



Respiratory  
Effectiveness  
Group

# ADVANCES

in Real-life Respiratory Research

The Respiratory Effectiveness Group Newsletter  
ISSUE SEPTEMBER 2020

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**NEW REG  
PRESIDENT**

Sinthia Bosnic-Anticevich

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## THE RESPIRATORY EFFECTIVENESS GROUP NEWSLETTER ISSUE SEPTEMBER 2020

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## Sinthia Bosnic-Anticevich new REG President

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### DEAR FRIENDS

It is such a great pleasure to connect with you as the incoming President of REG, following on from the wonderful leadership of my dear friend and colleague Prof Nikos Papadopoulos. Nikos has been an inspirational leader of REG and during his time as President REG has achieved many important outcomes for the organisation, key highlights being the re-branding of the REG, strengthening of its advocacy role and the securing of significant funding for several large REG real-world evidence projects across a number of our Working Groups. Thank you Nikos for your outstanding leadership and for handing over REG in such a strong position. I am delighted that Nikos is continuing to be an integral member of our REG Board of Directors.

It is fair to say that 2020 has been quite different to what any of us have expected with COVID-19 impacting on the day to

day lives of all of us, and the future of many. We have all faced/are facing challenges yet in amongst all of this, we have managed to stay connected and to continued to thrive; and never has real world data and real life research been more important.

I have to admit, when COVID-19 first became the force that it is, I did not imagine that so much of what I am used to in terms of staying connected to my colleagues could continue – after all, I do live in Sydney, Australia and at times like this, it truly can feel very, very far away. However, the research community has found a way to thrive. We continue to create, contribute and collaborate, albeit in different ways. I mean, would one ever have imagined attending the ATS or ERS remotely? As incoming President of REG, I would like to build on our connectedness, further the great work of our working groups and advocate for researchers and knowledge gain from real life research.

So in moving forward, I would like to encourage you to continue to connect with us, our global network and our thought and innovation leaders to generate novel, impactful real world evidence. Over the next few months, we will be hosting a series of short videos/interviews with the Chairs of our Working Groups. Please take a moment to listen to them and reach out to us regarding topics of interest and collaborations. During this time we are continuing to generate new ideas and secure funding which will see real world evidence, fill the knowledge gaps and provide insights into novel solutions to real world problems.

Please check out our website to find out more about our Board of Directors, our Working Groups and some of the outstanding work and outputs of our network. **[www.regresearchnetwork.org](http://www.regresearchnetwork.org)**.

I am so excited to lead REG moving forward, and encourage you to write to me to provide feedback and your views on real life research and how we can better connect with you.

### Stay safe and well

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#### Sinthia Bosnic-Anticevich

Professor

Woolcock Institute of Medical Research  
University of Sydney, Sydney, Australia

# REG TEAM UPDATE



**Michael Walker**  
REG CEO

Since our last newsletter, a lot has changed, and we have all been affected in some way by this global pandemic. As many readers will know, the REG Summit was due to take place in March in Barcelona. The REG Board made the decision to postpone the meeting due to the health crisis which we all have faced over the last months. I am pleased to announce that the REG Summit is now planned for 18th to

20th March 2021. The Summit will be a stimulating scientific programme providing participants with opportunities for Q and A and discussions about the many issues and controversies that challenge everyday care of patients. Importantly, the data and discussions will also focus on the pandemic and what we have learnt.

Many of the Working Groups held virtual meetings in place of the planned face to face meetings scheduled during the Summit and good discussions and progress was made. Face to face meetings of the Working Groups were also scheduled to take place during the ERS congress in Vienna. As this will not be a live event, we plan to hold more working group meetings online. The Working Group calls

are an important opportunity for our Working Group members to connect and continue our active projects or discuss new projects in development.

So far this year we have had 5 publications from REG projects. An update of the activities of the working group can be found later in this issue.

