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# 1

## **The Association between Congenital Central Hyperventilation Syndrome (CCHS) and the Marcus Gunn Jaw-winking Syndrome: A Case Study and Literature Review**

Dr James Baker, Dr Louise Selby  
Cambridge University Hospitals, Cambridge, United Kingdom

### **Abstract**

Background: We present a case of a 4 month-old male infant with CCHS and Marcus Gunn Jaw-winking Syndrome. He had a Neonatal Unit admission at birth for Hirschsprung's Colitis. Aged two weeks, he was diagnosed with Marcus Gunn Jaw-winking syndrome after it was noted that he had a partial left upper lid ptosis and intermittent lid elevation when he breastfed.

The family consented to participate in whole genome sequencing; results confirmed a PHOX2B heterozygous pathological variant. At four months of age he had central apnoeas on a sleep study, confirming the diagnosis of CCHS.

Objectives: To present a case of the association between CCHS and the Marcus Gunn Jaw-winking Syndrome and to perform a literature review evaluating the evidence for this association.

Methods: A literature search was performed utilising Medline via Ovid and Scopus – see figure one.

Results: Three papers in total were found. One paper was removed as a duplicate and one removed after screening for eligibility. This resulted in one paper: a case study of a 2 month-old presenting with apnoeas and a right sided ptosis. The two references in this paper and seven citations for this paper were reviewed but yielded no further papers of interest.

Conclusion: There is a documented association between CCHS and Marcus Gunn Jaw-winking Syndrome. However, there is limited literature about this association, likely due to the low prevalence of both CCHS and the Marcus Gunn Jaw-winking Syndrome. Our case study reveals the association between CCHS and the Marcus Gunn Jaw-winking Syndrome which is thought to reflect the PHOX2B mutation (which results in CCHS) also causing cranial dysinnervation in the oculomotor nucleus.

We recommend those infants with unilateral partial ptosis and intermittent lid elevation when feeding have targeted genetic screening for PHOX2B mutations.

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### **Categories**

5. PHYSIOLOGY, SLEEP, NIV

## **Reduced adherence <50% to prescribed nebulisers in children with cystic fibrosis is associated with increased hospital admissions and lower FEV1 Z-Score.**

Mr Kieren James Lock, Dr Louise Selby  
Addenbrooke's Hospital, Cambridge, United Kingdom

### **Abstract**

#### Introduction:

Adherence is a challenging factor when discussing treatment in patients with chronic conditions. Modi and Quittner (2006) reported adherence to treatment to be below 50% in children with Cystic Fibrosis. Goodfellow et al., (2015) found 49% of patients have low adherence to Physiotherapy. Poor adherence to treatment is linked to a decline in health outcomes such as increased use of IV antibiotics; this poses significant effects on health outcomes and cost to the NHS (Eakin et al., 2011). This analysis aims to explore one paediatric cystic fibrosis centre's adherence to nebulisers and how it has affected health outcomes.

#### Methods:

Ineb data was routinely downloaded at annual review. The percentage of time the child was fully, partially and non-adherent to prescribed doses was synthesised from this data. Children were split into those above 50% fully adherent and below 50% fully adherent, as per the average level of adherence documented by Modi and Quittner (2006). 17 children had <50% adherence to prescribed nebulisers and 28 had >50% adherence. Number of hospital admissions for the year of annual review was recorded. FEV1 and FVC Z-Scores were calculated based on GLL reference equations.

#### Results:

Data for 45 children (number female and number male), age 10 years (interquartile range 9-13 years) was available for analysis. Median adherence was 65% (28-82%). Median FEV1 Z-Score was -0.47 with median FVC Z-Score -0.13. Median number of hospital admissions for the year prior to annual review was 1. FEV1 and FVC Z-Scores were significantly lower in those patients with <50% adherence to prescribed doses of nebulisers given via the ineb,  $-1.43$  vs  $-0.26$ ,  $p=0.006$  and  $-0.65$  vs  $0.35$ ,  $p=0.018$  respectively. Number of hospital admissions were significantly lower in those children with adherence >50%,  $1$  vs  $0$ ,  $p=0.04$ .

#### Conclusion:

Adherence <50% to prescribed nebuliser treatment in our paediatric CF cohort shows significant differences in spirometry with lower FEV1 Z-Scores. Informing patients of these data patterns can generate positive dialogue between physiotherapist and patient with the aim of exploring adherence issues to move to more positive outcomes. There may also be a cost benefit for the NHS with significantly lower hospital admissions in the >50% adherent population.

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## **Categories**

### 2. CYSTIC FIBROSIS

### 3

## **“Less invasive surfactant administration (LISA) to preterm infants on high-flow nasal cannula therapy (nHFT)”.**

Mr Asad Nasim<sup>1</sup>, Dr Sanja Zivanovic<sup>1</sup>, Mr Charles Roehr<sup>1</sup>, Mr Muhammad Bakar<sup>2</sup>, Dr Alexandra Scrivens<sup>1</sup>

<sup>1</sup>John Radcliffe Hospital, Oxford, United Kingdom. <sup>2</sup>Wexham Park Hospital, Slough, United Kingdom

### **Abstract**

#### Background:

In Neonates with RDS to avoid intubation and Mechanical Ventilation(MV), LISA was developed. Systematic reviews report that LISA compared with the standard surfactant replacement was associated with a lower rate of death and BPD at 36 weeks, risk of BPD, need for MV within 72 hours of birth, or MV during the hospital stay.

#### Objectives:

- To longitudinally monitor the current local practice of LISA and its effectiveness when nHFT was predominantly used.
- To assess the efficacy of current protocol of providing a modified dosing regimen of conventional pre-intubation medication for giving LISA.

#### Methods:

Retrospective audit of nHFT-LISA in two Thames Valley network neonatal units. Unit one is the tertiary NICU at the John Radcliffe Hospital, Oxford and unit two is the level 2 Neonatal unit at Wexham Park Hospital, Slough. Data was collected between 01.10.2019 to 01.09.2020 and then analyzed. *The local LISA protocol suggests giving Fentanyl 1/3<sup>rd</sup> dose and atropine full dose just before doing LISA. The premedication were omitted only after consultant decision based on recent studies.*

#### RESULTS:

46 infants received surfactant by LISA (40 in tertiary center and 6 in level II neonatal unit). 26/46 neonates did not receive premedication, while the rest of the 20/46 neonates did receive premedication. All 6 patients in Level II unit were given premedication. When comparing the groups, the results are as shown in table 1 attached:

#### Conclusions:

In our small retrospective observational dual cohort study, LISA was an effective method of surfactant administration in RDS patients stabilized on nHFT. We observed reduced rates of MV in the first 72 hours following nHFT-LISA. nHFT-LISA was feasible and well tolerated without use of premedication. The use of premedication should be reserved for babies in whom procedural difficulties are expected, this will depend on baby's tone, size or gestation.

Based on our very positive experience with nHFT-LISA in a non-tertiary unit, we believe that there would be scope for use of LISA in level 2 units which will need more training of the staff there. It will reduce transfer to higher level care centers for more invasive respiratory therapies.

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## **Categories**

4. NEONATAL PULMONOLOGY, BRONCHOSCOPY, CONGENITAL MALFORMATIONS, RESPIRATORY INTENSIVE CARE & AIRWAYS

## The Difficult Asthma Multi-Disciplinary Clinic: Silver Linings of the COVID Cloud

Miss Lydia Roberts<sup>1</sup>, Dr Wanda Kozłowska<sup>2</sup>

<sup>1</sup>School of Clinical Medicine, University of Cambridge, Cambridge, United Kingdom. <sup>2</sup>Department of Paediatric Respiratory Medicine, Addenbrooke's Hospital, Cambridge University Hospitals NHS Trust, Cambridge, United Kingdom

### Abstract

**Introduction and Objectives:** Approximately 5-10% of children with asthma have problematic severe asthma, defined as poorly controlled asthma despite daily doses of at least 800µg budesonide or equivalent for 6 months. Such patients require referral to specialist tertiary care difficult asthma (DA) teams for systematic assessment and multi-disciplinary management. Like most outpatient services, paediatric DA clinics were disrupted by the COVID-19 pandemic, and restructured to optimise care despite restrictions on face-to-face appointments. This study aimed to assess the COVID-19 pandemic's impact on initial assessments by a tertiary centre paediatric DA clinic, specifically relating to multi-disciplinary team (MDT) member assessment and investigation completion.

**Methods:** A list of patients referred to the paediatric DA clinic between 1/9/2016 and 31/12/2020 was obtained from the electronic notes database. 144 patients were identified, and their electronic records retrospectively reviewed. Patients were considered to have been seen 'pre-COVID' if their initial appointment occurred prior to 23/03/2020, and 'post-COVID' if their initial appointment was on or after 23/03/2020.

**Results:** Of the 144 patients, 130 were initially seen pre-COVID and 14 were initially seen post-COVID. Post-COVID, fewer patients had fractional exhaled nitric oxide (FeNO) (71%) and spirometry (57%) as part of their initial work-up compared to pre-COVID (FeNO – 85%; spirometry – 96%). This contrasted the proportion of patients having physiotherapy and psychology assessment; in the post-COVID group, 64% had physiotherapy review and 50% had psychology review following their DA referral, compared to 52% and 26%, respectively, pre-COVID. Waits for specialist assessment after initial DA clinic appointments also reduced post-COVID. Median waits for physiotherapy and psychology assessments decreased from 91 and 180 days in the pre-COVID group to 70 and 35 days, respectively, post-COVID.

**Conclusions:** Unsurprisingly given restrictions on in-person appointments and aerosol-generating procedures, FeNO and spirometry assessment were lower in DA clinic patients first seen post-COVID. However, improvements were seen in physiotherapy and psychology assessment post-COVID, as physiotherapists and psychologists could attend more DA clinics to see new patients at their first appointment. This highlights changes to working in response to COVID-19 can actually help streamline services and promote early MDT input when managing patients with problematic severe asthma.

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### Categories

1. ASTHMA / ALLERGY

## **COVID-19: Impact, experiences and support needs of children and young adults with Cystic Fibrosis and parents.**

Dr N Collaço<sup>1</sup>, Dr J Legg<sup>2,3</sup>, Dr M Day<sup>2</sup>, Dr D Culliford<sup>4</sup>, Ms A Champion<sup>2</sup>, Ms C West<sup>2</sup>, Professor A Darlington<sup>1</sup>

<sup>1</sup>University of Southampton, Southampton, United Kingdom. <sup>2</sup>Southampton Children's Hospital, Southampton, United Kingdom. <sup>3</sup>NIHR Southampton Respiratory Biomedical Research Centre, University Hospital Southampton NHS Foundation Trust, Southampton, United Kingdom. <sup>4</sup>NIHR Applied Research Collaboration Wessex, University of Southampton, Southampton, United Kingdom

### **Abstract**

#### **Introduction and Objectives**

Little is known about the impact of COVID-19 and the United Kingdom's (UK) national shielding advice on patients with cystic fibrosis (CF) and their families. This study explored the experiences and support needs of children and young adults (CYAs) with CF and parents who have a child with CF during the COVID-19 pandemic.

#### **Methods**

CYAs with CF and parents of CYAs with CF completed an online survey of open and closed questions exploring experiences, information and support needs and decision-making processes in relation to the COVID-19 pandemic. Qualitative thematic content analysis and descriptive quantitative analyses were undertaken.

