



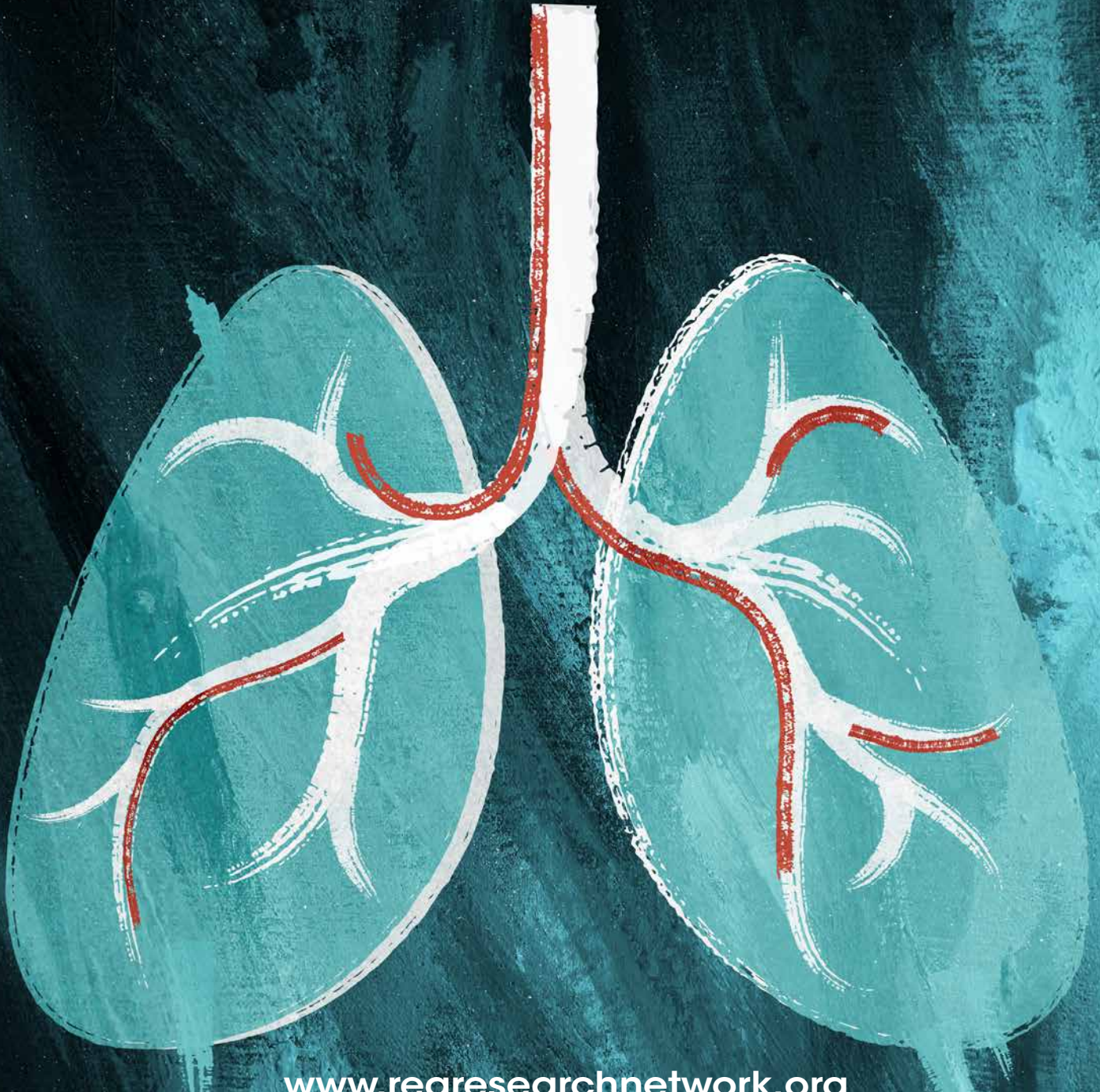
Respiratory  
Effectiveness  
Group

# ADVANCES

in Real-life Respiratory Research

The Respiratory Effectiveness Group Newsletter

ISSUE FEBRUARY 2025



[www.regresearchnetwork.org](http://www.regresearchnetwork.org)

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## THE RESPIRATORY EFFECTIVENESS GROUP NEWSLETTER ISSUE FEBRUARY 2025

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# EDITORIAL

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## Joan B. Soriano

### REG President

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### EXCITING TIMES FOR RESPIRATORY EFFECTIVENESS RESEARCH

It's showtime! Our next REG Summit will be held from March 20th to 22nd, 2025, in London, UK. On behalf of the entire REG Board, I already take this chance to congratulate in advance Prof Alan Kaplan, Summit Scientific Programme Chair and his team, namely Therese Lapperre (Co-Chair), Fulvio Braido, Antonio Anzueto, Mona Al Ahmad, and George Christoff. They have assembled again a program that is second to none. It will include revisiting old controversies such as the real-life impact of inhalers and propellants on our planet and patients; and selected topics on ILD/IPF, COPD, severe asthma and vaccines; with other innovative areas and melanges such as on readers', authors', and editors' perspectives on observational research; AI and digital revolutions in respiratory diseases; plus some surprises. The REG Summit will be seasoned with the savoir faire of many REG regulars, distinguished invitees, plus new blood.

The venue could not be more awesome: The Royal College of Physicians, now set in a modern building overlooking Regent's Park,

it is within walking distance to many hotels and all London's amenities. All in all, you cannot miss this REG Summit for a few days of spring in the Empire's capital, where this educational event will be held, with class and distinction.

In an era with international conflicts galore, and regrettably misinformation going berserk, opportunities for international exchange of scientific evidence, bonding, networking, and face-to-face interaction are to be considered precious. The ongoing and endlessly escalating explosive global situation requires many petite actions like ours, to create a better world for our patients and the next generation.

