



Update on Activities

To: All Stakeholders

News and Activities

It has been several months now since Action Cerebral Palsy launched the report of the parliamentary inquiry into cerebral palsy, "Enabling Potential – Achieving a New Deal for Children with Cerebral Palsy".

Whilst the intervening General Election meant that Government departments went into a period of 'purdah', we are pleased that Action Cerebral Palsy continued to maintain the links with the Departments for Education and Health which were developed during the parliamentary inquiry and after the publication of the report.

As a result, we have been able to have a number of meetings which have brought together officials from both departments, and other stakeholders, to focus on the issues facing children with cerebral palsies and their families.

Naturally, there is desire from both departments to monitor the implementation of the Children and Families Act 2014 and the SEND reforms.

Whilst these reforms apply to all children and young people across the spectrum of Special Educational Needs and Disability, Action Cerebral Palsy remains committed to ensuring that the specific and unique needs of children with cerebral palsies, as identified within our report, are addressed effectively as part of the SEND reforms. In relation to this, Action Cerebral Palsy has been asked by the Special Educational Needs and Disability Unit, Department of Education, to provide case studies, 'quotographs' and examples of good practice with regard to the implementation of the SEND reforms. **If** you would like to submit any such information, please send to info@actioncp.org and we will forward it to the Department on your behalf. We will also ensure that the recommendations of our report that do not directly relate to the SEND reforms, remains high on the agenda for further discussion and action, in particular, the need for specialist early intervention for 0-2 year olds and best practice guidelines and pathways of care. We are therefore very pleased to have been asked to join the Department of Health Disabled and Ill Child Services Team stakeholder group which will address issues facing disabled children and identify required changes in policy.

We were also privileged to be invited to a meeting with His Excellency Peter Szabadhegy, the Hungarian Ambassador, on 11th May, to discuss potential partnership working between Hungarian agencies and Action Cerebral Palsy.

Charity Registration

We are delighted that Action Cerebral Palsy will be registered shortly with the Charity Commission. This will be an important milestone which will enable the Charity to access the resources required to further our objectives and activities. We are very grateful to Paul Maynard MP, who oversaw the parliamentary inquiry so expertly, who has agreed to become the founding Patron of Action Cerebral Palsy, and to the Trustees who will be giving their time to support the growth of the Charity.

Action Cerebral Palsy

Our Vision

Our vision is that every child and young person in the UK with a cerebral palsy is able to access, from birth onwards, the best possible intervention, care, education and support which meets their complex and changing needs.

Our Mission

Action Cerebral Palsy works towards improving public, professional and political awareness of the issues facing children and young people with cerebral palsies.

We will represent the best interests of the cerebral palsy community to policy makers.

We are committed to developing models of best practice at national and local levels.

Our Strategic Goals

- To engage with policy makers in order to promote the creation of a national strategy and care pathways for intervention and provision for children with cerebral palsies.
- To be the preferred organisation for policy makers when seeking informed advice on cerebral palsy.
- To represent the best interests of the cerebral palsy community.
- To facilitate the development of best practice for intervention, care, education and support for children and young people with cerebral palsies across the UK.
- To facilitate and disseminate research on the cerebral palsies and therapeutic and educational intervention.

Website

We are delighted that we have now had over 1000 visits to our website, and continue to be followed on Facebook and Twitter by the many people whose lives are affected by cerebral palsy.

We look forward to giving you a further update on our activities in the Autumn.

Amanda Richardson, Chief Executive

Caroline O'Shea, Director

Action Cerebral Palsy

www.actioncp.org