#### **Results**

CYAs aged 10-30 years (n=99) and parents of CYAs aged 0-34 years (n=145) responded. Parents (72.7%) and CYAs (50.0%) worried about the virus, and both were vigilant for virus symptoms (82.7% and 79.7%). Over three-quarters of CYAs were worried about their own health if they caught the virus. CYAs worried about feeling more isolated during the virus (64.9%). Qualitative findings highlighted that families faced significant challenges in relation to the advice to maintain complete isolation (shielding). Whilst shielding acted as a safety net for some individuals, for many, there was a negative impact on their psychological wellbeing due to reduced social activities, lack of physical exercise, and absence from school/university/work. Parents also reported challenges regarding changes made to their child's care and access to support.

#### **Conclusions**

Parents and CYAs highlighted the need for clear, up-to-date, and tailored advice on individualised risks and shielding. Providing this information in a timely manner may help alleviate anxieties regarding the virus and may help promote confidence in managing the psychological impact of the disruption caused to the lives of these families.

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## **Categories**

2. CYSTIC FIBROSIS

## Overcoming COVID barriers through proactive collaborative care

Dr Isra Husain<sup>1</sup>, Dr Akshat Kapur<sup>1</sup>, Dr Simona Turcu<sup>2</sup>, Dr Camilla Hathaway<sup>3</sup>, Miss Victoria Powell<sup>2</sup>, Dr Shankar Kanumakala<sup>1</sup>

<sup>1</sup>Royal Alexandra Children's Hospital, Brighton, United Kingdom. <sup>2</sup>Evelina London, London, United Kingdom. <sup>3</sup>University Hospitals Sussex NHS Trust, Brighton, United Kingdom

### Abstract

#### Background

Prader-Willi syndrome (PWS) is a genetic disorder with an incidence of 1 in 10-30,000 individuals. Clinical features are hyperphagia and obesity; hypotonia and sleep apnoea add significant morbidity.

Recent guidance recommends early recombinant human growth hormone (rhGH) therapy. Its initiation is associated with worsening sleep apnoea, thus it is important to assess and support breathing first.

#### Case summary

We highlight a PWS male infant case, showcasing teamwork and effective communication, despite pandemic-related barriers.

Our patient was born at 33 weeks' gestation with hypotonia and poor swallow, requiring non-invasive ventilation (NIV) and nasogastric feeds. Genetic testing confirmed PWS (maternal uniparental disomy). Cardiorespiratory sleep studies (CR-SS) showed normal gas exchange. He was discharged at 4 weeks corrected gestational age (CGA) after weaning to home oxygen. Following detailed discussions with his parents regarding benefits of early rhGH therapy, we agreed to start rhGH at 6 months CGA.

In-hospital CR-SS at 3 months CGA showed significant obstructive sleep apnoea (OSA) with parents reporting daytime sleepiness. NIV was trialled at Hospital A and was referred to long term ventilation (LTV) team at Hospital B to establish home NIV. Hospital B liaised virtually with the family and admitted him for NIV trial and training. Parents subsequently noticed marked improvement in alertness and feeding abilities.

Both teams worked together with virtual consultations and home CR-SS, resulting in improved ventilation. rhGH therapy was started at 7 months CGA, at low dose to minimise risk of worsening OSA. CR-SS 6 weeks later were reassuring, confirming rhGH safety and allowed increasing to full dose. This strategy led to remarkable benefit, with improved daytime alertness and social interaction.

Proactive parental engagement was crucial in this clinical journey. Parents ensured effective three-way virtual communication, optimising care. Our patient's mother, as co-author, feels "delighted with his improved tone, posture and core muscle strength, allowing optimal interaction with surroundings".

#### Conclusions

We have emphasized the importance of patient and family-centred care despite the barriers due to the pandemic. Effective cross-hospital communication, parental engagement and adaptation to COVID-19 challenges facilitated prompt initiation of ventilation and timely rhGH therapy, optimising patient health outcomes.

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**Categories**

5. PHYSIOLOGY, SLEEP, NIV

## Asthma locked down by COVID-19.

Dr Richard Chavasse, [Dr Hafsa Jan](#)

St George's University Hospitals NHS Foundation Trust, London, United Kingdom

### Abstract

**Background:** The impact of SARS-CoV-2 on children and young people (CYP) was uncertain at the start of the pandemic although early evidence indicated CYP fared well with acute infection. Asthma precipitated by viral infections is one of the commonest reasons CYP present to hospital and was a potential cause for concern during the pandemic.

**Setting:** St George's Hospital, London

**Participants:** We compared the CYP (1-17 years) presenting to the hospital with acute asthma/wheeze between March 2020-February 2021 to the number who presented over the previous year. CYP were divided into preschool (1-5yr) and school-aged (>5yr) groups to understand any age-related difference in impact. Our asthma nursing team record all new presentations daily.

The primary objective was to compare differences in presentations during the pandemic and the impact of lockdown and school closures. Secondary outcomes included the severity of attacks and the number of PICU admissions.

**Results:** 386 children presented to our hospital with acute wheeze between March 2020 and February 2021. This represented a 65% reduction on the previous year (1090 presentations). The difference increased during periods of national lockdown / school closures (April-June 2020 and Jan-Feb 2021) with between 81-94% fewer attendances. The proportion of preschool and school-aged children was the same in both periods.

The number of severe or life-threatening attacks increased from 8.6% to 14%. 19 (5%) children were admitted to PICU, compared to 11 (1%) the previous year. 16/19 (84%) PICU admissions occurred between Sept-Dec when schools reopened. No CYP admitted to PICU had PCR evidence of SARS-CoV-2.

**Conclusions:** We noted a significant reduction in emergency presentations over the whole duration of pandemic, specifically during lock-down and school closure however there was a concerning increase in admissions requiring PICU when schools reopened. This may be explained by reduced viral transmission due to social distancing in conjunction with delayed hospital presentation due to fear of covid. Other potential factors postulated include improved adherence to preventer medications and air quality.

This unusual situation presents a rare opportunity to learn lessons as no other intervention has produced such a significant change in acute asthma presentations.

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### Categories

1. ASTHMA / ALLERGY

## **Clinical Pearls - A small step towards learning in the Pandemic**

DR GAYATHRI KARTHIKEYAN, DR SHRAVANTHI CHIGULLAPALLI, DR PAMELA OHADIKE, DR ASMA KIANI  
CALDERDALE ROYAL HOSPITAL, HALIFAX, United Kingdom

### **Abstract**

#### **Background**

In these unprecedented times, delivery of teaching has had many challenges. Here, we present our learning initiative which is made accessible to the entire team on a weekly basis. It encompasses sharing of snippets of clinical information on a digital platform and we named it 'Clinical Pearls'.

#### **Aim**

To improve learning by sharing knowledge and experiences among the multidisciplinary team in the COVID pandemic.

#### **Methods**

- A survey was conducted, which identified the unmet learning needs in the pandemic.
- We started to collate slides on google drive to include- problem based learning, interesting journal articles and sign posting to useful resources.
- The nursing team also came forth with learning points from their Quality improvement projects and recent clinical incidents.
- These learning sheets were circulated on an electronic platform every week amongst the entire team.
- After a trial period of 8 weeks, a survey was conducted, to gather valuable feedback on Clinical Pearls.
- We have also developed a certificate of appreciation to value each individual's contribution to Clinical Pearls.

#### **Results**

The response from the feedback survey, after a trial period of 8 weeks, are as follows-

- All the participants, unanimously supported and were satisfied with the quality and usefulness of the slides.
- 100% of the respondents recommended it to become part of ongoing departmental educational activity.
- 95% of the responses highlighted that Clinical Pearls encouraged more reflective practice.

Clinical Pearls has been very well received by the department. We were given appreciation in the recent local Clinical Governance and Quality Improvement meetings. This learning venture has been commented as good innovative practice and shared with Patient safety & Quality board.

## **Conclusion**

Clinical Pearls has become an integral part of departmental learning. This initiative has played a vital role to promote patient care, safety and improve reflective practice.

We are hoping to continue Clinical Pearls beyond the pandemic and to promote it across various specialities in the hospital and around the region.

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## **Categories**

6. LUNG HEALTH/ PUBLIC HEALTH / COVID-19 Pandemic

## Polysomnography findings of children with Neuromuscular Disease and the outcome following start of Home Mechanical Ventilation at a tertiary care hospital in India

Dr. Supriya Shinde, Dr. Ilin Kinimi  
Manipal Hospitals, Old Airport Road, Bangalore, India

### Abstract

**Background :** Sleep Disordered Breathing (SDB) is common in children with neuromuscular disease (NMD) and is often under-diagnosed especially in a developing country like India.

**Methodology :** This is a retrospective observational study. We included children with NMD upto 18 years of age who had undergone level 1 PSG between January 2018 to December 2020 and are on Home Mechanical Ventilation (HMV) at a tertiary care hospital in Bangalore, India.

**Results:** Forty six children diagnosed with NMD with a mean age of 8years 9months when the PSG was done were included. History of SDB was present in 43.47% of children and 36.95% had history of lower respiratory tract infection in the past.

The PSG findings showed a mean sleep efficiency of  $82.72 \pm 12.82$  minutes. The mean Apnoea Hypopnea Index (AHI) was  $17.16 \pm 15.12$  per hour of total sleep time, with 19.5% of children having mild and moderate OSA each, and 60.86% having severe OSA. Obstructive apnea, Central Apnea and Mixed Apnea was present in 71.73%, 23.91%, 23.91% of the children respectively. Mean arousal plus awakening index was  $10.76 \pm 8.20$ . The sleep disturbance was most common during REM sleep in 88.37% of children.

Average age at initiating ventilation was 8 years 10months. After the start of NIV there was a reduction in the rate of hospitalization in these children.

**Conclusion:** SDB is common in children with NMD. HMV improves quality of sleep in these children. In our study no child had any untoward event and the number of hospitalisations post HMV use had reduced. To the authors knowledge, this is the largest case series of children with NMD who had a PSG done and were started on HMV from India.

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### Categories

5. PHYSIOLOGY, SLEEP, NIV

## Home Mechanical Ventilation and it's importance in children with complex medical conditions

Dr Supriya Shinde, Dr. Ilin Kinimi  
Manipal Hospitals, Old Airport Road, Bangalore, India

### Abstract

#### Introduction:

Home mechanical ventilation (HMV) has improved the survival and treatment outcomes of children with complex medical conditions. In developing countries like India there is a hesitancy and lack of awareness of the usefulness of using HMV to help these children.

#### Case presentation:

Here we present two male babies with anorectal malformation, congenital heart disease and frequent hospitalisation for lower respiratory tract infections which decreased after start of BiPAP.

Case 1 : Term delivery with a stormy neonatal course requiring surgical correction for the complex congenital heart disease. However he still continued to require frequent ICU admission requiring ventilatory support for the first one and half years of life, which drastically decreased after start of BiPAP, with no PICU admission thereafter. Airway reconstruction surgery for subglottic stenosis was done and tracheostomy tube removed at 5year of age. The child is now 8years old, is developmentally normal and requires BiPAP support at night. Genetic study of the parents was done and was normal.

Case 2 : Born at 33 weeks, diagnosed with Downs Syndrome and PDA with severe pulmonary arterial hypertension. He came to us at one year of age when he was admitted for a pneumonia, at which point he was started on BiPAP and PDA device closure done subsequently. At present the child is 2years 6months his pulmonary pressures have come down, the child is doing well and is on BiPAP support at night.

#### Conclusion:

HMV helps discharge a child who is ventilator dependant home early which improves the social and neurodevelopment outcome in the child. It is essential to report the success stories of these patients who doing well on BiPAP, so as to familiarise the paediatrician with giving the parent and the child an option of HMV. From our experience we have noted that parents when provided with adequate training in India are able to take care of these children confidently at home.