The REG board very much looks forward to meeting you in London this spring, and together learn, with a smile. Your active participation in the REG Summit 2025 will undoubtedly ensure a successful and productive meeting. Looking forward to welcoming you in London. See all belated information and instructions in this Newsletter. See you this spring, and thank you!

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### Joan B. Soriano

President of REG

Pneumology Department

Hospital Universitario de la Princesa –

Universidad Autónoma de Madrid

Madrid (SPAIN)

# REG TEAM UPDATE



**Michael Walker**  
REG CEO

2024 was another busy year for the REG team with our projects progressing well. The PIF in COPD project was successfully concluded and reported, the Risk Prediction Model of First Exacerbation in COPD publication will shortly be submitted, and the Virtual ILD MDT survey was published in ERJ Open Research. New ideas have been developed, and we're looking forward to rolling

them out this year, including a triple therapy COPD project and a cost effectiveness of biologics in severe asthma project. We will continue to further expand our network of collaborators as we grow our research ideas and areas, as well as establish new collaborations with our partners.

In the past few months, our focus has been on preparing for the REG Summit 2025 in London, scheduled for March 20th - 22nd. The programme and speakers have now all been finalised. This year, we are returning to our individual Working Group Meetings format to report on new and ongoing projects as well as to generate new and innovative research ideas.

In this issue, you will find an update of the projects, as well as the tremendous work

of the International Severe Asthma Registry (ISAR) and the next instalment of Clinical Management Perspectives looking at familial ILD.

I would like to acknowledge the support from a number of long-term Sponsors. Without their ongoing support, much of the work of REG would not be possible. I hope others are encouraged and inspired by the activities of REG and the Summit in March and will collaborate with us this year or plan to in the future.

I look forward to meeting our many collaborators and supporters at the REG Summit 2025 in London.



# Transforming Respiratory Care

Our ambition is to transform Respiratory and Immunology care for patients, moving beyond symptom control to disease modification, remission and, one day, cure.





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THE RESPIRATORY  
EFFECTIVENESS GROUP

REG

SUMMIT 2025  
20-22 March, London, UK

## REG SUMMIT 2025

REG looks forward to the forthcoming REG Summit in **London**, which is being held at the prestigious **Royal College of Physicians**, a unique and famous location in central London. This gathering will bring together real-life research experts from around the world to discuss the latest findings and new areas for collaboration in their respective fields of real-life respiratory research.

The REG Summit is a well-known meeting of global respiratory key opinion leaders engaged in real-life research using and the generation of Real World Evidence. REG collaborators (researchers, clinicians, general practitioners and allied health professionals) have conducted numerous database and prospective pragmatic trials and continue to seek solutions to the many complex issues faced by respiratory patients.

The REG Summit 2025 is a globally important RWE respiratory meeting on the year's congress calendar. Commencing on Thursday, 20th March, this year's summit returns to our individual Working Group Meetings format to update collaborators on new and ongoing research projects as well as discuss new and innovative research ideas. We encourage all collaborators and supporters to join us at the Summit and actively participate in the Working Group Meetings. For those unable to attend in person, online participation options will be available. The scientific programme follows all day on Friday 21st, and concludes at lunchtime on Saturday, 22nd March.

The scientific programme will include robust and informative discussions and debate on the latest insights on treatment strategies. Our focus is on identifying the essential needs to propel the field forward and achieve a deeper understanding of how to enhance patient outcomes. Participants will debate the hottest topics within the field, in a variety of interactive and informative sessions designed to foster collaboration and facilitate knowledge exchange.

A distinguished line-up of experts will speak about new perspectives and address challenges in the management of COPD, respiratory diseases and our environment, the future use of biologics, rhinitis management, IPF referrals. management, and provide an update on the severe asthma registry from ISAR. A new feature at this year's meeting is the Early Career Abstract Presentation session, where successful travel grant winners will present their research in a plenary session.

This meeting presents an excellent opportunity for in-person networking with some of the world's foremost experts in the respiratory field, fostering connections with friends and colleagues.

The REG Summit 2025 will be the years' most important meeting in the field of respiratory real-life research, and everyone is encouraged to participate and get involved with the REG and its exciting projects.

We look forward to seeing you in London!



[www.regsummit2025.org](http://www.regsummit2025.org)

## INTRODUCING THE REG SUMMIT 2025 MEETING VENUE



### The Royal College of Physicians: Regent's Park, London

The Royal College of Physicians of London, commonly referred to simply as the Royal College of Physicians (RCP), is a British professional membership body dedicated to improving the practice of medicine, chiefly through the accreditation of physicians by examination. The RCP was founded by royal charter from King Henry VIII in 1518 and affirmed by Act of Parliament in 1523. The RCP is a charity and is the oldest medical college in England. Its home in Regent's Park is one of the few post-WW2 buildings to be listed at Grade I.

Membership of the RCP provides the benefits of being part of a global community of over 40,000 members and fellows, spanning every career stage from medical student to retired consultant.

The Royal College of Physicians has had a library collection since its foundation in 1518, although most of the original books were destroyed during the Great Fire of London in 1666. The rare books and special collections are diverse in coverage, reflecting the collecting habits of earlier fellows and the need to provide the broad educational base considered suitable for physicians. The historical collection includes approximately 130 books printed before 1502, including some of the earliest printings of the classical medical texts by Greek, Roman and Arabic doctors. It also consists of over 4,500 tracts from the 17th to the 19th century covering a wide range of subjects, both medical and scientific.

Within the building, there is also a museum with collections that relate to the history of the college, and that of the Physician's profession. They help to place the history and development of medicine and healthcare in its widest context. The collections include: portraits, silver, medical instruments, the Symons Collection, commemorative medals and anatomical tables.



