



## Welcome to the ARNS newsletter

**Beverley Bostock, Editor and ARNS Asthma Lead**

Welcome to the newly refreshed ARNS Newsletter, which aims to provide information on respiratory topics, update you on the work of the subcommittees and board, and generally keep you in the know!

We are putting this together shortly after the end of the 2024 conference, which was held in beautiful, sunny Brighton.



Brighton Festival was in full swing, so we got to see the full rainbow of humanity while we were there, which aligned nicely with our theme of 'All things colourful'. Our members definitely rose to the occasion with their bright outfits and accessories, not to mention the very bright minds that were clearly in attendance too! What a conference it was – shout out to the conference organising committee who worked so hard to put together an amazing agenda and who are already working on sessions for 2025!



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The conference included key topics, top drawer speakers and an extremely engaging exhibition. Here's some of the feedback we received:



*Well, what a fabulous conference! A welcoming experience, and a vast range of respiratory education, with all participants having something valuable to take away. The mix of formal education alongside patient experience provided emotive thoughts to transfer into daily clinical practice. An opportunity to network with like-minded respiratory nurses. I was particularly proud of one of my own team delivering a poster presentation, this being her first opportunity to present in such a forum. An excellent experience, a very well organised couple of days at an outstanding venue.*

One particularly fascinating review came via a blog from one of our committee members, Maria, who brought along a special guest...

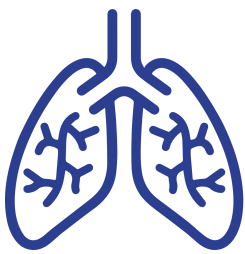
*It was that time of year again... the ARNS conference! I always enjoy going to conferences, especially ARNS – learning from others, networking and feeling inspired from talks to improve within my own practice. There was one big difference this time – it was the first time attending as a mother. I had just returned to work from maternity leave the week before the conference and we were already having a rough start. Not only was my 9-month-old son starting nursery (with all the emotional caveat that comes with that), but he also got ill after his first day...which meant a trip to ED, and taking carers leave from work. I had barely been back at work and was already needing to take the time off. Less than a week later, on Wednesday, I made my way to Brighton to attend the conference. Being part of the ARNS committee also means additional responsibilities with the organisation, logistics and time keeping of the event. It was going to be the first time I left my son overnight with his dad since he was born. I had such a mixture of emotions. I felt anxiety because my son was only ill last week; what if something happened? I felt sad because it's the longest time we have spent away from each other since he was born. Also, guilt – yes that “mum guilt” every mother seems to know about was rearing its ugly head again. It wasn't just negative emotions... I was excited to go to conference, having adult conversation – being “me” again, and not just “mum”. I was happy to be able to spend time with likeminded colleagues, who only want the best for their patients.*

*I still breastfeed, so despite being away I needed to use a breast pump regularly to keep up my*



*supply and have a stock. I needed to pump every 3-4 hours– so had to plan my time at conference before I got there, ensuring I had a good mix of enjoying conference, helping with ARNS committee duty and mummy duties. It meant that most of my “refreshment breaks” and “lunch breaks” had turned into pumping time in my hotel room. After spending the first day and night without them, my son and his dad joined me on the Thursday afternoon. I no longer had to pump or worry about him or his dad as they were here in Brighton with me! I felt I could relax more at this point and enjoy the conference more. I went to the energise yoga session on the Friday morning – I had attended yoga and mindfulness sessions regularly before I was pregnant. I didn't realise how much I had missed it – it's like a mind reset for me, a perfect start to the day. I continued balancing attending sessions, breastfeeding and committee duties as the day continued. Father and son made their own way back home on the train after checking out early afternoon. Towards the end of conference, Rosamund Adoo-Kissi Debrah's talk on her fight for clean air since the death of her daughter made me think about my own son and how air pollution is potentially affecting his future lung health. Being a mother has given me a fresh perspective on life, priorities, and purpose. I love being both a mother and a respiratory nurse. Finding the balance between the two will be a challenge, but one I will enjoy learning from. As always, I look forward to the next ARNS conference in 2025!*

As mentioned above, one of the most passionate and inspirational speakers we had at conference was Rosamund Adoo Kissi Debrah whose daughter remains the only person in the world to have air pollution as a cause of death. Ros's loss was profound, but her humour shone through along with her indefatigable determination to take action to reduce the risks posed to current and future generations as a result of poor air quality. On that note, our newly appointed Children and Young People's (CYP) lead, Viv Marsh, has put together some information about Clean Air Day 2024 and the impact of air pollution.