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#### Categories

5. PHYSIOLOGY, SLEEP, NIV





## **An Audit of Highflow Nasal Cannula Oxygen Weaning Practices in Patients with Bronchiolitis at Birmingham Heartlands Hospital, in the West Midlands**

Dr Isobel Fullwood, Dr Mirjam Kool, Dr Michael Seyani, Dr Titus Ninan  
University Hospitals Birmingham, Birmingham, United Kingdom

### **Abstract**

#### **Background**

There is no consensus on the best practice of weaning highflow nasal cannula oxygen (HFNC)<sup>1,2</sup>. This leads to wide variability in weaning practices. The current guideline for Birmingham Heartlands Hospital, a district general hospital in the West Midlands advises, for patients with bronchiolitis; wean FiO<sub>2</sub> to 30% then flow rate by 2L/min every 4-6 hours to a minimum of 6L/min.

#### **Aim**

An audit of adherence to local HFNC weaning guidelines.

#### **Method**

Retrospective analysis of patients admitted between 1<sup>st</sup>October 2019 – 1<sup>st</sup>March 2020, with bronchiolitis and treated with HFNC, aged <12 months. Patients were identified through coding; the first 30 patients treated with HFNC were selected for audit. Data was collected on the following: demographics, maximum FiO<sub>2</sub>, maximum and minimum flow rate, FiO<sub>2</sub> at time when flow rate first weaned, total time on HFNC, time from first wean of flow rate to stopping HFNC, length of hospital stay (LoS), documentation of decision making and who the decision maker was.

#### **Results**

Results were obtained for 26/30 patients with 4 exclusions (see table 1 for a results summary). In 7 cases, HFNC was not weaned despite receiving flow rates of >6L/min and 4 of these patients were on flow rates of >16L/min. For those with flow weaned, the median time taken to wean flow was 23 hours with a total duration of time on HFNC of 53 hours. For all patients, the median time on HFNC was 43 hours. Applying current guidelines, for 11 patients, the flow rate could have been weaned over a shorter duration of time. The decision to wean HFNC was documented in 77% (20/26) of records and the decision was made by the consultant in 42% (11/26), registrar 19% (5/26) and nurse 19%(5/26). Overall, current guidelines were not adhered to in 70% of cases due to lack of weaning flow or weaning too slowly.

#### **Conclusion**

This data demonstrates the need for a quality improvement project to increase adherence with the current HFNC weaning guidelines. Often, there is a potential for quicker weaning with the subsequent potential for reduced hospital LoS, as shown in previous studies.<sup>3,4</sup>

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#### **Categories**

3. INFECTIONS, EPIDEMIOLOGY, SUPPURATIVE LUNG DISEASE



## Experience in the management of allergic pathology in children with pandemic COVID-19

Experience in the management of allergic pathology in children with pandemic COVID-19 Nataliya Banadyha

I.Ya. Horbachevsky Ternopil National Medical University, Ternopil, Ukraine

### Abstract

**Aim:** to test new methods of management and control of allergic diseases in children during the COVID-19 pandemic.

**Methods.** 310 children were observed in an outpatient setting between March 2020 and March 2021. Boys predominated among patients (70.9%). The structure of the main pathology was dominated by bronchial asthma (BA)-38.4% and allergic rhinitis (AR)-16.8% of patients. The combination of asthma with AR- was in 14.8%, atopic dermatitis was in -15.8% of cases. Parents of 44 (14.2%) children applied for recurrent wheezing. All patients underwent a set of examinations; to monitor the flow used questionnaires, visual-analog scale, determination of VAS, SaO<sub>2</sub>. During the quarantine announcement for COVID-19 infection, various types of remote counseling (internet, telephone) were provided.

**Results.** The level of control over the course of allergic pathology in children, in particular BA and AR, under conditions of quarantine restrictions was analyzed. At the same time the recommendations of GINA (March 2020) were used. Basic therapy of BA and AR was continued in the previous dosage; allergy diagnosis in children with newly diagnosed pathology was postponed. Parents were warned about the symptoms of the threat and the need for further action. The first cases of COVID-19 respiratory disease were registered in the period August-October 2020 (n = 14), while we strengthened the basic therapy, all recovered in an outpatient setting. 19 (15.9%) patients applied for exacerbation of asthma; in whom therapy was revised; hospitalization was avoided. The rest of the children had good control over the course (64.8%) or remission (19.3%) of asthma. As a part of basic therapy of BA in children, 73.0% used inhaled steroids; in 27.0% of cases antileukotriene drugs. In patients with AR, basic therapy were represented by topical steroids (n = 52), antileukotriene drugs (n = 46), if necessary, additional appointment of second-generation antihistamines (n = 27).

**Conclusions.**1. The introduction of quarantine restrictions on COVID-19 has led to a review of existing outpatient care, with the introduction of active remote counseling.

2. Each patient must have an individual plan for the treatment of allergic pathology, while taking into account the epidemiological situation.

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### Categories

1. ASTHMA / ALLERGY

## Clinical regression of nasal polyposis in children after starting Kaftrio<sup>R</sup>

Dr Emily Bell, Ms Alice Day, Dr Beth Enderby, Dr Patrick Oades  
Royal Devon and Exeter NHS Foundation Trust, Exeter, United Kingdom

### Abstract

Those with the delta F508 mutation are more prone to nasal polyposis (NP) which is associated with early *Pseudomonas aeruginosa* colonisation, an increased frequency of pulmonary exacerbations and hospitalisation<sup>1</sup>. Symptoms and the treatment burden of NP are significant and impact on quality of life.

Surgical polypectomy is effective in improving symptoms in the short term, but has a high recurrence rate; ~75% within 4 years<sup>2</sup>.

CFTR modulators have been shown to increase airway surface liquid depth, ciliary beat frequency, and muco-ciliary transport, while also reducing mucus viscosity<sup>3</sup>. These changes may therefore be expected to improve sinus and nasal symptoms as well as pulmonary symptoms.

We present two cases of patients with cystic fibrosis who despite prior polypectomies and ongoing treatments with topical steroids, topical mucolytics (Pari-sinus<sup>R</sup>), nasal douching (Neti Pot<sup>R</sup>), targeted antimicrobials and, in one case, Orkambi<sup>R</sup>, suffered a recurrence of troublesome NP symptoms with extensive relapse confirmed on imaging. Both were listed for further surgical intervention.

However, their listing for surgery coincided with them commencing Kaftrio<sup>R</sup> and, within 4 months, their NP symptoms had completely resolved. SNOT-22 scores fell from consistently high values (>60) to beneath the threshold where surgical intervention would be considered (30). Improvement has been maintained as treatments have been reduced. Detailed histories and imaging will be presented.

The remarkable rapidity at which symptomatic resolution occurred in both these children is noteworthy. These cases allow for optimism about the long-term effects of CFTR modulators on nasal symptoms in paediatric patients and their potential to prevent this complication arising from the outset.

### References:

1. J Cyst Fibros. 2013 Sep;12 Suppl 2:S1-20. doi: 10.1016/S1569-1993(13)00150-1.
2. Otorhinolaryngol. 2017;83(6):677-682. doi: 10.1016/j.bjorl.2016.09.005.
3. Am J Physiol Lung Cell Mol Physiol., 310 (10) (2016), pp. L928-L939

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### Categories

2. CYSTIC FIBROSIS

## Long COVID in children and young people: what do we need to know?

[Dr Adam Lawton](#)<sup>1</sup>, Dr Rebecca Clarke<sup>1</sup>, Dr Camilo Stargardter<sup>1</sup>, Dr Atul Gupta<sup>2</sup>

<sup>1</sup>North Middlesex University Hospital, London, United Kingdom. <sup>2</sup>King's College Hospital, London, United Kingdom

### **Abstract**

#### **Aims**

There are increasing reports of prolonged symptoms following acute COVID-19 disease (so called “long COVID”) in the adult population. Comparatively little research has been published regarding long COVID in children. This project set out to review existing data on long term effects of SARS-CoV-2 infection in children.

#### **Methods**

We searched for published manuscripts or data regarding long COVID in children. We considered the existing literature regarding post-viral fatigue in children and young people, and how long COVID fits into this disease model. We identified key questions that must urgently be addressed in view of the increasing public awareness of this condition, and the anticipated demand in healthcare service provision as a result.

#### **Conclusions**

Our review identified a relatively small amount of published work on long COVID in children, and these were mostly small case reports or letters to medical journals. There was no consistent case definition of long COVID in children, and little attempt to differentiate this condition from other recognised post-viral fatigue syndromes.

Fatigue, problems with memory or concentration, and joint pains are frequently reported symptoms in adults. Dyspnoea, cough, and increased sputum production are persistent respiratory symptoms that have also been described.

Our recommendation is that further research is urgently required to explore long COVID in children and young people. International consensus on a clear case definition is required, as well as data on prevalence, disease phenotypes, and which treatments have and have not been effective.

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### **Categories**

6. LUNG HEALTH/ PUBLIC HEALTH / COVID-19 Pandemic

## **Audit of current practice for the follow up of children and young people admitted with life-threatening asthma to Bristol Paediatric Intensive Care**

Dr Sofia Cuevas-Asturias, Dr Clare Smith, Dr Katy Pike, Dr Peter Davis  
Bristol Children's hospital, Bristol, United Kingdom

### **Abstract**

Guidance from the British thoracic society recommends that children admitted to hospital with asthma should have clinic follow up within 4 weeks, with paediatric respiratory referral after life-threatening features.

Follow up supports assessment of triggers and the risk of future attacks, further investigation and changes to long term management. The National Review of Asthma Deaths also supports timely follow up: previous life-threatening attacks were a risk factor for subsequent severe attacks. Key findings showed that asthma deaths were also associated with a previous admission within 4 weeks and a large proportion were associated with errors or omissions in care, including failure to follow up. Paediatric intensive care (PICU) admissions are therefore a critical moment to identify high risk individuals and address modifiable features in a timely manner to avoid future severe attacks.

**Aim:** To audit against national guidelines current practice in the South West for follow up of children and young people admitted to Bristol PICU with life-threatening asthma.

**Methods:** Patient cohort identified via PICANET records 2015-2019, follow-up information derived from case note record first follow-up following PIC discharge Follow-up was assessed against a ten point list of guideline recommendations.

**Results:** Twenty eight severe asthma admissions were identified 2015-2019, one child was admitted twice and one died. Thirteen were admitted via Bristol emergency department and fifteen from one of thirteen regional hospitals. Data from regional follow up is awaited.

Follow-up in Bristol occurred between 4.7 and 15.1 weeks (median 8.9), medication was stepped up in 12 cases, 92%. Quality of assessment was assessed as median 7/10 (range 2/10-9/10).

### Summary severity (n= 28, includes one patient who died)

Year	Mean age (years)	% Male	Mean length of stay (days)	% iv steroids	% given antibiotics	% requiring ventilation	% requiring NIV	% not requiring ventilation support	% iv bronchodilator
2015	8.31	100	2.12	100	100	100	33	0	100
2016	7.61	86	2.16	100	86	100	43	0	100
2017	9.42	50	3.12	100	67	100	50	17	83
2018	12.44	100	0.99	100	67	100	33	0	100
2019	9.10	83	2.26	100	83	100	33	0	100
Overall	9.01	82	2.28	100	82	54	36	4	96

Conclusions: There is potential to improve our current service provision. Given the large area served by Bristol PICU we will improve follow-up following severe asthma attacks by developing a dedicated specialist asthma service in Bristol and a network of paediatricians with a specialist interest in Asthma throughout the South West. Changing the culture and practice in the long term follow-up and management of severe asthma will hopefully be the first step in the development of exemplary care and practice within the South West.