**Trevor Lambert**  
REG Oversight Committee



# FINAL PROGRAMME

20 – 22 MARCH 2025 | ROYAL COLLEGE OF PHYSICIANS, LONDON UK

## THURSDAY 20<sup>TH</sup> MARCH | WORKING GROUP MEETINGS

	Room 1:	Room 2:
12:00-13:00	<b>NETWORKING / LUNCH</b>	<b>NETWORKING / LUNCH</b>
13:00-14:00	<b>ILD/IPF</b>	<b>Adherence</b>
14:00-15:00	<b>Allergy</b>	<b>Database &amp; Coding</b>
15:00-16:00	<b>Technologies</b>	<b>Child Health</b>
16:00-16:30	<b>COFFEE</b>	<b>COFFEE</b>
16:30-17:30	<b>Cost Effectiveness</b>	<b>COPD</b>
17:30-18:30	<b>Environment, Epidemiology and Airways</b>	<b>Biomarkers &amp; Severe asthma</b>

## FRIDAY 21<sup>TH</sup> MARCH

08:50-09:00	<b>WELCOME</b> Joan B. Soriano, Spain REG President
09:00-10:00	<b>INHALER SESSION - Propellants, planet, and the patient - the real-life impact</b> <b>Chair:</b> Omar Usmani, UK & Mark Levy, UK - <b>What does it mean to the Regulator?</b> (12 mins)   Speaker: Maureen Donahue Hardwick, USA - <b>What does it mean to the industry?</b> (12 mins)   Speaker: John Bell, UK - <b>What does it mean to the Clinician?</b> (12 mins)   Speaker: Toby Capstick, UK
10:00-10:30	<b>ILD/IPF SESSION</b> <b>Chair:</b> Pilar Rivera Ortega, UK - <b>Time taken from primary care referral to a specialist centre diagnosis of idiopathic pulmonary fibrosis: an opportunity to improve patient outcomes?</b> (25 mins)   Speaker: Mark Jones, UK - <b>Q&amp;A</b> (5 mins)
10:30-10:45	<b>COFFEE BREAK</b>
10:45-11:30	<b>READERS', AUTHORS', AND EDITORS' PERSPECTIVES ON OBSERVATIONAL RESEARCH</b> <b>Chair:</b> Nicolas Roche, France & Therese Lapperre, Belgium - <b>How to lie with statistics to a chest physician</b> (15 mins)   Speaker: Joan B. Soriano, Spain - <b>An editor's perspective on observational research</b> (15 mins)   Speaker: David Price, UK - <b>Q&amp;A</b> (15 mins)
11:30-12:30	<b>EARLY CAREER ORAL ABSTRACT PRESENTATIONS (6 x 5 mins plus Q&amp;A)</b> <b>Chair:</b> Marc Miravittles, Spain & Dermot Ryan, UK
12:30-13:30	<b>LUNCH BREAK &amp; POSTER VIEWING</b>
13:30-15:00	<b>COPD SESSION</b> <b>Chair:</b> Bernardino Alcazar, Spain & Frits M.E. Franssen, The Netherlands - <b>Predicting the risk for first COPD Severe Exacerbation</b> (25 mins)   Speaker: Bernardino Alcazar, Spain - <b>Triple therapy and very severe COPD: Rational for a REG study</b> (25 mins)   Speaker: Chin Kook Rhee, S. Korea - <b>New Drugs in COPD: will they make a real-life difference?</b> (25 mins)   Speaker: Nicolas Roche, France - <b>Q&amp;A</b> (15 mins)
15:00-15:30	<b>COFFEE BREAK</b>
15:30-16:25	<b>UNITED AIRWAYS DISEASE SESSION</b> <b>Chair:</b> Piotr Kuna, Poland & Stefania Gallo, Italy - <b>Novel Treatments in Allergic Rhinitis</b> (8 mins)   Speaker: Walter G. Canonica, Italy - <b>Rhinitis +/- asthma: different diseases?</b> (20 mins)   Speaker: Ralph Mosges, Germany - <b>(R)evolution of care in CRSwNP'</b> (20 mins)   Speaker: Peter Hellings, Belgium



FRIDAY 21<sup>TH</sup> MARCH

16:25-17:10	<p><b>AI/DIGITAL IN RESPIRATORY DISEASES SESSION</b>  <b>Chair:</b> Job van Boven, Netherlands &amp; Fulvio Braido, Italy</p> <ul style="list-style-type: none"> <li>- <b>Can interactions with AIs provide patient support?</b> (20 mins)   Speaker: Alan Kaplan, Canada</li> <li>- <b>Can digital adherence support prevent disease progression?</b> (20 mins)   Speaker: Amy Chan, New Zealand</li> <li>- <b>Q&amp;A</b> (5 mins)</li> </ul>
17:10-17:55	<p><b>PRO/CON - VACCINES</b>  <b>Chair:</b> Joan B. Soriano, Spain</p> <ul style="list-style-type: none"> <li>- <b>Pneumococcal vaccine is the most important respiratory vaccine for our high-risk patients to receive</b> (15 mins)   PRO: Filipe Froes, Portugal</li> <li>- <b>RSV is the most important respiratory vaccine for our high-risk patients to receive</b> (15 mins)   CON: Alan Kaplan, Canada</li> <li>- <b>Vote &amp; Summary Discussion</b> (15 mins)   Joan B. Soriano, Spain</li> </ul>
17:55-19:00	<b>POSTER VIEWING AND NETWORKING</b>