**Pulmonary  
Fibrosis Trust**



01543 442 191



info@pftrust.org



www.pftrust.org

Raising **awareness** of **pulmonary fibrosis** and providing personal **support** to all those affected

**82**

is the number of people we were able to help with funding in 2023.



**£700**



helps the PF Trust fund a **mobility scooter**, which gives someone living with PF their **independence** back.

The Pulmonary Fibrosis Trust is a UK registered charity, established 10 years ago. Its primary aim to help those affected by the progressive, incurable lung disease, pulmonary fibrosis.

We do this in 4 main ways, emotional support, raising awareness, research funding and practical support. The latter we do by providing mobility aids like scooters, portable oxygen and stairlifts.

We also provide a holiday home for free use of patients. This fully equipped, mains connected 3 berth caravan, located by a sandy beach, has been a resounding success and is fully booked for the remainder of the year.

*"Thank you so much for this. It will transform my day to day life, being able once again to accompany my family on outings instead of being stuck in the car and hearing the stories second hand."*



SCAN ME





## Clean Air Day 20th June 2024

**Viv Marsh, Children and Young People's Lead,  
Respiratory Disease Sub Committee**

Clean Air Day, the UK's largest air pollution campaign, is approaching and this year's theme is "Clean up our air to look after your mind". [Global Action Plan](#), who head up the campaign, report that up to 36,000 deaths occur each year in the UK as a result of air pollution.

Awareness of the impact of poor air quality on our health is growing with both the public and health care professionals becoming increasingly concerned. At this year's ARNS conference we heard from Rosamund Adoo Kissi Debrah whose daughter Ella died at just 8 years of age as a result of exposure to outdoor air pollution. Rosamund, who campaigns tirelessly about air pollution, spoke clearly and passionately about Ella and her own ongoing fight for clean air; it was no surprise that she received a standing ovation from the ARNS audience. Find out more about Ella and about Rosamund's work at [The Ella Roberta Foundation](#).

In November 2022 a [coroner found that 2-year-old Awab Ishak died](#) as a result of a severe respiratory condition because of prolonged exposure to mould in his home. This landmark finding has resulted in wholesale change including legal requirements in the housing sector and adding weight to the requirement for health and housing to work more collaboratively. [The national bundle of care for children and young people with asthma](#) sets out a clear expectation that healthcare professionals will educate and support children and young people with asthma, and their families to understand and manage the impact of air pollution.

[Asthma and Lung UK](#) continue to be a leading force in the campaign for clean air; funding research, campaigning at all levels of government, raising awareness in communities, developing resources for healthcare professionals and supporting the public and patients directly.

[Discussing triggers with patients](#) is a vital and reasonably well-established element of asthma care and, when it comes to pollution we need to be thinking about both indoor and outdoor air quality.

So, as a respiratory interested healthcare professional, what can you do? Here's some suggestions from ARNS:

- Learn more about air pollution yourself
- Talk to your patients about air quality
- Sign post your patients to recommended resources that can help them to avoid, reduce or manage their exposure
- Support the Clean Air Day campaign to raise awareness amongst your colleagues and your patients
- Find out what actions are being taken in your area to improve indoor and outdoor air quality

### **Suggested reading and resources:**

[Clean Air Day Knowledge Hub for anyone working in health](#)

[Asthma + Lung UK webpage Lowering your risk from air pollution](#)

[NICE Guidance NG70 Air Pollution: Outdoor air quality and health](#)

[NICE Guidance NG149 Indoor air quality at home](#)

[DEFRA UK air information resource, tools and air quality index](#)

[Empowering community health professionals for effective air pollution information communication](#)

[Tan et al 2023](#)

# 10th King's John Price Paediatric Respiratory Conference Report

**Aleks Gawlik-Lipinski, Vice Chair of the ARNS Research and Education Sub Committee**

The 10th King's John Price Paediatric Respiratory Conference offered insights and revelations, diving deep into the issues affecting our little ones' lung health. From the hazards of vaping to the transformative potential of AI in healthcare, each session offered a truly unique perspective on the challenges and opportunities ahead.