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#### Categories

1. ASTHMA / ALLERGY



## Novel Respiratory Findings in FAM111B Mutation

Dr A Murray, Dr R Watson, Dr F Browne, Professor M O' Sullivan, Dr S Javadpour  
Children's Health Ireland at Crumlin, Dublin, Ireland

### Abstract

#### Aim:

Since the advent of whole exome sequencing, the clinical spectrum of FAM III B mutation has been expanding.<sup>(1)</sup> As well as the manifestations of poikiloderma and tendon contractures, adult-onset pulmonary fibrosis has been described in many cases.<sup>(1-3)</sup>

We present a female with FAM III B mutation, who has previously been reported for her dermatological issues<sup>(1)</sup> with the first reported case of childhood onset bronchiolitis obliterans. Her case may aid the genotype-phenotype correlation in the future.

#### Method:

Case report.

#### Case description:

A 3.5-year-old girl was referred the respiratory team with a 6-month history of non-productive cough, without recurrent LRTIs. She had known ectodermal dysplasia, raised liver enzymes and low-level malabsorption of uncertain significance at that time. She had been PEG fed since aged 10 months old due to faltering growth. She had a wheeze over winter months which was worse after exertion. She was trialled on asthma treatment along with prophylactic antibiotics but had no response. Her cough was anecdotally better when on oral steroids. She suffered from gastro-oesophageal reflux and aspiration was felt to be contributing to respiratory symptoms. At the age of 5 she was diagnosed with FAM III B mutation.

After no improvement on initial treatment, she had a CT Thorax in 2017 which showed bronchiolitis obliterans. At this point, she had a worsening cough and now breathlessness, and therefore a lung biopsy was performed. This showed constrictive bronchiolitis obliterans.

She was pulsed with methylprednisolone but unfortunately had no response.

In view of her underlying skin, Tofacitinib was commenced. She initially appeared to have a clinical improvement, with less cough and breathlessness. However, over the last 18 months she has had a gradual decline and has been referred for lung transplant assessment.

#### Conclusion:

The case of bronchiolitis obliterans in FAM III B mutation is the first of its kind and presents management difficulties as the patient's lung function continues to deteriorate. The case adds to the limited literature on this condition and will aid the diagnoses of other such cases worldwide.

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**Categories**

4. NEONATAL PULMONOLOGY, BRONCHOSCOPY, CONGENITAL MALFORMATIONS, RESPIRATORY INTENSIVE CARE & AIRWAYS

## Determining normal oxygen saturation reference ranges in moderate to late preterm infants: a feasibility study using pulse oximetry

Dr Olivia Falconer<sup>1</sup>, Ms Savannah Ivy<sup>2</sup>, Ms Dana Le Carpentier<sup>2</sup>, Ms Johanna Gavlak<sup>1</sup>, Ms Natasha Liddle<sup>1</sup>, Ms Emily Senior<sup>1</sup>, Ms Philippa Crowley<sup>1</sup>, Dr Aneurin Young<sup>1</sup>, Dr Mark Johnson<sup>1</sup>, Professor RM Beattie<sup>1</sup>, Dr HJ Evans<sup>1</sup>

<sup>1</sup>University Hospital Southampton, Southampton, United Kingdom. <sup>2</sup>University of Southampton School of Medicine, Southampton, United Kingdom

### Abstract

#### Introduction

Preterm infants with bronchopulmonary dysplasia are the single largest group of children discharged home with supplementary oxygen. Nocturnal pulse oximetry (NPO) studies are widely used to aid decision making around oxygen prescribing, but there are currently no reference ranges for NPO parameters in healthy preterm infants. This study aimed primarily to determine the feasibility of a larger study to establish reference ranges for oximetry parameters in healthy infants >32 weeks gestation, from birth to term. Preterm infants are known to have frequent oxygen desaturations, and our secondary aims were to investigate the aetiology of these events, and test the practicality of using near-infrared regional spectroscopy (NIRS) to quantify their impact on cerebral perfusion.

#### Methods

Healthy infants born between 32-37 weeks gestation were recruited from the Neonatal Intensive Care Unit. Babies underwent NPO weekly until 40 weeks corrected gestational age (CGA), alongside cardiorespiratory polygraphy (CRP) at study entry, 36 weeks and 40 weeks CGA. Acceptable studies contained >4 hours artefact free recording time. NIRS monitoring was attempted during CRP studies.

#### Results

94 NPO and 24 CRP studies, performed on 21 infants were included. Median 3% oxygen desaturation index (ODI3) was 39.8 (IQR 16.1–46.6) in the first week postnatally (PN), and peaked at 85.4 (IQR 62.1–99.6) in week 3 PN, before decreasing (figure). Central apneas/hypopneas followed a similar pattern, and obstructive events were rare. Regression modelling showed that ODI3 and mean saturations were significantly related to PN age ( $p < 0.01$ ) and models were not improved by introducing CGA as an independent variable. Parents found the NIRS equipment unacceptable when combined with CRP monitoring.

#### Conclusion

NPO is a feasible method for determining reference oxygen saturation ranges in this population. We found considerable heterogeneity, particularly at weeks 1-3 PN, and clinical guidelines for oxygen weaning will need to reflect this. To our knowledge we are the first group to describe in detail the significant relationship between PN age and oximetry parameters in this population. A definitive study is planned to define NPO indices in infants >32 weeks gestation, and investigate their impact on cerebral perfusion as determined by NIRS.

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## **Categories**

5. PHYSIOLOGY, SLEEP, NIV

## **The role of paediatric respiratory nurse specialist in management of non-CF bronchiectasis.**

Mrs Hollie Smith<sup>1</sup>, Mrs Teresa Evans<sup>2</sup>, Dr Prasad Nagakumar<sup>3</sup>, Dr Maya Desai<sup>1</sup>, Mrs Laura Morris<sup>1</sup>, Mrs Sarah Stone<sup>1</sup>, Mr Ciaran Mcardle<sup>1</sup>, Mrs Naomi Parsons<sup>1</sup>, Mrs Kiran Hunjan<sup>1</sup>, Mrs Brinderjit Heyeer<sup>1</sup>, Dr Priti Kenia<sup>1</sup>

<sup>1</sup>Birmingham Women's and Children's Hospital NHS Trust, Birmingham, United Kingdom. <sup>2</sup>Birmingham Women's and Children's Hospital NHSTrust, Birmingham, United Kingdom. <sup>3</sup>Birmingham Women's and Children's Hospital NHS trust, Birmingham, United Kingdom

### **Abstract**

#### **Background**

BTS 2010 bronchiectasis guideline recommends multidisciplinary care. Nurses play a vital role in bronchiectasis management. In paediatric bronchiectasis, the role of paediatric respiratory nurse specialist (RNS) is understated in literature. Our recent survey results from 287 health professionals showed no dedicated bronchiectasis RNS in any UK region. In 2019, RNS was allocated to take a more active role to support the paediatric bronchiectasis multi-disciplinary team (MDT), education and transition (0.6 WTE) at our centre.

#### **Objective**

- To appraise the current RNS role at a specialist paediatric bronchiectasis centre.

#### **Method**

Prospective review of RNS role and time spent in bronchiectasis management over a 12 month period.

#### **Results**

93 CT-diagnosed bronchiectasis patients (M43:F50) with a median age of 10.05 (range:3.6-16.5) years were cared for during that time. 136 hours were spent by the RNS in supporting children and young people and families with bronchiectasis. Over 12 months, the services provided by RNSs included:

- Attendance to monthly MDT clinics (4hours per clinic) to provided support, education, and advice.
- Telephonic reviews and advice (4hours)
- Admission avoidance following remote RNS input=7 patients
- 2 patients identified suitable for home IV programme were supported (out of 9 needing IV's)
- 35 hours were spent on service development including database setup and entry.

#### **Conclusion**

The RNS can support children and young people with emphasis on education, promoting adherence, remote reviews during exacerbations leading to reduced admissions, development of home treatment programmes and support transition. Nurse-led outpatient clinics can facilitate annual reviews and education. Future work involves developing such clinics further and a network approach with the district hospitals in West Midlands and evaluating the feedback from the families.

#### **References:**

British Thoracic Society guideline for non-CF bronchiectasis (2010). Thorax, 2010, Volume 65, pp.1-58.

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**Categories**

3. INFECTIONS, EPIDEMIOLOGY, SUPPURATIVE LUNG DISEASE

## **Administration of asthma biologics at home during the COVID-19 pandemic: one size does not fit all**

Mrs. Susan Frost, Mrs. Teresa Evans, Mrs. Sarah Stone, Dr. Ben Davies, Dr. Isobel Brookes, Dr. Priti Kenia, Mrs. Hollie Smith, Dr. Satish Rao, Mrs. Amy Burrill, Dr. Prasad Nagakumar  
Department of Respiratory Medicine, Birmingham Women's and Children's Hospital, Birmingham, United Kingdom

### **Abstract**

#### Background

The severe asthma MDT team at Birmingham Women and Children's NHS Trust (BWC) care for the severe asthmatic children and young people (CYP) across the West Midlands. The biologics were always administered in the hospital.

At the outbreak of Covid 19, we explored ways that the CYP could receive this treatment differently, whilst also continuing to assess their asthma control & supporting CYP with managing asthma.

#### Methods/results

Twenty CYP with severe asthma were on biologic therapies. Following a multi-disciplinary discussion, decision were made on whether this treatment could be moved to homecare. Some circumstances meant that 9/20 (45%) CYP continued with treatment & assessments at the hospital (mepolizumab in <12 yr. n.= 3, family/child refused n= 3, social circumstances n= 3). Although families were anxious about coming to hospital for the injection. They were reassured by the support & infection control measures in place at the hospital.

11/ 20 (55%) that had home care were provided training by respiratory nursing team, this was conducted face to face then subsequently virtually. The families were also provided & trained in performing spirometry at home.

Of those on home administration; 8 injections were given by parent, 2 CYP self-administering & 1 by a local respiratory nurse.

The BWC respiratory specialist nurses reviewed the patients at the time of the injection virtually. During the appointment, the nurse reviewed the spirometry, alongside administering asthma control (ACT), mini paediatric quality of life questionnaire (mPAQLQ).

Feedback from families (n=10): they like as it results in less time off school /work (n= 5) reduces the stress of travelling into the hospital (n= 4) taking less time (n=1). Similar asthma assessment as done when at hospital (n=10). The ACT & mPAQLQ showed improvement, no adverse events were reported with home biologic administration.

#### Outcome

The changes to treatment from hospital to home altered because of COVID 19, has resulted in positive outcome to patient care. 45% of CYP were not suitable for home biologics administration and continued to receive injections and assessments in hospital. We are currently reassessing CYP feedback 12 months post review of our practice.

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**Categories**

1. ASTHMA / ALLERGY



## **Mycobacteria, Modulators and Mood-swings - The Challenges of Cystic Fibrosis in Adolescence: A Case Report**

Miss Lydia Roberts<sup>1</sup>, Dr Doxa Kotzia<sup>2</sup>, Dr Louise Selby<sup>2</sup>, Dr Donna McShane<sup>2</sup>

<sup>1</sup>School of Clinical Medicine, University of Cambridge, Cambridge, United Kingdom. <sup>2</sup>Department of Paediatric Respiratory Medicine, Addenbrooke's Hospital, Cambridge University Hospitals NHS Trust, Cambridge, United Kingdom

### **Abstract**

**Introduction:** Cystic fibrosis (CF), an autosomal recessive disorder caused by mutations in the gene encoding the cystic fibrosis transmembrane conductance regulator (CFTR), affects approximately 10,600 people in the UK and 100,000 individuals worldwide. Although a truly multi-systemic disease, outcomes for CF patients have improved significantly over recent years. The advent of CFTR modulators marked a particularly exciting development, providing a pharmacological means to target the underlying cause of disease. We report the case of a 16-year-old girl with CF, with emphasis on her disease progression from 10 years of age, the development of CF-associated complications and the impact of novel therapeutics on her condition.