SATURDAY 22<sup>ND</sup> MARCH

09:00-10:00	<p><b>EXPANSION OF BIOLOGIC USE IN ASTHMA: WHERE TO?</b>  <b>Chair:</b> Nikos Papadopoulos, Greece &amp; Jenni Quint, UK</p> <ul style="list-style-type: none"> <li>- <b>Younger age</b> (20 mins)   Speaker: Adnan Custovic, UK</li> <li>- <b>Milder disease</b> (20 mins)   Speaker: Enrico Heffler, Italy</li> <li>- <b>Multimorbidities</b> (20 mins)   Speaker: Désirée Larenas-Linnemann, Mexico</li> <li>- <b>Q&amp;A</b></li> </ul>
10:00-10:45	<p><b>BRONCHIECTASIS SESSION</b>  <b>Chair:</b> Nicolas Roche, France</p> <ul style="list-style-type: none"> <li>- <b>Current and future perspectives in the treatment of bronchiectasis</b> (35 mins)   Speaker: Eva Van Braeckel, Belgium</li> <li>- <b>Q&amp;A</b> (10 mins)</li> </ul>
10:45-11:00	<b>COFFEE BREAK</b>
11:00-12:35	<p><b>IMPROVING SEVERE ASTHMA CARE - ISAR'S RESEARCH AND QUALITY IMPROVEMENT HIGHLIGHTS</b>  <b>Chairs:</b> David Price, UK &amp; Veronica Mendez</p> <ul style="list-style-type: none"> <li>- <b>Exploring definitions and predictors of severe asthma remission post-biologic (FULL BEAM II)</b>   Speakers: Luis Perez-de-Llano &amp; Ghislaine Scelo</li> <li>- <b>Does achieving remission change long-term outcomes in severe asthma</b>   Speakers: Walter G. Canonica &amp; Victoria Carter</li> <li>- <b>Practice change in severe asthma - where are we now in terms of standardizing care and data management</b>   Speakers: Désirée Larenas-Linnemann &amp; Celine Goh</li> <li>- <b>Impact of biologics on new onset of OCS-related outcomes in severe asthma (SOLAR II)</b>   Speakers: David Price &amp; Piotr Kuna</li> <li>- <b>Eliminating long-term OCS and frequent intermittent OCS</b>   Speakers: Pujan Patel &amp; Freya Tyrer</li> <li>- <b>Global Economic Impact of biologic initiation in severe asthma</b>   Speaker: Brett McQueen</li> <li>- <b>Modelling the impact of treating severe asthma earlier</b>   Speaker: Soram Patel &amp; Alison Evans</li> </ul>
12:35-13:50	<p><b>INTEGRATING RWE INTO GUIDELINES</b>  <b>Chairs:</b> Walter G. Canonica, Italy, Maria Jose Torres, Spain</p> <ul style="list-style-type: none"> <li>- <b>The need for RWE to be included in guidelines</b> (15mins)   Speaker: Stefano Del Giacco, Italy</li> <li>- <b>The GRADE system to integrate RWE</b> (25 mins)   Speaker: Holger Schunemann, Italy</li> <li>- <b>Real-life experience of guideline creation</b> (15 mins)   Speaker: Nicholas Roche, France</li> </ul>
13:50	<b>MEETING CLOSE</b>

# CLINICAL MANAGEMENT PERSPECTIVE



## Stefan Cristian Stanel

Consultant in Respiratory Medicine and Interstitial Lung Diseases  
Royal Devon University Healthcare  
NHS Foundation Trust  
Exeter, UK

## GENOMIC TESTING FOR INTERSTITIAL LUNG DISEASES

Genetic predisposition is a key driver for interstitial lung diseases (ILDs). The prevalence of pulmonary fibrosis is ten times higher in families where a member has idiopathic pulmonary fibrosis (IPF) (Borie R, 2022) and approximately 30% of asymptomatic first-degree relatives of sporadic IPF cases were found to have interstitial lung abnormalities (ILAs) on chest CT (Hunninghake GM, 2020). Familial ILD cases may also have extrapulmonary features sharing the same predisposition, but the clinical correlation is often missed. Relatives can have haematological conditions including leukaemia or myelodysplasia, autoimmune diseases, unexplained liver disease, or other features such as early hair greying or early menopause. Overall, familial ILD patients tend to have worse outcomes.

Genes related to the maintenance of telomere length and surfactant production have been implicated (Hurley K, 2024). There are several techniques to identify pathogenic gene variants, most centres performing whole exome sequencing with virtual panel testing. Telomere length measurement is also available, the gold standard being Flow-FISH leukocyte telomere length. Availability of ILD genomic testing varies around the world, often limited by cost, logistics of sampling, staff training, access to genetic counselling and lack of overall awareness of familial ILDs.

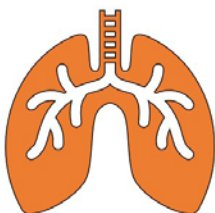
ILD genomic testing already has clinical implications for personalised treatment and prioritization of care, in addition to providing valuable answers to patients and their relatives. It can also support the implementation of targeted ILD screening programmes. There is also scope for real-world research into the clinical implementation of testing and follow-up of affected families, to characterise relevant comorbidities and identify gene targets for precision therapy development.

Despite being a niche field, the study of ILD genetic pathogenesis can lead to wide applications across multiple fields. As we start asking about family history of ILD, who knows what else we will find?

