeing.

Once the pilot study has been successfully completed, WSUK plans to apply for further funding, incorporating parent/carers feedback, to extend the project in the future for more WS carers.

For more information

To find out more about the new pilot or to register your interest in participating, please email the WSUK office (admin@wolframsyndrome.co.uk), or Marie (mariemcgee@wolframsyndrome.co.uk) or Gina (ginaisherwood@wolframsyndrome.co.uk) from the WSUK team. Alternatively speak with Jody, who can put you in contact with the WSUK team.

Please note contacting WSUK about this pilot project does not guarantee you will be able to participate.

Thanks to all the players of the National Lottery for making this new project possible.