**Case Description:** The patient's disease was well-controlled during the first decade of life, with the first significant deterioration in pulmonary health beginning in 2015, which was associated with lung colonisation with *Mycobacterium abscessus*. There were periods of significant decline in her spirometry, with her FEV<sub>1</sub> and FVC falling to lows of 37% and 48%, respectively. The patient experienced a range of CF-related complications, such as delayed puberty, reduced exercise tolerance, weight and height drops and diabetes. Treatment with two CFTR modulator therapies was started, lumacaftor/ivacaftor (Orkambi) in May 2016 and ivacaftor/tezacaftor/elexacaftor (Kaftrio) in July 2020. Both these therapies were associated with improvements in her lung function (FEV<sub>1</sub>:56%/FVC:81%), activity levels, overall wellbeing and quality of life.

**Discussion:** This case highlights the difficulty of managing CF patients, particularly through adolescence. Given what a challenging period this can be in young people's lives generally, the added complexities of trying to manage a disease as intricate as CF can place considerable strain on the patient and their family, as well as the clinical team. A multi-disciplinary approach is crucial to address the truly multi-systemic nature of the disease and its physical and psychological complications. The significant benefits the patient experienced from Orkambi and Kaftrio are in keeping with the excellent results seen in the published phase III clinical trials of these agents. Increasing numbers of CF patients are beginning to access these novel therapeutics, which will hopefully have a significant impact on the global CF community.

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### **Categories**

2. CYSTIC FIBROSIS

## Dupilumab Efficacy and Safety in Children With Uncontrolled Moderate-to-Severe Asthma: The Phase 3 VOYAGE Study

M.D. Leonard B. Bacharier<sup>1</sup>, M.D. Jorge F. Maspero<sup>2</sup>, M.D. Constance H. Katelaris<sup>3,4</sup>, M.D. Alessandro G. Fiocchi<sup>5</sup>, M.D. Remi Gagnon<sup>6</sup>, M.D. Ines de Mir<sup>7</sup>, M.D. Neal Jain<sup>8</sup>, M.D. Lawrence D. Sher<sup>9</sup>, Ph.D. Xuezhou Mao<sup>10</sup>, Ph.D. Dongfang Liu<sup>11</sup>, Ph.D., M.P.H. Yi Zhang<sup>12</sup>, M.B.B.S., M.P.H. Asif H. Khan<sup>13</sup>, M.D. Upender Kapoor<sup>10</sup>, M.D. Faisal A. Khokhar<sup>12</sup>, M.D. Paul J. Rowe<sup>10</sup>, M.D. Yamo Deniz<sup>12</sup>, M.D. Marcella Ruddy<sup>12</sup>, Ph.D. Elizabeth Laws<sup>10</sup>, M.D. Nikhil Amin<sup>12</sup>, M.D. Leda P. Mannent<sup>13</sup>, M.D., M.S. David J. Lederer<sup>12</sup>, M.D., M.P.H. Megan Hardin<sup>14</sup>

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### Abstract

**Rationale:** Despite optimized standard-of-care therapy, children with moderate-to-severe asthma may continue to have uncontrolled disease. Type 2 inflammation, defined by blood eosinophils or fractional exhaled nitric oxide (FeNO) levels, underlies most cases of asthma in children. Dupilumab, a fully human monoclonal antibody, blocks the shared receptor component for interleukin-4/interleukin-13, key and central drivers of type 2 inflammation in multiple diseases. VOYAGE, a 52-week randomized, double-blind, placebo-controlled phase 3 study (NCT02948959), evaluated the efficacy and safety of dupilumab in children aged 6 to <12 years with uncontrolled, moderate-to-severe asthma.

**Methods:** Patients receiving high-dose inhaled corticosteroids (ICS) alone or medium-to-high-dose ICS with a second controller were randomized (2:1) to add-on subcutaneous dupilumab 100mg/200mg every 2 weeks (body weight  $\leq 30$ kg/ $>30$ kg, respectively) or matched placebo. Primary populations: patients with type 2 inflammatory phenotype (baseline blood eosinophils  $\geq 150$ cells/ $\mu$ L or FeNO  $\geq 20$ ppb) and patients with baseline blood eosinophils  $\geq 300$ cells/ $\mu$ L. Assessments: annualized rate of severe asthma exacerbations (primary endpoint), change from baseline in pre-bronchodilator FEV<sub>1</sub> percent predicted (FEV<sub>1</sub>pp), FeNO and Asthma Control Questionnaire-Interviewer Administered (ACQ-7-IA).

**Results:** Of 408 patients randomized, 350 had a type 2 inflammatory asthma phenotype; 259 had blood eosinophils  $\geq 300$ cells/ $\mu$ L at baseline. In patients with a type 2 phenotype, dupilumab reduced exacerbations by 59.3% ( $P < 0.0001$ ), and improved FEV<sub>1</sub>pp (least squares [LS] mean difference vs placebo 5.21%;  $P = 0.0009$ ) and reduced FeNO levels (LS mean difference vs placebo  $-17.84$ ppb;  $P < 0.0001$ ) at Week 12 compared with placebo. At Week 24, dupilumab showed greater improvement in ACQ-7-IA scores from baseline vs placebo (LS mean difference vs placebo  $-0.33$ ,  $P = 0.0001$ ). Similar findings were observed in patients with eosinophils  $\geq 300$ cells/ $\mu$ L (**Table**). In the safety population, overall rates of treatment-emergent adverse events (TEAEs) in dupilumab vs placebo groups were 83% vs 80%. 13/271 (4.8%) dupilumab-treated patients and 6/134 (4.5%) placebo-treated patients reported serious TEAEs; 5/271 (1.8%) dupilumab-treated and 2/134 (1.5%) placebo-treated patients reported AEs leading to permanent study discontinuation. Median blood eosinophil values decreased to below the baseline value by Week 52 in the dupilumab group.

**Conclusions:** Dupilumab demonstrated efficacy and an acceptable safety profile in patients aged 6 to <12 years with uncontrolled, moderate-to-severe asthma with a type 2 phenotype.

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**Categories**

1. ASTHMA / ALLERGY

## **Spirometry measurements remain consistent from 2019 to Summer 2020 in a cohort of paediatric cystic fibrosis patients**

Mr Kieran Lock, Mrs Laura Lowndes, Dr Louise Selby  
Addenbrooke's Hospital, Cambridge, United Kingdom

### **Abstract**

Introduction:

With reduced face-to-face outpatient visits as a result of the Covid-19 pandemic, there was concern from the cystic fibrosis multi-disciplinary team (MDT) about preservation of lung function and optimisation of lung health amongst paediatric patients.

The aim of this analysis was to review formal laboratory lung function results from 2019 annual reviews prior to the outpatient clinic restrictions imposed by the Covid-19 pandemic, comparing them with formal laboratory lung function results obtained at the nearest face to face appointment after restrictions had lifted.

Method:

A retrospective cohort study using lung function measurements and heights as recorded at both outpatient appointments in 2019 and 2020. Statistical analysis was carried out using Prism 8, using Wilcoxon signed rank test to compare pairs of values from each patient.

Results:

Data from 53 children with CF aged 6-16 years was available, median age 11 years (range 8-14 years). There were no significant differences between FEV1 and FVC Z-Scores across the time period. Median FEV1 Z-Score in 2019 was -0.47 (-1.48-0.19) vs -0.33 (-1.22-0.11). Median FVC Z-Score in 2019 was -0.27 (-0.96-0.9) vs 0.02 (-0.83-0.78).

Conclusion:

Reassuringly, no significant differences were found in lung function during a period of reduced face-to-face CF appointments. With the advent of use of home spirometers, lung function measurements can continue to be monitored remotely to detect early decline and prompt MDT intervention.

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## **Categories**

2. CYSTIC FIBROSIS

## Exploring Factors Influencing Asthma Control and the Effectiveness of Asthma Education among Children and their Parents

Dr SK Ng, Dr JW Cheng, Ms PK Ma, Dr WK Chiu  
United Christian Hospital, Hong Kong, Hong Kong

### Abstract

#### Introduction

According to the Health Belief Model, education is essential to change individual health-related behaviours. The effectiveness of an in-hospital multimedia asthma education intervention for asthmatic children and their parents was proven by a randomized controlled trial (RCT) which had 112 child-parent dyads ( $p < 0.05$  for knowledge attitude and practice (KAP) on asthma, readmission rates and unscheduled visits for the intervention group). The control group were provided with informational leaflets only (usual care). However, the asthma control test (ACT) scores were statistically insignificant.

#### Aim

To analyse an RCT and explore the factors influencing the effectiveness of asthma education.

#### Results

The intervention group had a significantly large effect on the KAP score, but the improvement of attitude was not sustained over time with only a small effect size. The ACT was improved in both groups but statistically insignificant, which is partly explained by the findings in the attitude score.

The intervention effect on readmissions was small but statistically significant, due to decreased episodes of readmissions in the intervention group while the control group remained unchanged. However, the intervention effect on unscheduled visits was significantly larger, as the hospitalisation experience created a large deviation between the two groups - those in the intervention group were able to recognize asthmatic symptoms and self-administer appropriate home management, while those in the control group were often unconfident in self-management and often ended up making unscheduled doctor visits.

The relatively high compliance to asthma diaries (60.7%) was found to have positive correlation with recency of asthmatic attacks, presence of rewards (e.g. asthma control reports), provision of medical feedback for entered data, and negatively correlated with longer follow-up periods or hospitalisations.

#### Conclusion

This analysis identifies 4 important factors that influence asthma control. The multimedia-based intervention was effective in improving participants' ability to recognize asthma symptoms. The individual discussion sessions were effective in clarifying myths on medications and asthma symptoms. Asthma diary adherence was improved by the use of more frequent follow-ups, with a web-based format shown to be effective on monitoring medication compliance and providing timely feedback to asthma symptoms, thereby improving adherence and ultimately asthma control.

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#### Categories

## 1. ASTHMA / ALLERGY

## **Noses are for breathing/ Mouths are for eating: the overlooked importance of nasal breathing**

Mrs Clare-Louise Chadwick

St George's University Hospitals NHS Foundation trust, London, United Kingdom

### **Abstract**

The nose is an important organ with multiple functions including being our first line defence. Nasal breathing has an extensive role in our health and wellbeing. It filters, humidifies, warms and slows the air in preparation for entering the lungs. The paranasal sinuses produce nitric oxide which kill pathogens and helps with oxygenation through its vasodilatory effect. Nasal breathing sustains appropriate carbon dioxide levels, maintaining a fine acid base homeostasis, as well as having an important function within the oxygen dissociation curve and Bohr effect. Nasal breathing also stimulates diaphragmatic breathing which helps posture and stability. In comparison, mouth breathing allows dry, cold, impurified air into the airway and lungs, precipitating bronchospasm, cough, and laryngeal irritation. Mouth breathing allows more carbon dioxide to be expired which can chronically alter our acid base levels, having significant long-term effects. Mouth breathing as a child can lead to poor formation of the facial bones and nasal passages, leading to orthodontic issues and narrow airways predisposing them to sleep disorders.