Prof Andy Bush's presentation exposed devastating impact of vaping on lungs. With acute toxic injury being greater than from tobacco, it's a sobering wake-up call to confront this growing epidemic.



**Aleks at the 10th King's John Price Paediatric Respiratory Conference**

Dr Umang Patel and Dr Hammad Khan's talks were equally engaging, highlighting the ground-breaking role of AI in reshaping paediatric respiratory care. Their discussions painted a rather vivid picture of a future where technology empowers clinicians to deliver more precise diagnoses and personalised treatment plans.

However, Dr Mark Levy's reminder of asthma's lethal consequences brought us back to earth. Despite medical advancements, asthma continues to kill, urging us to increase our efforts in prevention and management.

And let's not forget Prof Ian Sinha's eye-opening talk on the impact of poverty on respiratory health. His insights shed light on how socioeconomic disparities exacerbate respiratory diseases, emphasising the urgent need to "poverty-proof" our healthcare system.

As I reflect on the conference's wealth of knowledge, it's clear the future of paediatric respiratory health hinges on our collective action. It's up to us to heed these lessons, take action, and ensure every child has the chance to breathe easy.

## ARNS Conference 2024 Award Winners

ARNS would like to congratulate all nominees and award winners at the ARNS Conference 2024.



**ARNS Award for Outstanding Contribution to Respiratory Care - Claire Adams**



**ARNS Award for Excellence in Respiratory Care - RESPS Team, East Sussex**



**Best Poster - Stef Cormack - "I wish it was cancer": a survey exploring pulmonary fibrosis patient experiences of healthcare across the UK**



**Best Oral Presentation - Chellan Eames - Using ABC (adherence, biomarkers and co-morbidity) in the nurse-led asthma clinic (NLAC) to reduce inappropriate use of oral steroids and antibiotic in patients with worsening asthma symptoms during a clinical assessment**

## ARNS Conference 2024

As well as being an amazing opportunity to network, the ARNS conference offers an opportunity to share best practice, through keynote talks like Ros's and via plenaries, breakout sessions and in the poster presentations. There were some superb posters giving examples of how research projects are helping to shape practice. These included the role of the multidisciplinary team in ILD, offering palliative care to people with COPD, the cost-effectiveness of using FeNO in diagnosing children's asthma, a one-stop, nurse led COPD diagnostic clinic, service provision for biologic therapy assessment in severe asthma, the question of whether we should carry out spirometry for incidental finding of emphysema during a lung health check, patients' experiences of pulmonary fibrosis and more.



Other work that might help ARNS members to rethink their local service provision, is the paper by Ludlow et al (2023) on the 'Multidisciplinary management of inducible laryngeal obstruction and breathing pattern disorder' *Breathe* (Sheffield, England), 19(3), 230088. <https://doi.org/10.1183/20734735.0088-2023> co-authored by sub committee member Rachel Daly. Key findings from this study were that inducible laryngeal obstruction and breathing pattern disorder are common causes of breathlessness, and multidisciplinary assessment can prevent unnecessary medication use and hospital admissions as well as facilitating effective management of these complex conditions.

Highlighting the importance of sharing all research findings, Rachel also presented her work on the role of nasal nitric oxide measurements in a complex breathlessness clinic. The conclusion was that it was unlikely to be useful, findings which might help others who are setting up similar services.

