

WELCOME TO THE EDUCATION PACK

The idea to produce this pack indirectly came from the families of children with neuromuscular disorders. Week after week they came to the Neuromuscular clinic here at Great Ormond Street Hospital with stories of difficulties that their children were facing in nursery, schools and colleges.

As a result the team decided to do an audit of families' experiences of education and the overwhelming need was for educational establishments to be provided with better information about their child's medical condition and needs. We felt that the best way to do this would be to provide an Education pack for families which would have specific and general information about their child's needs.

The contents of this pack include some general information about the special educational needs process, information about factsheets from other organisations including the Muscular Dystrophy Campaign and Contact A Family and some more specific information about your child's needs and medical condition.

We would welcome any feedback about this pack including comments on ways to improve or change it and you can do this by e-mailing us at:

Muscle.service@gosh.nhs.uk

We would like to finish by giving a big thank you to classmates from St James Senior Boys School and friends of Euan whose fundraising helped to produce this pack. We also would like to thank all the families who supported this project by completing the questionnaires that were handed out to them in clinic.

Best Wishes,

Dubowitz Neuromuscular Team