Despite all these advantages, many healthcare professionals still overlook the importance of nasal breathing and majority of the public have little or no idea of its wide-reaching benefits.

Method: Retrospective review of 100 CYP between the ages of 6-17 years (64% female), referred for a breathing pattern assessment within the Breathing Clinic at St George's Hospital.

Results: 29% CYP were mouth breathers and a further 19% partial mouth breathers. Therefore, half of the children assessed breathed fully or partially through their mouths at rest. Only a proportion of mouth breathers have true, ongoing nasal obstruction. Identifying the problem has allowed interventions to improve nasal function including, nasal rinsing, habit breaking behavioural techniques, nasal decongestant exercises and education.

Conclusion: Early identification of CYP with mouth breathing may allow earlier intervention to retrain them to use their nose for its primary purpose and reap the above benefits. This may reduce the numbers of CYP referred with breathing pattern disorders, ILO, significantly improve their quality of life and reduce further co morbidities that can occur in adult life due to mouth breathing.

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### **Categories**



## 1. ASTHMA / ALLERGY

## Characteristics and outcome of infants with Bronchopulmonary Dysplasia established on Long-Term Ventilation from Neonatal Intensive Care

Dr Jonathan W. Y. Ong, Dr Lucy Everitt, Ms Jodie Hiscutt, Ms Catherine Curran, Ms Alison McEvoy, Dr Hazel J. Evans

Department of Respiratory Paediatrics, Southampton Children's Hospital, Southampton, United Kingdom

### Abstract

**Aim:** To report a case series of neonatal intensive care unit (NICU) graduates with bronchopulmonary dysplasia (BPD) established on long-term ventilation (LTV), focusing in particular on mechanisms of ventilation and outcomes.

**Introduction:** Ex-preterm infants with BPD sometimes receive LTV to facilitate weaning from respiratory support. This can present challenges, in particular whether infants can be supported non-invasively or instead considered for tracheostomy invasive ventilation (TIV). Factors determining this include ventilator and oxygen dependency and infant size at the time of referral.

**Method:** Infants born <32 weeks gestation with BPD (defined as persistent oxygen requirement at 36 weeks corrected gestational age) referred to the LTV service Jan 2015-Dec 2020 were identified from the LTV database at Southampton Children's Hospital. Data was retrospectively collected from electronic records.

**Results:** Twenty-five infants were referred during the study period. Median birth gestation was 26+1 weeks (IQR 25+3 to 27+2) and birth weight 645g (IQR 564-799) with z-score -1.289 (IQR -2.119 to -0.602). Median length of invasive ventilation was 40.5 days (IQR 26.5-55.8). 80% (20/25) received at least one course of DART steroids prior to LTV initiation.

**Table 1: Anthropometry at initiation of LTV**

Age (days)	97 (IQR 91 to 112)
Corrected Gestational Age (weeks + days)	40+2 (IQR 39+0 to 42+6)
Weight (g)	2583 (IQR 2418 to 3423)
Weight (z-score)	-2.309 (IQR -2.929 to -1.128)
Length (cm)	44.6 (IQR 42.4 to 50.1)
Length (z-score)	-3.277 (IQR -4.023 to -1.515)
Occipital frontal circumference (cm)	31.8 (IQR 30.4 to 33.4)
Occipital frontal circumference (z-score)	-2.690 (IQR -3.812 to -1.354)

Nineteen infants were successfully weaned using non-invasive ventilation (NIV). Four infants had TIV either for failure to wean ventilation or malacia. The smallest infant started on LTV weighed 1930g (NIV was 2260g). All infants were established on NIPPY Junior+ or Trilogy ventilators using Respireo SOFT Baby (Air Liquide Healthcare) or NeoQ (RemServe Medical) interfaces. 40% of patients had echocardiographic evidence of pulmonary hypertension and/or were on sildenafil. One infant had significant periventricular leukomalacia at term. At present, 20% (5/25) remain on LTV, 72% (18/25) have

been discontinued and sadly, 8% of patients (2/25) died. Median total time spent on LTV was 43 days (IQR 33-399).

**Conclusion:** This case series from a single centre reports that NICU graduates mostly wean successfully from LTV, although this can take several months or years. NIV is practical and possible in small babies with the advent of interfaces and headgear suitable for infants as small as 2kg. Initiation and weaning should take place in a facility where the required expertise is available.

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### **Categories**

5. PHYSIOLOGY, SLEEP, NIV

## Restructuring Delivery of Paediatric Difficult Asthma Services during COVID-19

Mr Mayank Sonnappa-Naik<sup>1,2</sup>, Dr A. Nichols<sup>1</sup>, Dr L. Gardner<sup>1,3</sup>, Ms C. Richardson<sup>1</sup>, Ms N. Orr<sup>1</sup>, Ms A. Jamalzadeh<sup>1</sup>, Ms R. Moore-Crouch<sup>1</sup>, Ms S. Makhecha<sup>1</sup>, Ms C. Wells<sup>1</sup>, Ms P. Hall<sup>1</sup>, Professor A. Bush<sup>1,3</sup>, Dr L. Fleming<sup>1,3</sup>, Professor S. Saglani<sup>1,3</sup>, Dr S. Sonnappa<sup>1,3</sup>

<sup>1</sup>Royal Brompton Hospital, London, United Kingdom. <sup>2</sup>Anglia Ruskin University, Chelmsford, United Kingdom. <sup>3</sup>National Heart and Lung Institute, Imperial College, London, United Kingdom

### Abstract

**Background:** Due to the COVID-19 pandemic, outpatient face-to-face consultations were suddenly reduced prior to the first national lockdown in March 2020. Consequently, new approaches to deliver our difficult asthma (DA) service in the home setting were explored.

**Aims:** We aimed to assess whether children with asthma can reliably perform home spirometry and could be managed remotely without compromising asthma control and whether the rate of failed appointment attendance reduced when telephone and video consultations replaced face-to-face appointments

**Methods:** We rapidly switched to virtual clinics for most patients. Provision of home spirometers was based on clinical need including number of unscheduled hospital admissions and courses of steroids in the previous year, whether on a biologic; family and patient willingness to perform home spirometry. Forced expiratory volume in one second (FEV<sub>1</sub>) and forced vital capacity (FVC) measurements were collected from home spirometers from April 7<sup>th</sup>-October 31<sup>st</sup>, 2020. The total number of FEV<sub>1</sub> measurements, FEV<sub>1</sub> reductions >20% and new actions taken (defined as requesting: face-to-face, general practitioner or Emergency Department review or initiating: a course of steroids or antibiotics, an electronic monitoring device or directly observed therapy once school resumed) were documented from electronic patient records.

Additionally, we compared hospital admissions, courses of oral steroids received and multi-disciplinary team (MDT) clinic attendance, either virtual or face-to-face, from March-August 2019 and 2020.

**Results:** From April-August 2020, 50 DA patients performed 253 home spirometry measurements, of which 39 demonstrated >20% decrease in FEV<sub>1</sub>, resulting in a new action plan in 87% of these episodes. From March-August 2020, 110 DA patients were seen in clinic (68% virtually), while all were face-to-face appointments in 2019. DA clinic cancellation/ non-attendance (16% vs. 43%; p<0.0003); hospital admissions for acute asthma (6 vs. 26; p<0.01) from March-August 2020 were significantly lower compared to the same period in 2019. There was no difference in the number of courses of steroids prescribed (47 vs. 53; p=0.81).

**Conclusions:** We demonstrate that virtual MDT clinics and home spirometry can be introduced quickly and effectively to manage children with DA without compromising asthma control. Virtual clinics were associated with improved attendance during COVID-19 pandemic.

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**Categories**

1. ASTHMA / ALLERGY

## **Is all Pre-School Wheeze just ‘Wheeze’? If we considered swallow assessment with first Wheeze admissions, could we reduce admissions?**

Ms Nicoll Bell, Dr Dominic Carr, [Dr Ritu Handa](#)

St Helier's Hospital, Epsom and St Helier's Trust, Sutton, United Kingdom

### **Abstract**

#### Introduction:

Dysphagia increases risk of aspiration (Arvedson & Brodsky, 2002), and inhalation into the lower airway. Consequences include respiratory illness presenting with wheeze, necessitating hospital admission (Tutor, 2020). Physicians do not always recognise dysphagia and chronic aspiration as a cause of wheeze in Paediatrics (Tutor, 2020). This study aims to prove significance of timely aspiration identification on reducing hospital admissions.

#### Methods:

Children with aspiration risk were identified using a combination of wheeze admissions data from medical records and SLT records over the year 2019. A retrospective review of these patients records was performed, noting hospital admissions via A&E for respiratory complaints of bronchiolitis and viral induced wheeze before and after a diagnosis of aspiration was made. The patient group encompassed all wheeze admissions, including patients with diagnosed neurological, cardiac or ENT pathology.

Potential aspiration red flags were also analysed to assist with developing a clinician screening tool to assist earlier SaLT referral.

#### Results:

The average age of first presentation of wheeze (to A&E) was 5.7 months (n=35, range: 0-27) with average age of first admission being 8.9 months (n=25, range 0-70). On average children were diagnosed with aspiration at 14.9 months.

There was a significant reduction in admissions/year following diagnosis of aspiration,  $p=0.00018$ . The average number of admissions/year dropped to 0.3 (from 1.6) in the year after diagnosis was made.

Children had on average 2.7 (+/-1.7) identifiable risk factors for unsafe swallow on SaLT assessment. The most common risk factor identified was coughing on drinking, identified in 63% (22) of children, of which on only 17% (6) were identified by a clinician at presentation. The next most common were “Wet vocal quality or needing to clear throat when eating or drinking” (13; 37%) followed by “Fussiness when feeding” (11; 31%).

#### Conclusions:

If aspiration is identified and treated earlier with a child's first hospital presentation of wheeze, subsequent admissions are significantly reduced. Identification of red flags at assessment for wheeze admissions such as cough on drinking, wet vocal quality with drinking and fussiness with feeding further highlight need for SaLT referral and assessment.

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**Categories**

5. PHYSIOLOGY, SLEEP, NIV

## The impact of COVID-19 guidance on the ability of children and young people with tracheostomies to access an educational setting

Ms Jodie Hiscutt<sup>1</sup>, Ms Catherine Crocker<sup>1</sup>, Dr Lucy Everitt<sup>1</sup>, Dr Catherine Doherty<sup>2</sup>, Dr Simon Langton Hewer<sup>3</sup>, Dr Hazel Evans<sup>1</sup>

<sup>1</sup>Southampton Children's Hospital, Southampton, United Kingdom. <sup>2</sup>Royal Manchester Children's Hospital, Manchester, United Kingdom. <sup>3</sup>Bristol Royal Hospital for Children, Bristol, United Kingdom

### Abstract

**Introduction:** At the onset of the COVID-19 pandemic (March 2020), the majority of children and young people (CYP) were sent home from their educational setting (pre-school, school, college) as part of national lockdown measures. At this time, the adverse effects of COVID-19 were unknown, particularly in CYP with complex or additional health needs including tracheostomies and ventilation. In June 2020 CYP returned to school; however for CYP with tracheostomies +/- ventilation national guidance regarding tracheostomy care and specifically aerosol generating procedures (AGP) presented significant restrictions.

**Aims:** To evaluate the impact of COVID-19 guidance on the ability of children and young people with tracheostomies +/- ventilatory support to access an educational setting.

**Method:** An online survey was distributed to families via the National Tracheostomy Safety Project paediatric working group and WellChild Children's nurses (November to December 2020). Response to the survey implied consent for information sharing.

