



MGA National Children's Branch Family weekend Butlins June 2012

Notes from conference: Taken by **Mary Fenner**

Welcome from Chair person Melissa Jones.

All members present introduced themselves and their link to MGA.

Guest speaker – Jim Hiew – Introduced; Hayden Collins helping with slides.

Home NIV

Slides introduced us to Bipap and Cpap and basics of ventilation discussed.

A show of hands revealed that many of the families present have children with respiratory difficulties but have no support in the home for this.

Suggestion to those who have concerns: to request a sleep study to monitor Oxygen saturation.

Suggestion is to ask for two nights in a row – doing the study at home in own surroundings is more beneficial than in a hospital setting. Ensure that they are looking at their AHI and Oxygen saturation in relation to the meds the child takes.

Note: ensure that those carrying out the study know when their child takes their meds and realises that as the night goes on they wear off; certain parts of the night will inevitably be better/worse than others.

Jim explained the mechanics of respiration showing details of gaseous exchange in normal breathing.

He went on to show different varieties of ventilators.

Pressures required explained:

Home ventilation is pressure ventilation.

No pressure = normal breathing.

CPAP gives a constant pressure.

BIPAP supplies two pressures dependent on inspiration and expiration – suggestion that this breaths for them.

BIPAP improves tidal volume and CO₂ removal.

Jim also introduced the concept of a humidifier to moisten the air in the child's bedroom.

Gary Collins posed the question – What are the warning signs for parents?

Jim Hiew replied:

Fatigue

Lack of concentration.

- it was discussed that this is difficult as these are generally symptoms of CMS and MG.
Discussion had of how difficult it is to apply masks to children – suggestion from Jim Hiew was the potential use of a nasal pillow.

Helen Bedford informed us that she has a copy of a paper from Anita Symons – possible PDF copy to be made available for those interested in sleep study and ventilation.

Ventilation -

Improves quality of life – fight to get one

Some personal testimonies from members about their use of ventilation in helping to reduce infection and therefore reduce hospital stays.

Second guest speaker introduced – Steve Bradshaw; Benefits advocate.

Steve to make the presentation available online,

Key points:

Applications are evidence based

Get a home assessment from local authority – don't be afraid of involving social services they are a good source of evidence. Contact them directly or via a GP referral.

Online assessment available: http://www.direct.gov.uk/en/diol1/doitonline/dg_10017715

– ask for enhanced rate.

If you require more in the way of funding/support take a look at funderfinder:

<http://www.funderfinder.org.uk/>

Turn2us – an A to Z of charities.

Remember that every local authority will differ – be insistent about your child's needs.

Educational needs:

Contact Local Education Authority to initiate statements for children as soon as possible to ensure all support is available for each child.

Parents must push for everything.

Transport needs discussed; advice on presentation.

Shape your argument on the boundaries of legislation – make sure you know your entitlement and push to get it.

Talk to local MP for support of getting nowhere.

Transition from child to adult discussed.

Advice is available from Steve Bradshaw.

MGA Children's Branch CEO Ruth Bury introduced.

Ruth Discussed the national debates that we have been involved in

- Consultation UK plan Rare Diseases focus is the provision of specialist nurses, the transition from child to adult, services for Neurological conditions working with neurological alliance. Long term conditions outcomes strategy.

Ruth made a plea for help from parents who might be able to provide feedback on what we want from the MGA – most parents agreed to help if needed.

MGA currently provides:

Care – 5 of 6 nurses funded

Research

Education

DVD's and leaflets to health professionals – if they haven't got any when we go for a consultation/clinic let MGA know.

Discussion about fundraising:

Asda token collections – nominate your child in your local store.

The potential patient registry was also discussed.

Ruth introduced the young people branch who meet regularly in London – could be useful for those in transition.

Need for higher profile on social media.

Can they do more with the posters/leaflets? General view is they are getting better!

Presentation of certificates to those who have been fundraising from Ruth.

Some outcomes from the conference:

What should we do with our fundraising?

We need to encapsulate all of our knowledge into one place to make information readily available.

Do we need an advocate to help inform us of everything we need to know?

AGM

Welcome

Chair: Melissa's report – update on how things are going

Fundraising continues

Getting new members

Facebook page has been a success

Website revamp – needs to be a more useable resource.

Ideas for fundraising:

Supermarkets – as suggested nominate your child in your local Asda token collection – use the registered charity number.

Sainsburys

Tesco

And Waitrose all have similar initiatives.

New ebay selling leaflet made available to help members sell for the MGA.

Can we sell our bottles and badges on here?

Sourcing raffle prizes – best to ask businesses after Christmas or after the April Budget. Tesco have their new charity budget every summer.

Kay Rose has had her local pub agree to sponsor us for three months.

Treasurer report:

Bank account

£2297 approx

Head office £24, 682 (Butlins has not come out of this yet)

Children in Need money yet to be received – must be spent within a certain time.

Discussion of what to do with the money to be had at a later date.

Nominations:

Chair Melissa Jones

First Helen Bedford

Second Lisa Beaten

Secretary Helen Bedford

First Gary Collins

Second Melissa Jones

Treasurer Garry Hall

First Gary Collins

Second Helen Bedford

Media Gary Collins

First Melissa Jones

Second Helen Bedford

Schools Advisor Kerry Webster (nominated in her absence)

First Gary Collins

Second Helen Bedford

Fundraising officers Geraldine Thompson and Maxine?

First Helen Bedford

Second Melissa Jones

Benefits Advisor Rachel Collins

First Helen Bedford

Second Melissa Jones.