

- Breathtakers is now a registered charity and therefore able to benefit from the Gift Aid scheme on all donations recieved.

- Children's health

The government wants to get parents' views on the new Child Health Strategy. It is vital that this strategy sets out what the plans are for disabled children's health services. A consultation event is running between 12-4pm on **Thursday 26th** June in central London. The organisers say that 'Those selected to take part would be given £100 to compensate them for their time and to put towards any additional child care costs; and transport would be arrange for those who require it.'

If you or any parents you know are interested in taking part, please email Ben Knight on BKnight@opinionleader.co.uk and copy your email to info@edcm.org.uk. They will then contact you with a briefing of the key issues to help you take part. You can also call Ben for more information on 020 7861 3285.

- Breathtakers received generous donation cheque from Conplusion 2008

- There is a new and much improved version of the Orphanet website, available now at www.orpha.net.

Orphanet has been working hard over the last two years to develop the new website in order to contribute to the effort being made for patients with genetic diseases across Europe.

- I am pleased to say that my local MP Rt Hon Sir George Young, has confirmed that he will be attending a joint meeting of the All Party Parliamentary Groups for Children, Youth Affairs, Autism, and Disability on Tuesday 6th May, 5.00-6.00pm, Committee Room 2, House of Lords. He will report back on the findings. He is also happy to support our e-petition. Please contact your local MP and ask for their support too.

- **Every disabled Child Matters** need your help to get local authorities and Primary care Trusts signed up, and to make sure those that have signed deliver on their commitments.

To help you get involved, they have produced a new supporter briefing - 'Making Disabled Children Matter Locally'. There are also new actions for supporters to take for those local authorities and PCTs who have signed the Charters.

So to download the briefing and to take part in the actions please go to <http://www.edcm.org.uk/localaction>

and help make disabled children a priority in your area. Please get involved!

- **New version of the Easyfundrasier site** makes it easier to earn to money for Breathtakers -

see our fundraising page

- Breathtakers took delivery of its new posters today which will be distributed to respiratory centres across the UK. They look great and will help raise awareness of OB. Many thanks to Dan at **Advent Colour Ltd**, Andover for his kindness and generosity.
- Breathtakers has gratefully received a cheque via Contact-a-Family small grants fund for £250 this will be spent on printing posters/leaflets to raise awareness of OB in respiratory hospital waiting rooms and wards.
 - Breathtakers has been added to the new BPOLD site as a link
 - Breathtakers was featured on the December Contact-a-Family e-news letter

- RARE DISEASES: "EUROPE'S CHALLENGES"

This is a Public Consultation regarding a future European Commission Communication on rare diseases. You can now view the document from the link on our Research page.

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Details of the website have now been sent electronically to all members of the British Paediatric Respiratory Society. Many thanks to Dr Ian Balfour-Lynn, Chair of BPRS. This is a fantastic step in raising awareness amongst professionals.

- Breathtakers is now listed on the databases, contacts or links of Contact-a-Family, British Lung Foundation, Orphanet, Netmums, Eurodis and Specialistinfo.com. We are now easier to find and contact.
- Breathtakers also has links now to the USA, Australia and New Zealand. We are looking to develop this as a collaborative role.