### Suggested criteria to consider genomic testing for interstitial lung disease (ILD)? \*

Patient diagnosed with ILD and one of the following:

1. No clear cause and age < 50 years
2. Family history of ILD
3. Haematological abnormalities
4. Unexplained hepatic abnormalities
5. Early hair greying (age < 25 years)
6. Early menopause (age < 45 years)
7. Frequent cancer diagnosis within the family
8. Consideration of lung transplantation
9. Diagnosed telomere-related disease



\* Local testing criteria may vary

## References

1. Borie R, Kannengiesser C, Antoniou K, Bonella F, Crestani B, Fabre A, Froidure A, Galvin L, Griese M, Grutters JC, Molina-Molina M, Poletti V, Prasse A, Renzoni E, van der Smagt J, van Moorsel CHM. European Respiratory Society statement on familial pulmonary fibrosis. *Eur Respir J*. 2023 Mar 16;61 (3):2201383. doi: 10.1183/13993003.01383-2022. PMID: 36549714.
2. Hunninghake GM, Quesada-Arias LD, Carmichael NE, Martinez Manzano JM, Poli De Frías S, Baumgartner MA, DiGianni L, Gampala-Sagar SN, Leone DA, Gulati S, El-Chemaly S, Goldberg HJ, Putman RK, Hatabu H, Raby BA, Rosas IO. Interstitial Lung Disease in Relatives of Patients with Pulmonary Fibrosis. *Am J Respir Crit Care Med*. 2020 May 15;201(10):1240-1248. doi: 10.1164/rccm.201908-1571OC. PMID: 32011908; PMCID: PMC7233344.
3. Hurley K, Ozaki M, Philippot Q, Galvin L, Crosby D, Kirwan M, Gill DR, Alysandratos KD, Jenkins G, Griese M, Nathan N, Borie R; COST Open-ILD Group Management Committee. A roadmap to precision treatments for familial pulmonary fibrosis. *EBioMedicine*. 2024 Jun;104:105135. doi: 10.1016/j.ebiom.2024.105135. Epub 2024 May 7. PMID: 38718684; PMCID: PMC11096859.
4. Molina-Molina M, Borie R. Clinical implications of telomere dysfunction in lung fibrosis. *Curr Opin Pulm Med*. 2018 Sep;24(5):440-444. doi: 10.1097/MCP.0000000000000506. PMID: 30067250.

Adapted from Borie R, 2022, Molina-Molina M, 2018 and NHS England - National Genomic Test Directory

# WORKING GROUP UPDATE





## ADHERENCE WORKING GROUP

The Adherence Working Group welcomed Amy Chan as the new chair following Sinthia's decision to step down from the role (Sinthia remains in charge of the scoping project, which includes two manuscripts currently under revision).

Last December, Amy chaired her first WG meeting virtually. Together with WG members, she brainstormed new project ideas, including a retrospective study to assess changes in medication use, particularly following the 2019 GINA guidelines update. Other ideas included an international multi-centre investigation on OCS use, a comparison of ED guidelines in relation to adherence to national asthma and COPD guidelines, and an exploration of the use of biologics in asthma. These ideas will be finalised during the next in-person WG meeting heads at the REG Summit in March 2025.



## ALLERGY WORKING GROUP

The group are currently developing new project ideas in allergic asthma, rhinitis, and allergen immunotherapy.



## CHILD HEALTH WORKING GROUP

The WG has been actively working in a retrospective database study, analysing data obtained from the OPCR to assess the prevalence and incidence of severe asthma in children within UK primary care, using seven different definitions. The analysis has been completed, and the results were used to finalise a study report last December. The WG is now preparing a manuscript, expected to be submitted in the coming months.

Also, the group has been involved with the PEARL project, following the publication of recommendations for asthma monitoring in children, endorsed by APAPARI, EAACI, INTERASMA, REG, and WAO. They are now working on two new papers focusing on biomarkers and treatments, which are expected to be submitted to a peer-reviewed journal in 2025.



## COPD WORKING GROUP

The final results from the follow-up visits of the prospective observational study, which aimed to determine the prevalence of suboptimal PIF in COPD patients and investigate its predictive value for exacerbations and symptom burden, have been used to prepare a manuscript currently under revision. Whereas, the manuscript, which includes data from the baseline visits, is under second revision by BMJ Open Respiratory Research.

The group has been also working on the PRECISE-X project, developing a risk prediction model for initial severe exacerbations in COPD patients. After accessing data from the CPRD, the group analysed the data, finalised a study report, and is now using the interesting results to prepare the first draft of a manuscript, which is expected to be submitted to a peer-reviewed journal by next month.

Last December, the group also started a new COPD study focused on the effects of triple pharmacological therapy on post-discharge outcomes in COPD patients. The investigators involved in this study are currently working on their ethical approval application.



## COST EFFECTIVENESS WORKING GROUP

The AstraZeneca-funded project "A Global Evaluation of the Economic Impact of Time to Initiation of Biologic Treatment of Severe Asthma Patients" is underway. The project seeks to assess the national-level cost-effectiveness of biologic treatment, examining and comparing the economic impact and lifelong disease burden associated with time to initiation of treatment between countries.



## DATABASES AND CODING WORKING GROUP

The WG has finalised the research idea to assess the interplay between COPD, T2D, and cardiovascular outcomes. A detailed study proposal has been prepared, outlining the methodology and objectives, and it will be sent to pharmaceutical companies to seek funding for the project.



## ENVIRONMENT, EPIDEMIOLOGY AND AIRWAYS WORKING GROUP

The manuscript "Respiratory Effectiveness Group Position Statement: Inhaler Choice: Balancing Personalised Healthcare and Environmental Responsibility" is under peer review at the Journal of Aerosol Medicine and Pulmonary Drug Delivery. The group looks forward to the next working group meeting at REG Summit to discuss future projects.



## ILD WORKING GROUP

The manuscript "The Interstitial Lung Disease Patient Pathway: From Referral To Diagnosis" was published in ERJ Open Research (<https://doi.org/10.1183/23120541.00899-2024>). The project aimed to characterise ILD diagnosis across 64 countries, identifying similarities and differences in the patient diagnostic pathway between ILD specialist centres, non-ILD-specialist centres, and different regions.