### The Exhibition

ARNS could not put on a conference of this size and magnitude without the support of our partners and exhibitors. Those who had stands including charities such as Asthma and Lung UK and the Pulmonary Fibrosis Trust, along with the pharmaceutical industry, legal companies supporting people with occupational lung disease and device companies. Exhibitors reported excellent interaction with delegates, which is important if we are to secure funding for future conferences. We are continually told that the ARNS conference offers these organisations an opportunity to hear from the grass roots of respiratory care and offer information about initiatives and products in a friendly setting. It is perhaps not surprising that we sold out of exhibition space very quickly! Here's a comment from an exhibitor:



*Last week I had the privilege of attending the ARNS conference in Brighton and I still can't express how blown away I still feel. The respiratory nurses are so incredibly passionate about their field, about patient care and about how they can affect change in the industry. I understood the camaraderie felt by respiratory nurses despite the challenges faced by the NHS. I can't wait to help support these nurses in whatever way I can to help them to do their jobs.*

One of the new developments we heard about from Jo, the chair of ARNS, was the Asthma and Lung UK Respiratory Champions pilot. Facilitated by funding from Astra Zeneca, six Integrated Care Boards in England have been selected to trial the role of a Respiratory Champion for one day a week. These areas and individuals were selected after a competitive process which garnered a great deal of interest. Their role will reflect the needs of the area in which they work but if the pilot project is successful, the aim will be to roll the programme out. Asthma and Lung UK were on site to explain more about the project and showcase their resources too. Here are their thoughts: *I wanted to personally congratulate you all on a fantastic conference! It was my first ARNS experience and I have to say I loved it, so different from other conferences I have been to. It was clear how much effort and hard work had gone into the conference. Fantastic speakers, networking, and pharma. It was professional but also super fun, thought-provoking and inspiring, with so many talented and helpful people there. One for the memory bank!! Many thanks and I will be back next year – hopefully with our Champions and some poster presentations and/or speakers.*

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AS SEEN ON



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## Guidance updates

ARNS is often asked to be involved in developing and/or reviewing new guidance and we make sure we are registered as stakeholders for relevant publications. At the time of writing, the new BTS/SIGN/NICE asthma guidelines were due to be shared in draft form for consultation. The GINA guidance has recently been updated for 2024 <https://ginasthma.org/2024-report/> and shares a lot of common ground with the 2024 All Wales Adult Asthma guideline which can be found here: <https://awttc.nhs.wales/medicines-optimisation-and-safety/medicines-optimisation-guidance-resources-and-data/prescribing-guidance/all-wales-adult-asthma-management-and-prescribing-guideline/> It will be interesting to see if the stars align to produce another guideline from BTS/SIGN/NICE which has a similar approach.

Meanwhile, NICE is looking at different elements of COPD management (such as the use of technology and the place for biologics) and ARNS has been involved in offering feedback on these proposals. Two members of the board have helped to inform national guidance on malnutrition in COPD and our COPD lead, Jo, is also supporting the development of the European Society for Clinical Nutrition and Metabolism nutrition guidance for COPD 2024: <https://www.espen.org/> Our acute lead, Emma, has also been busy, publishing papers including this one: [Nurse-led oscillating positive expiratory pressure Independent Nurse : May 2024 \(mydigitalpublication.co.uk\)](https://mydigitalpublication.co.uk) Emma has also taken part in the non-tuberculous mycobacterial disease (NTM) Standards of Care publication which can be found [here: https://www.ntmnetworkuk.com/standards-of-care](https://www.ntmnetworkuk.com/standards-of-care)



Emma is passionate about disease prevention and has put together some pragmatic recommendations regarding COPD here:

Chronic obstructive pulmonary disease (COPD) is a progressive life-threatening lung disease that causes breathlessness (initially with exertion) and predisposes to exacerbations and serious illness (WHO, 2017). Although predominately affecting the lungs, COPD is a multi-system disorder (systemic) which is one of the most common and burdensome chronic conditions globally (Global Initiative for Chronic Obstructive Pulmonary Disease [GOLD] 2020 and British Lung Foundation, 2019). In the early stages of the condition, patients are somewhat symptom free. However, patients report increasing breathlessness, cough and chest tightness, as well as sputum production as the disease progresses (National Institute of Clinical Excellence [NICE], 2018). Unfortunately, COPD is a progressive disorder of persistent airflow limitation which is not fully reversible and associated with inflammation caused from noxious gases and particles (for example cigarette smoke) (Bashir et al 2016).

