

Our Ref: CH/AJ/AH1565586

Date of Clinic: 05/09/2017

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Alder Hey
East Prescott Road
Liverpool
L14 5AB
www.alderhey.nhs.uk
Tel: 0151 228 4811

Fax: 0151 252 5929

The Parent/Guardian of
Miss Gwendolyn Vials-Moore
2 Coronation Drive
Crosby
Liverpool
Merseyside
L23 3BN

Department of Respiratory Medicine
Drs Halfhide/Selby (0151) 252 5165 Dr Semple 293 3641
Prof Southern/McNamara/Dr Mayell/Thursfield 252 5777 Dr Sinha 252 5054

Dear Parent/Guardian of Gwendolyn Vials-Moore

Gwendolyn VIALS-MOORE
2 Coronation Drive
Crosby, Liverpool L23 3BN

D.O.B. 22/08/2014
Hospital No. AH1565586
NHS No. 701 057 1422

Diagnosis

1. Trisomy 21
2. ? Burnside-Butler Syndrome
3. Previous gastroesophageal reflux disease ? not controlled at the moment
4. Obstructive sleep apnoea, on nocturnal CPAP
5. Recurrent lower respiratory tract infections
6. Cardiac arrhythmias ? neurogenic in origin, no structural cardiovascular defect
7. No evidence of Hirschsprung's

Medications

1. Omeprazole soluble MUPS 10 mg (5ml at night and 2.5ml-5ml in the morning)
2. Gaviscon 5ml 4 times a day and also at night
3. Movicol for constipation

History/Current Symptoms

It was lovely to see Gwendolyn in clinic today and you have lots of concerns with Gwendolyn and her breathing overnight. She continues to have problems with sleep initiation and self-settling if she wakes up. She will sometimes fight having her ventilator on her but similarly she is quite strong minded on whether she wears her glasses and/or her BAHA. She is on a CPAP of 8 and usually there is no mask issues except that she knows how to move it, take it off and play with the vent and she has had her adenoids and tonsils taken out in October. We have had a sleep study done earlier this year which I wrote to you with the results and we went through a little bit more. Basically, on the CPAP of 8, this shows that this is treating her sleep related upper airway obstruction. We also found no reason for her to have a disturbed sleep ie there was no obstruction that was causing her sleep to be disturbed. I just reiterated that her CO² was within the normal range although it was at the top end. We don't worry unless the CO² is consistently above 50 for about 25% of the total sleep time which hers was not. There was also drift of the CO² as it went throughout the study and her average was 48.6. You commented that this is going up.

Management Plan

1. I don't feel at the moment that we have enough evidence to increase the CPAP and potentially if she doesn't need more pressure then we may make her gut symptoms worse. I was pleased that you have finally had agreement for a bed and that actually being slept upright might help her gastro symptoms. You have been recently seen by the Gastro Team who are thinking about her reflux.
2. I did suggest again today whether is it worthwhile thinking about a small dose of Melatonin to help initiate sleep. I appreciate that we can't give her long acting at the moment, but it may be enough just to put her to sleep at the beginning of the night but you are not that keen on that at the moment but I am more than happy to start that if you would like to. Otherwise I think we should just see how we go and organise a sleep study again in the near future.
3. I was disappointment to hear that Gwendolyn has been taken off a Child in Need. I wasn't aware that Gwendolyn was a Child in Need and that she has been downgraded. I think Gwendolyn and Isaac both have a lot of problems that are difficult for you to manage as a family and that any review of Gwendolyn's needs need to be borne in context. Obviously I will continue to be happy to help you in any way we can. I know that from a behavioural sleep point of view we don't have a designated sleep hygienist and I know that you have accessed some sleep training via SENSE and obviously Clare Chamberlain-Parr has initiated some strategies with you as well and obviously we will try and help wherever we can.

I will catch up with Gwendolyn in the near future.

Yours sincerely

Electronically checked and authorised by Dr Clare Halfhide

Dr Clare Halfhide
Consultant in Respiratory Medicine

Copy to:

Dr NA Tong
Blundellsands Surgery
Blundellsands
Liverpool
L23 6TZ

Dr A Van Heerden
Associate Specialist in Community Paediatrics
Alder Hey Children's NHS Foundation Trust

Mr D Perry
Consultant Orthopaedic Surgeon
Alder Hey Children's NHS Foundation Trust