I would like to acknowledge the support from our long-term supporters. Without their ongoing collaboration a lot of the work of REG would not be possible. I hope others are encouraged by the activities of REG and the REG Working Group meetings and will collaborate with us later this year or plan to in 2021. We will continue to support and reach out to our partners as we work together in real-life research.



# REG RECENT PUBLICATIONS IN 2020



## Changes in Control Status of COPD Over Time and Their Consequences: A Prospective International Study

REFERENCES: Miravittles M, Sliwinski P, Rhee CK, Costello, RW, Carter V, Tang JHY, Lapperre TS, Alcazar B, Gouder C, Esquinas C, García-Rivero JL, Kemppinen A, Tee A, Roman-Rodríguez M, Soler-Cataluña JJ and Price DB on behalf of the Respiratory Effectiveness Group (REG)

### ONLINE LINK:

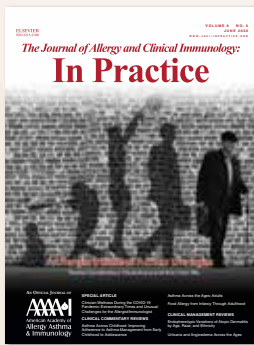
<https://doi.org/10.1016/j.arbres.2020.06.003>

## Predictive value of control of COPD for risk of exacerbations: An international, prospective study

REFERENCES: Miravittles M, Sliwinski P, Rhee CK, Costello RW, Carter V, Tan JHY, Lapperre TS, Alcazar B, Gouder C, Esquinas C, García-Rivero JL, Kemppinen A, Tee A, Roman-Rodríguez M, Soler-Cataluña JJ, Price DB, Respiratory Effectiveness Group (REG).

### ONLINE LINK

<https://onlinelibrary.wiley.com/doi/abs/10.1111/resp.13811>



## Research Priorities in Pediatric Asthma: Results of a Global Survey of Multiple Stakeholder Groups by the Pediatric Asthma in Real Life (PeARL) Think Tank

REFERENCES: Alexander G, Mathioudakis, Adnan Custovic, Antoine Deschildre, Francine M. Ducharme, Omer Kalayci, Clare Murray, Antonio Nieto Garcia, Wanda Phipatanakul, David Price,

Aziz Sheikh, Ioana Agache, Leonard Bacharier, Matteo Bonini, Jose A. Castro-Rodríguez, Giuseppe De Carlo, Timothy Craig, Zuzana Diamant, Wojciech Feleszko, Despo Ierodiakonou, James E Gern, Jonathan Grigg, Gunilla Hedlin, Elham M. Hossny, Tuomas Jartti, Alan Kaplan, Robert F. Lemanske, Peter Le Souef, Mika J Makela, Paolo M. Matricardi, Michael Miligkos, Mário Morais-Almeida, Helena Pite, Paulo MC Pitrez MD, Petr Pohunek, Graham C. Roberts, Sylvia Sanchez-García, Ioanna Tsiligianni, Steve Turner, Tonya A. Winders, Gary Wong, Paraskevi Xepapadaki, Heather J. Zar, Nikolaos G. Papadopoulos.

*The Journal of Allergy and Clinical Immunology: In Practice* Volume 8, Issue 6, June 2020, Pages 1953-1960.e9

### ONLINE LINK

<https://www.sciencedirect.com/science/article/abs/pii/S2213219820301471>

## Opportunities to diagnose fibrotic lung diseases in routine care: A primary care cohort study

REFERENCES: Jones MG, Hillyar CRT, Nibber A, Chisholm A, Wilson A, Maher TMM, Kaplan A, Price D, Walsh S, Richeldi L (2020).

*Respirology*. 2020;10.1111/resp.13836.