In the UK, there are currently 1.2 million people diagnosed with COPD with estimations of a further 2 million underdiagnosed (BLF, 2019). Due to this, it is difficult to identify the true disease burden (Brines & Thorne, 2007). According to WHO, (2017) it is predicted COPD will become the third leading cause of death by the year 2030. COPD is extremely life limiting with poor prognosis and no cure to date (Oliver, 2001).

Are you interested in submitting an article, report, update for future newsletters?

Would you like to advertise in future newsletters?

Please contact ARNS Secretariat at [info@arns.co.uk](mailto:info@arns.co.uk) for more information.





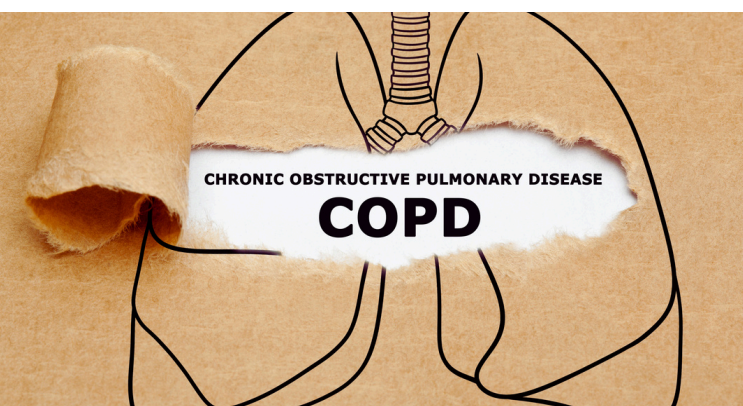
## Pre - COPD and PRISM

GOLD (2023) is the only document to talk about prevention in COPD and to date there are no other known prevention clinics in the UK. If we compare this to cardiology, there are multiple documented prevention policies ACE, angiotensin-converting enzyme; AF, atrial fibrillation; CVD, cardiovascular disease; QOF, Quality and Outcomes Framework, The NHS Long Term Plan, Version 1.2 (2019). NICE Quality and Outcomes Framework Indicator (2023).

GOLD (2023) details new discussion of risk factors as well as new approaches to terminology and recommendations for their use:

- GOLD (2023) details new discussion of risk factors as well as new approaches to terminology and recommendations for their use:
- Early COPD – to be used when discussing “biological early” rather than “clinical early” when initial symptoms become apparent.
- Mild COPD – to be used only to describe the severity of airflow obstruction measured spirometrically.
- Young COPD – to be used to describe COPD in patients aged 20-50 years old.
- Pre-COPD – for identifying individuals of any age with respiratory symptoms and/or structural and/or functional abnormalities but no evidence of airflow obstruction
- PRISM – to describe individuals with no airflow obstruction but abnormal spirometry

It is recognised that patients fall on a continuous spectrum on the three major aspects of COPD: rate of lung function decline, frequency of acute COPD exacerbations and symptom burden, with little correlation between the three (Burgel et al, 2017 and Johnson et al, 2018). Such categorising results in COPD phenotypes that are numerous, loosely defined, and not always mutually exclusive. To continue, Adibi and Sadatsafavi, (2020) proclaim that two-pronged definition of COPD and its severity grades creates categories that cannot be directly classified as either normal lung function or COPD. One such category consists of patients who have reduced FEV1 ( $FEV1 < 80\% \text{ pred}$ ) and reduced FVC, in such a way that  $FEV1/FVC \geq 0.7$ .