The ILD Working Group had an excellent meeting at the 22nd International Colloquium on Lung and Airway Fibrosis (ICLAF) in Athens. The group discussed the flagship ILD project "Towards Standardisation in IPF / PPF Registry Data: A Global Initiative", consisting of three subprojects:

- **Project 1:** "Identifying Key Variables through a Global Prioritisation Task".
  - The project aims to define the most critical diagnostic, clinical, and patient reported variables that should be captured across IPF/PPF registries.
  - Variables will be linked to multiple clinical outcomes, ensuring that they reflect key aspects of disease progression, treatment response, and patient well-being. Using conjoint analysis, global prioritisation task for ILD clinicians and patients will be conducted to assess the relative importance of different diagnostic and prognostic procedures, disease outcomes and essential data elements.
- **Project 2:** "Identifying Data Elements for Disease Management".
  - Utilising the registry standardisation tool from Project 1, we will collect real-world data from multiple centres and IPF / PPF patients worldwide, evaluating the framework's ability to assess key clinical outcomes, and refining the standardisation process based on practical data collection insights.
  - The dataset will be populated with patient records and patient-reported outcomes capturing diagnostic tests, clinical interventions, treatment, clinical outcomes and patient priorities associated with the predefined variables from Project 1.
- **Project 3:** "Development of a Global Composite Staging System for IPF / PPF Disease Progression".
  - Harnessing the global dataset created in Project 2, the project aims to determine the relevant diagnostic and clinical indicators associated with disease progression in IPF and PPF.
  - The goal is to create and validate a global comprehensive staging system for IPF and PPF, utilising worldwide retrospective data from ILD centres and registry data.

The flagship project is currently under discussion with potential funders.

The group have also developed proposals focussing on pulmonary hypertension in ILD patients (PH-ILD):

- "Genetic Determinants of Pulmonary Hypertension in Interstitial Lung Disease: Uncovering Pathways for Early Detection".
- "Predicting Pulmonary Hypertension Risk in ILD Patients Using Real-World Data".

Proposals are currently under discussion with potential funders.



## SEVERE ASTHMA AND BIOMARKERS WORKING GROUP

Discussions on project opportunities and new ideas are ongoing.



## TECHNOLOGY WORKING GROUP

A proposal for the project "Vaccine Uptake and Clinical Outcomes in High-Risk Chronic Respiratory Patients: A Retrospective Database Study" is under development. The project aims to examine vaccine coverage and uptake trends in high-risk chronic respiratory patients, as well as identify the clinical and economic impacts of vaccination. New projects will be discussed at the upcoming REG Summit.



## VACCINES WORKING GROUP

A proposal for the project "Vaccine Uptake and Clinical Outcomes in High-Risk Chronic Respiratory Patients: A Retrospective Database Study" is under development. The project aims to examine vaccine coverage and uptake trends in high-risk chronic respiratory patients, as well as identify the clinical and economic impacts of vaccination.



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# WHAT REG MEANS TO ME

As the new incoming Chair of the adherence working group for REG, I am thrilled for the opportunity to contribute to improving respiratory care through working with REG. REG holds a special place internationally to advance respiratory care through collaboration and innovation among global leaders and experts. I was invited to join REG back in 2022 and have seen it grow in its reach and impact through real-life, high-quality impactful research. I am currently an Associate Professor at the University of Auckland, School of Pharmacy and the Respiratory lead of our Medicines Intelligence research group. Being based in New Zealand, I've often found it challenging to connect with colleagues and experts across the globe due to the physical distance. However, being part of REG bridges this gap by providing invaluable opportunities to network and connect with respiratory leaders worldwide. REG means much more to me than a global think-tank for respiratory research. To me, I think REG could be a global leader in research innovation and be the central translation hub for respiratory research to achieve its greatest impact in our global communities. By engaging with a wide range of experts, each bringing their unique skills and perspectives, we have the opportunity to enhance the capacity of our research and drive forward innovative

solutions to complex respiratory health issues. One of the most exciting aspects of REG are the diverse working groups that exist. These various groups focus on different aspects of respiratory health. I see key opportunities for the working groups to learn from each other and collaborate, whilst specialising in its own area. This diversity and collaborative environment within REG fosters the exchange of research ideas and novel approaches, and I am excited for the upcoming REG summit in London where I hope we can brainstorm new ideas, share insights, and develop strategies to advance respiratory care in various domains. It is invigorating to be part of a community of researchers who have a shared commitment to research excellence, and I believe REG will give me opportunities to give back to the research community and make significant strides to improve patient outcomes and advance respiratory medicine.

## AMY CHAN

Associate Professor  
Faculty of Medical and Health Sciences,  
Pharmacy, New Zealand



I first got involved with REG at the summit in Lyon, France, back in March 2016. At the time, I was an enthusiastic PhD student at the University of British Columbia, Canada, with Drs. Mohsen Sadatsafavi and Mark Fitzgerald on my dissertation committee. Thanks to their generous support, I had the amazing opportunity to attend the summit and present my research on the excess costs of asthma, comorbidities, and social disparities using BC's health administrative data.

That experience was incredible. I received insightful feedback on my work and connected with leading scholars in respiratory medicine—some of whom I later had the privilege to collaborate with. The summit's atmosphere was inspiring, seeing REG's commitment to advancing respiratory healthcare through shared knowledge and teamwork, I was greatly motivated and gained lots of inspiration and confidence to continue my research in this field.

REG continued to support me as I transitioned to a faculty position at the National University of Singapore. Arranged by Dr. Job van Boven, I attended multiple REG online meetings to brainstorm novel research ideas with both senior and junior faculties, and later I've had

the opportunity to collaborate with Dr. David Price and the International Severe Asthma Registry Group, which supported me to lead several impactful projects on the real-world effects of biologic therapy in severe asthma. These collaborations have resulted in high-impact publications and successful funding proposals. I'm also working with Dr. Graham Lough on the cost-effectiveness of biologic therapy timings, which has enriched my research portfolio.