**Results:** 66 questionnaires were distributed; 95% response rate (n=63) from 10 UK centres. 41.3% (26/63) CYP were unable to return to their educational setting. Respondents identified infection and lack of separate space to perform AGP's as causative factors in 61.5% (16/26) of non-returners. COVID testing was regularly performed in 8% CYP and 77.8% (49/63) advocated weekly testing for their child to facilitate a return to an educational setting. Modification to delivery of care was reported in 75.7% (28/37) of education returners. Key themes identified were site of care, use of heated moisture exchange filters, personal protective equipment and isolation from peers. Respondents escalated their concerns to multiple professionals within health and social care, education and government.

**Conclusions:** These data suggest a number of CYP with tracheostomies +/- ventilation were unable to access an educational setting during the pandemic where inter-grated therapy support is frequently provided alongside education. Reasons are broad, however are associated with variable interpretation and implementation of guidance. Individual risk assessments should be undertaken in consultation with clinicians to facilitate CYP with tracheostomies +/- ventilation accessing educational settings safely. These risk assessments should consider regular COVID testing alongside teacher and carer vaccination.

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## **Categories**

6. LUNG HEALTH/ PUBLIC HEALTH / COVID-19 Pandemic

## **Clinical Question: Is it impORtAnt to be PICCky about antibiotic levels and lines?**

Dr Chu-Hai Wong

Sheffield Children's NHS Foundation Trust, Sheffield, United Kingdom

### **Abstract**

Scenario: As the paediatric junior covering the wards out-of-hours, one of the nurses has asked if you can take a tobramycin trough level from a patient with cystic fibrosis (CF). You ask whether the patient has a port-a-cath® (port) or a peripherally inserted central catheter (PICC). The nurse tells you that the patient has a PICC but they "never take antibiotic levels from central lines". You refer to the CF guidelines, and it confirms that this is something that you must 'NEVER' do. The patient refuses venepuncture but agrees to a capillary sample. She is upset with having capillary bloods as her PICC was inserted yesterday and remains patent.

Clinical Question: In paediatric patients receiving intravenous antibiotics for respiratory infections requiring therapeutic antibiotic monitoring, is there a clinically significant difference (affecting drug dosing regimes) between levels taken via central venous catheters (CVC) compared with peripheral (venous/ capillary) samples.

Method: Literature review from keyword searching on Ovid Medline® (482 articles from the past 10 years) and Google® (3 articles). No upcoming trials were registered. Titles were screened and 12 papers were deemed relevant and appraised.

Results: Studies varied significantly in patient subgroups, CVCs, type of level (trough, peak or random) and flush/discard protocols. Some studies suggested statistical significance but no clinical significance on the use of CVCs. Others reported significant variance between their paired samples, which would have led to inappropriate alterations in drug dosing. However, all studies which advised upon the use of CVCs specified strict terms and conditions of applicability. Most studies recognised other considerations in sampling from CVCs, such as contamination, occlusion and damage, especially with smaller PICCs. Beyond aminoglycosides, debate continues on CVC sampling for cyclosporin and cefepime, with sampling for both generally considered unreliable.

Conclusion: At present, I think there is insufficient evidence to support a change in my practice from taking peripheral samples. It has highlighted that future CVC monitoring for one type of antibiotic may not be applicable with other medications. Importantly, if I were to counsel patients on the benefits of CVCs, I would also discuss the occasional requirement for peripheral sampling.

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### **Categories**

3. INFECTIONS, EPIDEMIOLOGY, SUPPURATIVE LUNG DISEASE

## Regional response of paediatric long-term ventilation department at Cambridge University Hospital during the COVID-19 pandemic: 24-month retrospective data of monitoring and management of this population

Miss Lucy Carson<sup>1</sup>, Dr Doxa Kotzia<sup>2</sup>

<sup>1</sup>University of Cambridge, Cambridge, United Kingdom. <sup>2</sup>Cambridge University Hospitals, Cambridge, United Kingdom

### Abstract

**Introduction:** In the last 20 years, there has been a 30-fold increase in children receiving long-term ventilation (LTV). The paediatric LTV service at Cambridge University Hospitals (CUH) is a multidisciplinary team working in close collaboration with local hospitals across East Anglia, in home and hospice settings. This quality improvement study follows the publication of a NCEPOD report and assesses a) LTV team response at a local and regional level during the pandemic and b) new services implemented during the pandemic. **Methods:** Retrospective data from 01/03/19-28/02/20 and 1/3/20-28/02/21 (pandemic year), of patients on non-invasive ventilation (NIV), with tracheostomy in situ and on tracheostomy ventilation. **Results:** 69 patients identified in 2019/20, 82 patients in 2020/21, with similar gender ratio and mean age. 14 NIV initiation referrals for patients with neuromuscular/neurodisability/skeletal/upper airway anatomical abnormalities/sleep disordered breathing disorders, airway malacia/obstruction and respiratory failure. Hospital restrictions reduced face-to-face consultations, however 96.3% of patients reviewed at least once, most via telephone (vs 89.9% in 2019/20). In 2020/21, 54 inpatient sleep studies conducted vs 76 in 2019/20. Home sleep studies introduced in May 2020 and 42 successfully performed. Regional LTV teams performed home reviews for 25 patients and changed ventilator settings for 8 patients under guidance from our team. Escalation plans now in place for 56.1% patients (vs 8.7% in 2019/2020). In 2020/21, more patients had ventilation stopped and more successful decannulations performed compared to the year before. Increase in acute admissions at CUH, but reduction in ED presentations, acute admissions at local hospitals and oral or IV antibiotics for infective exacerbations observed in 2020/2021, probably related to the effect of shielding. 87.5% patients required no or one GP appointment in 2020/21 compared to previous year (64.4%). More patients on regular medications, and patients receiving physiotherapy and on cough assist doubled in 2020/21. **Conclusions:** In 2020/21, the LTV team dealt with more patients, despite reduced hospital capacity. Technology helped improve the service during the pandemic. Excellent patient satisfaction feedback. Stronger links built with regional community team and other tertiary hospitals in East England and London. Further service development planning as per NCEPOD report guidance.

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### Categories

6. LUNG HEALTH/ PUBLIC HEALTH / COVID-19 Pandemic

## Home cardiorespiratory sleep studies: a UK tertiary respiratory centre experience

Dr Nikoletta Lofitou Zochiou, Dr Roisin Kay, Dr Sadhu Dhuwalia, Mrs Fiona Robinson, Mrs Brindey Heyeer, Mrs Amy Burrill, Mrs Kiran Hunjan, Mrs Joanna Bennet, Mrs Laura Morris, Dr Benjamin Davies, Dr Satish Rao, Mr Ciaran McArdle, Dr Priti Kenia  
Birmingham Children's Hospital, Birmingham, United Kingdom

### Abstract

**Introduction:** Home sleep studies have been utilised in children within our institution. Over a period of five years, our home sleep studies programme was extended to a wide group of patients including children on long-term ventilation.

**Aims:** To assess feasibility, quality and success rates of home sleep studies for investigation and monitoring including those undertaken whilst on long term ventilation, and evaluate parental views on equipment use at home.

**Methods:** Retrospective review of home cardiorespiratory sleep studies was performed at a specialist paediatric respiratory centre.

**Data recorded included:** pulse oximetry, nasal pressure flow with snore, respiratory effort and body position. Transcutaneous carbon dioxide monitoring was not undertaken. For patients on long term ventilation, built-in software data of home ventilator was used to assess adherence to treatment, pressure efficiency, leaks, asynchronies, and estimate the presence of respiratory events. Two nights of data recording was planned in all cases.

**Quality of study** was assessed based on acquisition of interpretable data  $\geq 4$  hours of artefact-free data and study was deemed successful where clinical interpretation was possible.

**Results:** Ninety-four patients corresponding to 110 sleep studies were included (Table 1). Nine studies were not interpretable and overall success rate was 92%. Main pathologies included: adenotonsillar hypertrophy, Down's syndrome, skeletal abnormalities, neurological disease and those on long-term ventilation.

Families were contacted by telephone. 46/94 (49%) of the respondent families completed a questionnaire. 76% found the equipment "easy to use" and 65% reported "very good" experience. 70% expressed preference for a home instead of in-hospital sleep study and 74% expressed willingness for their child to have a repeat home sleep study should the first study failed. 64% of families reported uninterrupted or usual sleep pattern during the night of the study and 15% reported staying awake most of the night.

Conclusions: Performing good quality, interpretable cardiorespiratory polygraphy at home is feasible and successful, even for younger patients and those on long-term ventilation. Patients well established on long-term ventilation could potentially benefit the most. Parents report positive experience with a preference toward home sleep studies rather than in-hospital investigations.

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### **Categories**

5. PHYSIOLOGY, SLEEP, NIV

## Current barriers and practical solutions to incorporating air pollution health promotion into routine Paediatric practice in a DGH - a quality improvement project.

Dr J.K. Dykes<sup>1,2</sup>, Ms Catherine Kenyon<sup>3</sup>

<sup>1</sup>Bristol Royal Hospital for Children, Bristol, United Kingdom. <sup>2</sup>Gloucestershire Royal Hospitals NHS Foundation Trust, Gloucester, United Kingdom. <sup>3</sup>Global Action Plan, London, United Kingdom

### Abstract

#### Introduction:

Air pollution is an important determinant of children's respiratory health – as Ella Kissi-Debrah's death tragically highlighted.<sup>1</sup>

NICE Quality Standard 181 states 'children...with chronic respiratory...conditions [should receive] advice' on air pollution.<sup>2</sup> However, anecdotally we found many colleagues weren't confident providing this. For a quality improvement project around NICE Quality Standard 181 we aimed to formally quantify baseline Paediatric Staff skills in air quality health promotion advice (AQHPA) and the efficacy of an intervention to improve them, in a DGH.

#### Methods:

Two on-line questionnaires, assessing staff baseline and the efficacy of the intervention, respectively. We disseminated the baseline questionnaire via departmental email. Next, we delivered an hour-long session in the departmental education meeting, covering air pollution's health impact, simple AQHPA, and patient information materials from Global Action Plan. Session attendees completed the intervention questionnaire.

#### Results:

**Baseline questionnaire** – thirty respondents: fourteen General Paediatric Consultants (two PRM SPIN), ten Registrars, six Respiratory AHPs.

None reported receiving formal training in AQHPA. Seventeen reported 'never' giving AQHPA to patients; eleven reported doing so only 'infrequently'. Twenty-eight reported being either 'not at all confident' or only 'a little confident' providing AQHPA.

Departmental teaching and patient leaflets were the 'training or resources I would find most useful' in improving confidence delivering AQHPA (twenty-three and twenty-two respondents).

The biggest barrier to delivering AQHPA identified, apart from professionals' lack of knowledge, was lack of "good-quality patient information" (twenty-five respondents).

**Intervention Questionnaire** – 8 respondents: four Consultants, two Registrars, two Specialist Nurses:

		<b>Before</b>	<b>After</b>
<b>Please rate your knowledge of air</b>	Minimal	25%	0
	Little	50%	0
	Moderate	25%	62.5%

<b>pollution's health impact.</b>	Know quite a lot	0	37.5%
	Extremely well-informed	0	0
<b>How confident do you feel providing AQHPA?</b>	Not at all	12.5%	0
	Only a little	50%	0
	Moderately	25%	50%
	Quite confident	12.5%	50%
	Extremely	0	0

### Conclusions:

Paediatric Health Professionals in our hospital did not feel knowledgeable or confident delivering AQHPA. Pragmatic interventions via departmental education programmes and quality materials can overcome the biggest barriers, providing the tools to close the gap between the vital need for AQHPA and current patchy practice.