### ONLINE LINK

<https://onlinelibrary.wiley.com/doi/full/10.1111/resp.13836>

## The evolving algorithm of biological selection in severe asthma

REFERENCES: Nikolaos G. Papadopoulos, Peter Barnes, Giorgio Walter Canonica, Mina Gaga, Liam Heaney, Andrew Menzies Gow, Vicky Kritikos, Mark Fitzgerald "The evolving algorithm of biological selection in severe asthma"

*Allergy*. 2020;75:1555-1563

### ONLINE LINK

<https://onlinelibrary.wiley.com/doi/full/10.1111/all.14256>

# A SPANISH PERSPECTIVE

I'm a respiratory epidemiologist, and last March during the peak of the COVID-19 pandemic, we were being bombarded with descriptive epidemiology statistics and other numbers, as accurate as they are cold.

In the past, there have been other devastating epidemics of other diseases: cholera, the 1918 flu (misnamed "Spanish"), the black plague, AIDS, etc. Other more recent outbreaks, such as SARS, MERS, or Ebola, were considered exotic and distant events.

Yet no one, not even in the wildest nightmares of a science fiction screenwriter in Hollywood, would have anticipated that 2020 would have started with so much drama and suffering. As we were raising our glasses to toast New Year's Eve, few were aware of a health alert reported that same Tuesday morning in Wuhan, Hubei Province, China due to a cluster of cases of pneumonia of unknown etiology.

Just ten days later, on January 9, 2020, China's CDC reported that a new coronavirus was the causative agent of that local outbreak. As for better and for worse, our world is globally interconnected, that small incident in China is why we have been living in confinement, basic civil liberties were limited, there has been so much death and suffering, and locally my hospital has been on the verge of collapse.

The Hospital de La Princesa, an old 450-bed tertiary hospital, in the Salamanca district of Madrid, Spain, had its D-Day on March 30, 2020, when a total of 552



**Covid-19**

COVID-19 patients were admitted, and another 120 more patients were in the ER, impatiently waiting for admission. Many of the two-bed rooms already had three, including four occupants. We had to expand our cute, but modern ICU room from 17 to 73 beds, with the invasion of two operating rooms converted into intensive care, as well as the entire Psychiatry floor.

Recalling past times, we had to send all mentally ill people home, including those in active bursts of severe paranoid schizophrenia or major depression, to make room for other patients who required invasive mechanical ventilation, especially with makeshift ventilators, or by reusing disposable ones, or duplicating machines with homemade technology. Even some friends who have been volunteering with Médecins Sans Frontières in the Syrian civil war or in the Ebola area of Sierra Leone, were not prepared.

Using military terminology, La Princesa was a frontline war hospital. My pulmonology department with 13 senior pneumologists plus 8 residents suffered 11 "casualties", counting quarantines, infections, and one admission with severe bilateral pneumonia. But in other hospitals in Madrid the blow was even harder: colleagues from Hospital La Paz or Gregorio Marañón were suffering an even worse avalanche of patients. A modern hecatomb, literally from the ancient Greek *ἑκατόν*, hekatón, "one hundred" and *βοῦς*, boŭs, "ox", a religious sacrifice of a hundred oxen to indicate a great catastrophe with great mortality, or the end of the world.

We are still facing a cruel disease and a worldwide epidemic of biblical proportions. It is still seriously affecting our seniors or those with heart, lung and other chronic diseases. But not only to them. Several of my young, completely healthy, even athletic colleagues have had to be admitted to the same room where they were seeing patients the day before; two friends have been in the intensive care unit, with a tracheostomy, fighting for their lives. Why? We still don't know whether an immune, genetic factor, a combination of risk factors, or chance causes this tiny RNA virus to collapse bronchi and lungs with a thick "mucus or snail slime," accompanied by an inflammatory cascade that kills people. previously healed.

The COVID-19 solution will not be political, nor legislative, neither even medical. Learning the lesson from history of past new diseases and viruses, the endgame of COVID-19 will be through research. And it is for granted that the REG membership, with so much talent and wisdom, which is considered THE respiratory think tank, will contribute to end COVID-19.