REG has helped me build lasting professional relationships and given me a strong sense of belonging in the global respiratory research community. Its support has been invaluable, facilitating collaboration and expanding my international research footprint. My journey with REG is a testament to the transformative power of mentorship and collaboration in advancing meaningful research.

## WENJIA CHEN

Assistant professor, affiliation is Saw Swee  
Hock School of Public Health, National  
University of Singapore





# WHAT REG MEANS TO ME



As a pulmonologist from Brazil who had been working in a small town in Sweden, with very little experience in clinical research and who had recently moved to “the Other Side”, joining the Respiratory Effectiveness Group (REG) could have felt daunting. In my first meeting, about 10 years ago, I half-expected to sit quietly in the corner, nodding wisely while pretending to understand advanced observational study methodologies. Instead, from the very beginning, my opinions were not only heard but genuinely respected, even among some of the world’s most accomplished researchers in respiratory medicine.

REG is much more than just a research initiative; it is a global community built on collaboration, networking and mutual respect. Here, what matters is the shared passion for moving respiratory science forward.

Coming from a clinical background, I have always been aware of the gaps between randomized controlled trial results and everyday patient care, the messy, unpredictable world of actual human beings, especially in the field of inhalation therapy. At REG, I’ve witnessed how real-life research can bridge that gap, providing the framework for effectiveness research in respiratory medicine, generate the evidence that complements randomized trials, as well as invaluable insights that make guidelines and treatments more relevant to diverse patient populations.

But beyond the science, REG is also about friendship. The connections I’ve made here go further than professional collaboration, bonds built over shared passion, dreams, frustrations, common interests and great discussions over the years.

In essence, REG is not just an organization, it’s a place where science, collaboration, and friendship come together to make a real difference, shaping the future of respiratory care and, ultimately, improving the lives of patients and families all over the world. It has been an inspiring journey and an honor for me to be part of REG, and I will always have a soft spot in my heart for this group.

## GUILHERME SAFIOTI, MD

Sr Director Global Medical Affairs  
Teva Pharmaceuticals



# INTERNATIONAL SEVERE ISAR ASTHMA REGISTRY

## ◆ ISAR Country Updates

The **International Severe Asthma Registry (ISAR)**, enters its 8th year with data from **35,199 severe asthma patients** from **30 countries**. As part of the 3-year ISAR extension (2024 – 2026), we have started implementing quality improvement initiatives with our collaborating countries

## ◆ ISAR in 2024: Publications

ISAR is delighted to have published eight articles in 2024. To view ISAR's publications, please visit the **ISAR website**.

Le T.T., et al.

**"Disease Burden and Access to Biologic Therapy in Patients with Severe Asthma, 2017–2022: An Analysis of the International Severe Asthma Registry"**

*J Asthma Allergy, 2024*

**Key Findings:** There is global disease burden in patients with severe asthma, regardless of biologic accessibility and receipt of biologic treatment.

[Full Article](#)

[Press Release](#)

[Slide Deck](#)

Perez-de-Llano et al.

**"Impact of pre-biologic impairment on meeting domain-specific biologic responder definitions in patients with severe asthma"**

*Ann Allergy Asthma Immunol, 2024*

**Key Findings:** The percentage of biologic responders varied by domain and increased with greater pre-biologic impairment.

[Full Article](#)

[Press Release](#)

[Slide Deck](#)

Porsbjerg C.M., et al.

**"Association between pre-biologic T2-biomarker combinations and response to biologics in patients with severe asthma"**

*Front Immunol, 2024*

**Key Findings:** Higher BEC and FeNO levels were associated with larger improvement in lung function following biologic initiation.

[Full Article](#)

[Press Release](#)

[Slide Deck](#)

Wechsler M.E., et al.

**"Association between T2-related co-morbidities and effectiveness of biologics in severe asthma"**

*Am J Respir Crit Care Med, 2024*

[Full Article](#)

[Press Release](#)

[Slide Deck](#)

**Key Findings:** Chronic rhinosinusitis +/- nasal polyps were key components in predicting successful treatment with biologics.

Lee T.Y., et al.

**"International variation in severe exacerbation rates in patients with severe asthma"**

*CHEST, 2024*

[Full Article](#)

[Press Release](#)

[Slide Deck](#)

**Key Findings:** There was large between-country variation in severe exacerbation rates in patients with severe asthma.

Perez-de-Llano L, et al.

**"Exploring definitions and predictors of severe asthma clinical remission post-biologic in adults"**

*Am J Respir Crit Care Med, 2024*

[Full Article](#)

[Editorial](#)

[Press Release](#)

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**Key Findings:** Patients with less severe impairment and shorter asthma duration at initiation had a greater chance of achieving remission after biologic treatment.

Scelo G, et al.

**"Exploring definitions and predictors of response to biologics for severe asthma"**

*J Allergy Clin Immunol Pract, 2024*

[Full Article](#)

[Editorial](#)

[Press Release](#)

[Slide Deck](#)

**Key Findings:** High response does not mean remission; there is a need for flexible interpretation of response to biologics.

Denton E., et al.

**"Real-world biologics response and super-response in the International Severe Asthma Registry cohort"**

*Allergy, 2024*

[Full Article](#)

[Press Release](#)

[Slide Deck](#)

**Key Findings:** Biologics were initiated in patients who have worse baseline impairments than non-initiators despite similar biomarker levels.

## ◆ ISAR in 2024: Abstracts

ISAR presented three posters at the ERS 2024 congress. To view ISAR's abstracts, please visit the [ISAR website](#).

Torres-Duque C, et al.  
"Phenotype and biomarkers in patients who initiated biologic therapy stratified by oral corticosteroid use in the International Severe Asthma Registry"

*Eur Respir J 2024 64(suppl 68): PA438*

Abstract

**Key Findings:** OCS use was associated with significant morbidity, even with intermittent use. OCS use changed biomarker distribution, particularly with long-term OCS use.