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### Categories

6. LUNG HEALTH/ PUBLIC HEALTH / COVID-19 Pandemic

## **Does the use of home spirometry kits reduce the need for face-to-face reviews in a Paediatric Cystic Fibrosis clinic?**

Mr Kieren Lock, Dr Sara Warraich, Dr Louise Selby  
Addenbrooke's Hospital, Cambridge, United Kingdom

### **Abstract**

#### **Introduction and Objectives:**

The SAR-COV-2 pandemic necessitated a reduction in hospital and clinic footfall, to minimise exposure and spread of this corona virus.

This posed a challenge for children with cystic fibrosis (CF) requiring regular face-to-face multi-disciplinary input to assess and optimise lung health. In particular, this would hinder the pulmonary function testing (PFT) in clinics, used to monitor disease progression and exacerbations.

Our tertiary CF team obtained funding and access to home spirometry kits, to enable PFT at home during the pandemic.

Objectives: 1) If home PFT is an effective substitute to clinic testing 2) If the introduction of home PFT impacted on clinic appointment distribution.

#### **Method:**

Children with CF aged 6-16 were included. Data was collected from October 2020–March 2021.

Over two weekends in November, families were invited to have home spirometry readings measured alongside clinic PFT, ascertaining baseline compatibility. Spirometry technique was taught and assessed.

For clinics during the months of October 2020–March 2021, patients underwent face-to-face, video and or telephone consultations.

Data was collected retrospectively, using our electronic patient system.

#### **Results:**

In the two months prior to the introduction of home spirometers (October-November), 74.2% of appointments were face-to-face.

The number of face-to-face appointments reduced to 61% in the first month after home spirometry introduction. However, only 20% of patients had performed home spirometry prior to their virtual appointment. This may be considered a pilot month and some additional sessions were required to help with equipment set-up and for staff to prompt its use prior to clinic.

In the following months between January-March, 49-56% of appointments were face-to-face. The number of patients performing home PFT prior to the virtual clinics also increased, being 75%-85%. The home spirometry reliably predicted clinical exacerbations in three patients, leading to admissions for intravenous antibiotics.

#### **Conclusion:**

Home spirometry was associated with a reduction in the need for face-to-face appointments, whilst enabling remote monitoring of lung function and health in a virtual setting.



This method holds the potential to reduce travel and absence from school whilst promoting patient autonomy and greater ownership of care.

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### **Categories**

2. CYSTIC FIBROSIS

## Getting a 'handle' on nebuliser compliance in young children

mrs Claire Lord, miss Pauline Singleton, Miss Fiona Lindsay  
South Tees NHS trust, middlesbrough, United Kingdom

### Abstract

**Objectives:** Time taken to nebulise medication multiple times a day affects quality of life for families. Little is known about the stress and anxiety for parents administering these therapies in young children compared to evidence for those caring for an adolescent. Nebulisation times in our cohort varied from 5-20 minutes, those taking longer had decreased compliance and increased apprehension around treatment. Our objective was to find a solution to improve technique therefore decreasing nebulisation time, reducing physical support parents give the child thus achieving better adherence.

**Methods:** Informal discussion by the physiotherapist highlighted the challenges parents face with nebulised therapies on a daily basis using the PARI eFlow®. One idea was that a 'handle' might make it easier to hold the nebuliser in the correct position to optimise drug delivery therefore reduce time taken to administer treatment. In collaboration with the CF team, local families and Medical Physics at James Cook University Hospital, a 'handle' attachment was developed that clips onto the nebuliser handset without changing how it works. Families then trialled the handle and completed an anonymised questionnaire.

**Results:** Results from the questionnaires showed an increased level of acceptance of nebulised treatments. Parents found it quicker to complete therapy; children were able to manage it independently without parents holding the nebuliser and had a free hand to play games, keeping them distracted. Overall an increase in compliance and acceptability was found for both children and parents.

**Conclusion:** Following positive feedback from our families, the 'Handle' has since become commercially available under the name Nebigrip. It has been commended in innovation North Bright Ideas in Health Awards. This highlights that for parents struggling with daily problems, a small change can have a big impact and emphasises the importance of listening and involving parents with innovative ideas

### Categories

2. CYSTIC FIBROSIS

## **Tailoring treatments to adolescent girls presenting with stridor and suspected exercise induced laryngeal obstruction (EILO).**

mrs Claire Hepworth, Mr Ian Street, Mr Philip Lawrence, Mrs Su De, Mr Ian Sinha  
Alder Hey Hospital, Liverpool, United Kingdom

### **Abstract**

**Background:** EILO is diagnosed through continual exercise laryngoscopy (CLE) in our multidisciplinary complex breathlessness service. Three distinct presentations of stridor were revealed on CLE in 5 adolescent girls.

**Aims:** To describe different presentations of stridor, and how they informed personalised treatment plans.

**Method:** Five girls underwent CLE, a holistic assessment of co-morbidities including breathing pattern disorder (BPD), Fraction Exhaled Nitric Oxide & pre-&-post exercise spirometry. Follow up treatment was guided by the findings.

**Results:** Case 1 & 5: Two athletes, peaking their physiological limit, no asthma or psychosocial problems. One had BPD. CLE on both revealed anterior passive prolapse of the arytenoids and mid-vocal fold indrawing. Treatment was EILO management and breathing retraining with successful outcomes. Case 2: A teenager with asthma, multiple hospital admissions, significant anxiety & BPD. CLE showed active adduction of the entire vocal cords, along with anterior-posterior contraction of the supraglottis. Successful treatment was breathing retraining alongside holistic anxiety management. Case 3: A teenager with asthma, BPD & significant anxiety requiring CAMHS. CLE revealed symmetrical adduction of the whole vocal cord length similar to case 2. Stridor was also inducible at rest. Treatment was psychology led and focused away from symptoms and more on distraction and relaxation. She is still receiving active treatment. Case 4: A teenager with stridor at rest, exacerbated with activity, present since a child. Spirometry revealed a fixed obstructive upper airway problem & CLE showed symmetrical but very limited abduction at vocal cord level bilaterally, likely idiopathic vocal cord palsy. There was no BPD or anxiety. She was referred to neurology for second opinion.

**Discussion:** There were 2 similar presentations of EILO in case 2 and 3 with active glottic and supraglottic constriction on inspiration demonstrated, in addition to a strong psychosocial component, managed with holistic support addressing wider psychological components. Case 1 & 5 were similar presentations of stridor in athletes managed by typical EILO and breathing retaining techniques. Case 4 had distinctive laryngoscope findings & history.

**Conclusion:** CLE revealed different patterns of stridor in cases with strong psychosocial elements, compared to those without. This helped to guide personalised treatment.

### **Categories**

1. ASTHMA / ALLERGY

## **The use of technology and web based exercise programmes to improve education, engagement and quality of exercise session delivered to paediatric inpatients during admission**

Ms Louisa Wallbridge, Mrs Hannah Day, Ms Rosie Percy, Ms Rebecca Brown  
Sheffield Children's Hospital, Sheffield, United Kingdom

### **Abstract**

The purchase of a large interactive screen and new software has enabled us to significantly improve the service we can provide to our inpatients. Using the screen in our inpatient gym we are able to facilitate exercise sessions in a number of new ways including, accessing you tube videos, patient selected web based exercise programmes, school based exercise provisions and games. Using a parent and patient feedback questionnaire, we have found that we have been able to improve adherence to exercise sessions, increased enjoyment, improved engagement of family members and more effective education around the importance of exercise within our population. We have also been able to provide exercise sessions to groups of patients using Ipads in their rooms and a physiotherapist on the big screen. This has enabled patients to communicate with peers and enjoy exercise in a group, something that they aren't usually able to enjoy. When current restrictions have eased, we are hoping to be able to present results using exercise testing as an outcome measure.

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### **Categories**

2. CYSTIC FIBROSIS

## **Understanding doctors' frontline antibiotic prescribing decisions in children with respiratory symptoms (A qualitative study)**

Dr Tom Hampton<sup>1,2</sup>, Prof Jane Ogden<sup>3</sup>, Dr Helen Higgins<sup>1</sup>

<sup>1</sup>University of Liverpool, Liverpool, United Kingdom. <sup>2</sup>Alder Hey Children's Hospital, Liverpool, United Kingdom. <sup>3</sup>University of Surrey, Guildford, United Kingdom

### **Abstract**

**Objectives:** To explore the factors that influence hospital doctors antibiotic prescribing decisions when treating children with respiratory symptoms in UK emergency departments.

**Methods:** A qualitative study using semi-structured interviews based on a critical incident technique with 21 physicians of different grades and specialties that treat children in emergency departments in the UK.

**Results:** Four themes were identified that impacted on clinician prescribing. The three principle themes were Authorities, Pressures and Risk. The fourth transcending theme that ran through all themes was clinician awareness and complicity (“Knowing but still Doing”).

**Conclusions:** It is concluded that hospital doctors prescribe antibiotics even when they know they shouldn't, due to the influence of those in charge or external pressures whilst weighing up the immediate and longer term risks, and that they do this with full insight into their actions. These findings have implications for invested parties seeking to develop future antimicrobial stewardship programmes. It is recommended that stewardship interventions acknowledge and target these themes which may in turn facilitate behaviour change and antimicrobial prescribing practice in emergency departments.

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### **Categories**

6. LUNG HEALTH/ PUBLIC HEALTH / COVID-19 Pandemic

## Air Pollution and Unplanned Respiratory Presentations

Dr Helena Jones<sup>1</sup>, [Dr Adam Lawton](#)<sup>1</sup>, Dr Abigail Whitehouse<sup>2</sup>, Dr Katie Knight<sup>1</sup>

<sup>1</sup>North Middlesex University Hospital, London, United Kingdom. <sup>2</sup>Royal London Hospital, London, United Kingdom

### Abstract

#### Background and Aims

In January 2021 an inquest confirmed for the first time that air pollution contributed to a child's death from asthma. We sought to explore the correlation between air pollution levels and respiratory presentations to North Middlesex Hospital Children's Emergency Department.

#### Methods

45000 attendance records for January 2019 to January 2020 were analysed for respiratory presentations. Data was collected on admission date, and if available, home postcode. We then used publicly available data from <https://www.londonair.org.uk> to find daily and weekly average levels of nitric oxides (NO, NO<sub>2</sub> and NO<sub>x</sub>) for two fixed monitoring sites for the local area. Data was analysed for descriptive purposes and correlations using Spearman's rank.

#### Results

There were 3490 presentations from the London Boroughs of Enfield and Haringey with respiratory symptoms between 1st January 2019 and 1st January 2020. 2452 children had a home postcode in Enfield, and 1038 in Haringey. Within Enfield, significant correlations were noted between weekly averages of NO, NO<sub>x</sub>, and NO<sub>2</sub> and weekly attendances with respiratory symptoms, with a correlation co-efficient of 0.617 (p-value 1.092x10<sup>-6</sup>), 0.564 (p-value 1.326x10<sup>-5</sup>), and 0.426 (p-value 0.0016) respectively. Weaker correlations were noted in Haringey, and a larger dataset to include 2018 will be analysed to identify whether statistically significant correlations exist for Haringey.

#### Discussion

We found positive correlation between weeks with higher pollution levels and increased respiratory presentations. Currently, we see limited action to improve pollution levels in the UK. Many organisations have called for the declaration of a climate emergency in recognition of this inaction. It is reasonable to expect that a persistence of air pollution levels above WHO mandated levels will continue to result in excess respiratory illnesses. Now is the time to put tackling air pollution and climate change at the forefront of Trust and NHS agendas.

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