



ILD-IN BLOG

EDITION 2 ● JULY 2023 ● NEW COMMITTEE MEMBERS

WELCOME TO TWO NEW ILD-IN COMMITTEE MEMBERS

We are delighted to announce our two newest members of the ILD-IN committee, Rosie Boorsma and Laura Fabbri. Rosie is a respiratory specialist nurse with the Regional East Sussex Pulmonary Service (RESPS). Laura is a clinical research fellow at the Margaret Turner Warwick Centre for Fibrosing Lung Disease. Read all about them here..

ROSIE BOORSMA

My journey with ILD began at home with my amazing dad. He was diagnosed in 2004 and as is often the case for many patients and families facing the diagnosis, it was the first we had heard about it. Dad was seen in the local DGH for many years and eventually read an article in the Daily Mail and asked for a referral to the Brompton. It was then that he started to receive treatment and we felt that he was getting the care he needed. Once his fibrosis had progressed and he was discharged from the Brompton to local care, I became very aware of the absence of local support. I felt it was unjust that if he had a cancer diagnosis we would have had more understanding from our friends and family but also a Macmillan nurse to support us and answer any questions. Dad and I muddled through his last few months with a million courses of Doxycycline for what I now realise was simply worsening breathlessness due to him dying. When Dad was in ITU for his last few days, I saw a job come up for a Respiratory Specialist Nurse with RESPS. I loved the idea that I could help other patients with ILD and felt that having lived through it myself, I could offer a unique perspective. I had the interview a week after dad died and got the job.

RESPS



In my role in RESPS, I took on the role as the "ILD link" as well as being an oxygen nurse. Again, in this role, it was clear to me that there is a huge gap for patients and their families when managing with ILD. They are diagnosed in a clinic and only receive nursing support if they are referred to a tertiary centre or into the RESPS team for pulmonary rehabilitation or oxygen assessment. I have worked hard to create a more supportive ILD service within the RESPS team which means that I can offer patients and their families support during the end stage and when they are deteriorating, but also help counsel them when they are commenced on new medications or need oxygen treatment. I formed two face to face support groups to help cover our extensive area and also an online Zoom group for patients who cannot attend.



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I also developed the East Sussex Pulmonary Fibrosis Handbook so that our patients had all the information they need in one book. More recently, we have started the respiratory virtual ward which gives us a great opportunity to support unwell patients with ILD in their own homes and avoid hospital admissions.

There are still huge gaps between the care we can provide to patients' with ILD and the care they deserve. There is a lot of development needed in the community to better support our patients and help manage their conditions

I've attended the ILD-IN conferences for the last 3 years and found them incredibly valuable and enjoyable.

I look forward to working with the team in the ILD-IN committee to help improve the co-ordination of care from primary care to tertiary care and ensure that there is a better understanding of pulmonary fibrosis and its' management.

FAMILY

In my personal life, I am married with 2 often feral boys who are 2 and 6. Living where we do means we can enjoy lots of time at the seaside and also going for walks in the forests. The boys are excellent at ensuring I make the most of every day by waking us up by 6am, 7 days a week and improving my people management skills by arguing over everything!

LAURA FABBRI

I was born in Italy, where I lived most of my life, with a couple of years spent between Spain and France. In 2019 I moved to Nottingham just before the pandemic hit! Since 2021 I have been living in London and have fallen in love with the city. I discovered theatre shows, taking advantage of the endless offer by the hundreds of theatres around the city, from famous West End productions to smaller independent companies. I am always up for a show! If I am not at the theatre, especially on weekends, you may find me wandering around the city, exploring new corners, or baking in my kitchen. In the photo a recent apple and cinnamon cake I was pretty proud of. I have always loved improvised dinners with friends, pasta is quick and easy and will never disappoint.





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MY FRIENDS DEFINE ME AS “RESOURCEFUL, UNSTOPPABLE AND ALWAYS POSITIVE. THERE’S ALWAYS SOMETHING TO LEARN FROM LAURA AND IF YOU NEED SOMEWHERE TO GO OR SOMETHING TO DO, SHE’S SURE TO FIND ALL THE BEST ACTIVITIES!”



CAREER JOURNEY

The Italian university system is slightly different from the UK, mainly focused on clinical skills. I got my medical degree in Perugia, with a thesis on smoking habits among healthcare professionals and the first data about vaping, which were still called “electronic cigarettes.” I then moved to Modena for my speciality training in respiratory diseases, where I discovered the niche of the rare lung diseases, including ILDs, and decided to subspecialise. To graduate, I ran a project about unclassifiable ILDs, in collaboration with a French ILDs centre. Finally, I moved to Nottingham to join Prof. Jenkins’s team, and with them, I ended up at Imperial College London. Our group (a few of us in the photo during the last Secret Santa) investigates interstitial lung diseases, from translational medicine to extensive data analysis to purely clinical trials. My coffee has been defined as “rocket fuel” by my boss, and I am proud to have taught everyone what a moka is. And no, it does not involve chocolate!

CURRENT ROLE

I am now in my 3rd PhD year, working as a clinical research fellow at the Margaret Turner Warwick Centre for Fibrosing Lung Disease. My projects aim to define the best management to early diagnose and prevent the progression of pulmonary fibrosis, following a patient-centred approach. In my first year, I was collaborating with the charity Action for Pulmonary Fibrosis, meeting amazing people who taught me so much with their stories and experiences. Seeing their impact on patients’ lives and families, and the lack of awareness and support available, I decided to get training for patients and public involvement and engagement. I recently completed an “engagement academy” and designed and ran an activity to explain pulmonary fibrosis to the public, which I would like to bring to schools, too. Besides research, I still do clinical work, mainly at the outpatient clinics at the Royal Brompton Hospital, one of the biggest referral centres in the UK. I love my clinical work, and I missed this part when I could not work in clinics during the pandemic.