Al-Ahmad M, et al.  
"Characteristics of long-term oral corticosteroid users stratified by blood eosinophil count in the International Severe Asthma Registry"

*Eur Respir J 2024 64(suppl 68): PA439*

Abstract

**Key Findings:** Patients with severe asthma and long-term OCS use had high steroid burden, among whom, those with high BEC had worse asthma control and lung function.

Chen W., et al.  
"Impact of biologic initiation on oral corticosteroids in the International Severe Asthma Registry and the Optimum Patient Care Research Database: a pooled analysis"

*Eur Respir J 2024 64(suppl 68): PA2175*

Abstract

**Key Findings:** Biologic initiation results in reduced OCS burden in patients with severe asthma over two years versus usual care.

## ◆ ISAR in the SPOTLIGHT

- Our **FULL BEAM I** study on "Exploring definitions and predictors of response to biologics for severe asthma" is noted in an **editorial** to "enable physicians to manage patients with severe asthma in a way that is both evidence-based and personalized".
- Our **FULL BEAM II** study on "Exploring definitions and predictors of severe asthma clinical remission post-biologic in adults" is highlighted in an **editorial** to be "the largest prospective analysis and the most useful information we have on remission and its determinants in severe asthma".
- Our **GLITTER II** study, "Impact of Initiating Biologics in Patients With Severe Asthma on Long-Term Oral Corticosteroids or Frequent Rescue Steroids (GLITTER): Data From the International Severe Asthma Registry", has been recognized as a highly-cited publication.

## ISAR in 2024: Events



**European Respiratory Society  
(ERS) Congress**  
**Vienna, Austria**  
7-11 September 2024

### Highlights:

#### ISAR's achievements:

- ISAR's growth to >33,000 patients across 30 countries and release of 25 publications were celebrated.

#### Research updates and opportunities:

- The ISC-prioritized research project for 2024, GLEAM, and other active projects were discussed.
- Ground-breaking results from the SOLAR II project were highlighted: biologic users were at lower risk of OCS-related adverse events than non-initiators..

#### Quality improvement (QI) updates:

- To drive QI and improve data quality, the ISAR REDCap Cloud data capture tool and interactive QISAR dashboards were developed. Professor Carlos Torres showed how Colombia has integrated the use of dashboards into their workflow.
- Ideas for achieving practice change goals were discussed, e.g., the establishment of ISAR accreditation for centres of excellence and endorsement of clinical tools developed based on real-world evidence (e.g., the RESA asthma risk prediction modelling tool by Dr Wenjia Chen).



**Asian Pacific Society of  
Respirology (APSR) Conference**  
**Hong Kong**  
7-10 Nov 2024

### Highlights:

- Professor David Price delivered a presentation on the management of asthma by primary care physicians. He outlined the goals that are not currently achieved in primary asthma care, and highlighted the importance of phenotyping and early intervention with targeted therapies.



**Taiwan Society of Pulmonary  
and Critical Care Medicine  
(TSPCCM), Dec 2024**

### Highlights:

- Professor David Price delivered a webinar presentation on real-world evidence from ISAR for severe asthma. He showcased the impact of ISAR research on improving the understanding of severe asthma and highlighted the future of severe asthma management.

## Upcoming ISAR Event 2025



### Thursday 20th March 2025

#### ISAR research updates meeting 10:00-11:00 (open to all ISAR collaborators):

- ISAR research updates (including SOLAR, GLEAM and SPOTLIGHT); ISAR research prioritization 2025; global economic impact of time to biologic initiation in severe asthma; modelling the impact of treating severe asthma earlier

#### GLEAM working group meeting 11:15-11:45 (for GLEAM working group members):

- Results of GLEAM: "Assessing the impact of earlier access to biologics on remission and natural course of asthma"

#### ISAR quality improvement meeting 13:00-14:30 (open to all ISAR collaborators):

- Quality improvement in the International Severe Asthma Registry (QI-ISAR) working group
- Quality improvement updates
- Practice change

#### ISC meeting 14:45-15:45 (for ISC members only):

- Delphi 2024 results; ISAR research prioritization 2025

#### SPOTLIGHT working group meeting 16:00-16:30 (for SPOTLIGHT working group members):

- Updates on SPOTLIGHT: "Impact of remission on long-term outcomes and trajectories in severe asthma"

### Saturday 22nd March 2025

#### ISAR Session 11:00-12:35 (open to all ISAR collaborators):

- Exploring definitions and predictors of severe asthma remission post-biologic (FULL BEAM II)
- Does achieving remission change long-term outcomes in severe asthma?
- Practice change in severe asthma - where are we now in terms of standardizing care and data management
- Impact of biologics on new onset of OCS-related outcomes in severe asthma (SOLAR II)
- Eliminating long-term OCS and frequent intermittent OCS
- Global economic impact of time to biologic initiation in severe asthma
- Modelling the impact of treating severe asthma earlier



**Join ISAR today!**

To register interest as a collaborating country, or to submit a research request or proposal, please contact us [here](#).

# THANKS TO OUR SUPPORTERS

The work of REG would not be possible without the contributions from our invaluable supporters to fund innovative research projects developed by our expert Collaborators.

REG is looking to launch a number of ambitious research initiatives, which offer the opportunity to impact clinical management guidelines and patient care.

We welcome any suggestions from Supporters and would be happy to discuss your ideas in more detail.

You can always get in contact with the REG team by email at [enquiries@regresearchnetwork.org](mailto:enquiries@regresearchnetwork.org),

or write to Michael Walker, REG, CEO, at [michael@regresearchnetwork.org](mailto:michael@regresearchnetwork.org)



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20-22  
MARCH 2025

LONDON  
UNITED KINGDOM

# REG

## SUMMIT 2025



[www.regsummit2025.org](http://www.regsummit2025.org)

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