In this patient population, known as PRISM, classification as having reduced lung function, do not meet the spirometry definition of COPD. For that, such patients have largely been excluded from major therapeutic trials (Sin et al, 2016). As such, characteristics of these populations, and their prognosis and appropriate treatments, remain poorly defined. Given that PRISM resembles COPD in terms of reduction in FEV1, but not in terms of FEV1/FVC ratio, a natural question is whether the prognosis in such a “intermediate” group is closer to that of COPD or that of the general non-COPD population (Wijnant et al, 2020). Wijnant et al, (2020) also provide evidence for a potential role of obesity on transition into and out of PRISM. Findings suggest that patients with persistent PRISM generally had higher body mass index and higher likelihood of gaining weight between the visits. This will be addressed during health promotion in initial clinics and an offering a referral to ‘activity for life’ to encourage exercise will a free 3 month pass to a local gym. The most important findings of Wijnant et al, (2020) study, was that PRISM is associated with significant risk of mortality, especially cardiovascular mortality. In summary, the overall literature review outcomes suggest that in terms of outcomes such as lung function trajectories and mortality, PRISM course is closer to COPD than to those with normal spirometry and is a cause for concern. To continue, GOLD board of directors published a statement in the European Respiratory Journal declaring that “it is time for the world to take COPD seriously” (Haplin et al 2019). The lack of data following a literature review is suggestive of more research in this area, and as GOLD board suggest, it’s time to take COPD seriously and contribute to evidence-based practice in preventing this irreversible disease from progressing.

## Prevention of COPD clinics

**STRENGTHS** - Prevention of COPD - Money saving to the NHS - Improve QoL - Reduce mortality - Improve overall lifestyle - prevent co-morbidities - Cost effective

**WEAKNESS** - Longitudinal monitoring - Wide spread adoption - Time consuming - Persuading overstretched teams to adopt prevention

**OPPORTUNITIES** - Change culture - Improve management of patients - Streamline respiratory care - Contribute to evidence-based practice - Set new standards of care and prevention in COPD - Health promotion for patient population

**THREATS** - Fill clinics with patients who don't have COPD and don't have capacity for those with COPD



## ARNS Conference 2024 Report

**Dr Lucy Speakman, Research and Education Sub Committee**

ARNS conference 2024 in Brighton was a great few days spent with fellow nurses sharing a passion for respiratory care.

I presented at the conference for the first time. Although it was a great opportunity to share my doctorate research, I had to overcome my fears about presenting as, as nurses this is not something we get the opportunity to do very often. I was pleased I did it and had some great feedback from people.

I especially enjoyed a session I chaired where a Respiratory Nurse from a hospice spoke about end of life care. This isn't a subject that's often been discussed at conference but is so important for community respiratory nurses who care for many people at end of life. Discussing advanced care planning and DNR is a challenging subject but so important for our patients if they are to receive the care they deserve if they want to receive care in their own homes.

I helped run a research workshop with colleagues which were well attended, it was really good to empower nurses to develop their research ideas and consider wider perspectives of care delivery. We had discussions about the theory-practice gap in nursing. Nurses generally feel competent and confident in their clinical skills and are aware of what to expect from practice but research can be intimidating because it can feel abstract and "less safe" with unpredictable outcomes, can be long-winded and difficult to navigate. Looking at ways to help nurses overcome/navigate/recognise these obstacles or barriers is surely pivotal to increasing engagement with research and something we will continue to address.

The conference was bookended by two incredible women: Professor Laura Serrant and Rosumund Adoo-Kissi-Debrah who challenged us to call out injustice, inequalities and inequities in our working environments, in the care we provide and in society.

Spending time with nurses is always time well spent. This conference was a wonderful opportunity to learn, feel challenged morally and emotionally and spend time with energetic, passionate people.



If all of this has inspired you to get more involved in ARNS, we would love to have you! Whether through an informal contact via [info@arns.co.uk](mailto:info@arns.co.uk) or more formally as vacancies come up (we are about to recruit for an ILD lead) the more involvement our members have, the better we can represent people living with respiratory disease. That links nicely to the news that we are in the process of setting up a Patient and Public Involvement group, to ensure that everything we do remains patient-focused.

We hope you have enjoyed reading this newsletter. Feel free to submit ideas for (or even contribute to) future newsletters.



**Bev Bostock - ARNS Newsletter Editor and ARNS Asthma Lead**