

What difference  
does it make?

All the difference to us!

For a moment, imagine having no strength in your arms, or legs, or even the strength to keep your eyes open, or to chew... or even the energy to breathe.... Imagine being young, with an active and inquisitive mind, with a desire to live a full, active and fulfilling life.

These are the frustrations and challenges faced daily by children with Myasthenia...

For parents, imagine the anxiety of discovering your child has a condition no one has ever heard of... imagine the feeling of isolation, uncertainty and fear about the future.

Ellie's facial weakness



Then with medication...

Myasthenic Kids is a charity which aims to support children with this rare condition, and the parents and carers who look after them.

Let us introduce ourselves...

## Contact details

For more information about the support network or to get in touch with us to join our network please email [info@myasthenickids.org](mailto:info@myasthenickids.org)

In September 2009 the MGA gave permission for creation of the MGA National Children's Branch. The new branch officers are:

**Melissa Jones, Chair.**  
[melissajones999@hotmail.co.uk](mailto:melissajones999@hotmail.co.uk)

**Helen Bedford, Secretary.**  
[helen@infopub.co.uk](mailto:helen@infopub.co.uk)

**Garry Hall, Treasurer.**  
[garry.hall8@ntlworld.com](mailto:garry.hall8@ntlworld.com)

**Myasthenic Kids**  
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Jim, aged 14 with CMS, says "It was good to see other children with Myasthenia as I never meet anyone else who has this... I loved the breakfasts and I liked going on HEX at Alton Towers. I have never been there before."

The Myasthenia Gravis Association  
Registered Charity No 1046443

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No 3038358

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[www.myasthenickids.org](http://www.myasthenickids.org)



## Myasthenic Kids

- staying in touch
- reaching out
- creating opportunities

the support network for  
myasthenic children,  
young people and their  
families

# What is Myasthenia?



## About Us

## Finding Strength Together

Myasthenia is a very rare condition characterised by fluctuating muscle weakness, which occasionally can be fatal, particularly if left untreated. Because it is so uncommon, many people have not heard of it, and so it's hard to raise the profile of the condition in the public realm.

There are two main types of Myasthenia;

### Myasthenia Gravis (Auto-Immune)

The body's immune system, in the form of antibodies, attacks and damages the nerve signal reception areas on the muscles - causing a breakdown in communication between nerve and muscle; this results in a loss of effectiveness of the muscle. The weakness commonly affects the muscles of speech, swallowing, eyes or breathing, as well as the legs and arms. MG is rare - one in 5,000 - even less frequent in children. The cause of this auto-immune reaction is not yet known.

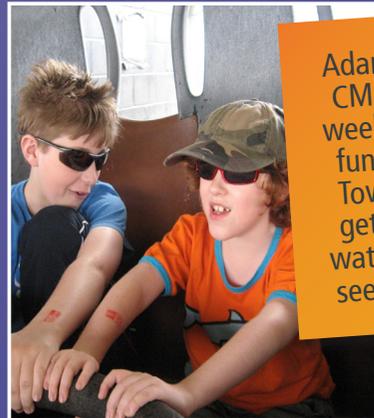
### Congenital Myasthenia (Inherited, Genetic)

Similar in symptoms to MG, (auto-immune), the causes of Congenital Myasthenic Syndrome, (CMS), are very different. In these cases, a number of different gene anomalies cause a spectrum of myasthenic symptoms. CMS manifests at birth or in early childhood and is less common than MG (one or two in a million).

Consequently there are very few myasthenic children in the UK.

So we are talking about a condition which is already very uncommon, and for children it is even less so. Which means there is often little information available for parents, medical practitioners and schools.

As parents, we have often struggled with the frightening path of finding a diagnosis for a seriously ill child and then with learning how best to support our children to grow and blossom into the inspirational young people that they are. Myasthenic Kids believe it is vital for parents, health professionals, and children to communicate and learn from each other.



Adam, aged 9 with CMS, "I think the weekend was really fun. I loved Alton Towers, especially getting wet in the water battle. I liked seeing my friends."

To that end, we have - since 2009 - organised an Annual Childrens Weekend. This has been an excellent time for everyone, where we can all share experience, hear about medical research, and have an enjoyable day at a theme park.



As well as this we hold occasional get-togethers, maintain web-based forums and support, and a member-generated e-mail advice and support network.



Some of our members have been seen on both local and national media discussing issues regarding the condition, and general children's disability issues.