

MCADD and Disability Living Allowance (DLA)

Our lovely son Marco was born in April 2006 and we were extremely fortunate to be screened for MCADD on the pilot study that was taking place in the United Kingdom. We wanted to find out as much information as possible and thanks to the support of **Climb** we joined the forum. This is how we found out about disability living allowance; it seemed very hit and miss as to who received it but we wanted to give our son everything he was entitled to. It did take me some time to decide if it was appropriate for us to apply and this is, I feel, a personal decision. At the time I do recall thinking that I really did not want him labelled and in retrospect it has not been like that at all.



We first applied for DLA when Marco was three months old. The form was very daunting and I filled it in to the best of my ability but unfortunately six weeks later we were refused. I chose to appeal and this took several more weeks and we had to face an independent panel of four professionals, which was very hard. After considering our case they agreed we were not entitled. They deemed that Marco needed no extra care than any other child of his age would need. It really is ironic that all those extra night feeds and extra care we provide is the only reason we have healthy MCADD children in the first place!

When Marco was eight months old we had our first serious illness which put us in hospital for five days and it was then that the seriousness of MCADD hit me, we were admitted to hospital quite a few times over the winter, and it was at this time I started to keep a note book of illness, I even jotted down when we used the emergency regime or just did more than the usual night feed. Some families do keep a care diary, which you can also submit.

In March this year out of the blue a community nurse I had met at our playgroup contacted me to ask if I was going to try again and she had made contact with a few people that were willing to help me fill out the form if I wanted them to. So I sent for the form and to be honest, I put it in a drawer because I really could not face it again. However she was very persistent and e-mailed me to remind me to fill it in. So reluctantly I sat for an afternoon and used my notes that I had made to fill out the form and it really was quite gruelling but you have to fill it in using your worst moments and that's just what I did. It was almost like reliving the experiences and this was mentally very tough. I also contacted **Climb** who sent me a personal supporting letter and some articles; you have to remember that MCADD is relatively new to the medical world and the chances are the people reviewing your application will know very little about the disorder so you really do have to spell it out for them. Send them as much information as you can as it all helps.

Eight weeks later we were shocked and thrilled to find out that we were going to get DLA and we will continue to get it until Marco is three years old and it will then be reviewed again.

We are so grateful to all the offers of help from the professionals and other families that helped us in our claim and we are so pleased that we are helping to raise awareness of MCADD.

Good Luck.

Love from Anita, Max, Finn and Marco Brady x