**Joan B Soriano**  
Medical epidemiologist

# WHAT REG MEANS TO ME

I have been involved in REG since its inception under the leadership and guidance of Dr. David Price. His knowledge and enthusiasm as well as his interest in this topic spurred many of us to look at research in a different way. Many thought leaders, often involved in double blind randomized control trials (RCTs) and guideline creation recognized that there were questions that these processes could not answer. The patient with illness X that has any of a number of reasons why they would not have been included in the RCT still gets treated based on those guidelines that are governed by RCT evidence. Examples are too numerous to mention, but to give you an idea: asthmatics smoking > 10 pack years, COPD patients with a history of Asthma, Either one with significant comorbidities.

What is really needed is a measure of effectiveness in real life, beyond just the efficacy of a clinical trial. What happens if patients take a therapy with less regularity or with other comorbidities. What if the diagnosis is suspected but not proven...just so many questions. Technically we call this the difference between internal validity (RCT) and external validity (how does it work in real life).

Real life research fills in those gaps with a variety of types of evidence. These include observational prospective trials such as pragmatic RCTs and retrospective evaluations such as with database reviews, pharmacy data, claims data, mortality data, post marketing data and patient reported outcomes. This data assists us to identify the best treatment options

by identifying responsive populations, adding value and knowledge to the evidence provided by RCTs. Post marketing data allows finding of unusual but related side effects that the numbers of an RCT may not allow recognition. How many medications have come off the market due to adverse issues found. Gatifloxin, Telithromycin to name a couple.

The science needs to be done right, and it has been terrific with important issues being looked at such as COPD control, small airways, cough, pediatric management, severe asthma, adherence and how to evaluate data bases. We have truly made a difference in the scientific literature and even the guideline makers have started to look at evidence beyond the RCT.

Beyond the science is the even more wonderful opportunity to meet like minded people, with a craving for knowledge and answers, a drive to educate and a tremendous camaraderie which occurs across traditional separations of primary to secondary care and even different secondary type professions. Our annual summit, though missed this year due to COVID, is a tremendous opportunity to meet up with friends and colleagues. We have so much more to learn, and so much more to give. REG gives us tremendous opportunities to do both.

**Alan Kaplan MD CCFP(EM) FCFP**  
Vice President



Throughout my training, I was taught to follow evidence-based medicine and particularly the results of randomised controlled trials. However, it became increasingly clear this was a naïve viewpoint: for the great majority of clinical decisions I made there either was no RCT evidence, or the patient in front of me would have been excluded from the relevant trial. Definitive trials are so costly that they are almost exclusively conducted by the pharmaceutical industry on new products. We therefore are still heavily reliant on eminence-based medicine, doing things because our predecessors have always done them that way. It cannot be the way forward to have numerous trials of expensive niche products, but still no studies that tell us which antibiotic or steroid to use at what dose for how long during an exacerbation of asthma or COPD. I felt there was a pressing need for studies that focussed on the quality of care for the broadest groups of patients.

In the Respiratory Effectiveness Group, I found an

innovative platform that was beginning to disrupt this turgid state of affairs and aiming to improve clinical outcomes, patient experience and cost-effectiveness. It was refreshing to meet people from around the world that were committed to answering the questions that were most important to patients and clinicians, not just the most academically interesting. Through REG I have gained confidence to pursue research with early clinical impact, learned from experts, formed great collaborations, and also engaged in robust debate. I hope to be part of the group of clinical academics that can reflect on a period of genuine progress in the care of people with common respiratory diseases.

**John Blakey**  
Associate Professor, Curtin University  
Perth, WA, Australia





To me as a paediatrician, REG means addressing clinically-important questions in large numbers of children from a real-life perspective. Asthma is the only common chronic respiratory condition, and you might think that REG has little to offer the world of paediatrics relative to adult respiratory medicine where there are several conditions other than asthma where REG can provide insights (e.g. COPD, pulmonary hypertension, pulmonary fibrosis). However, childhood asthma is shrouded in anecdote and greyness, and REG has provided an neat evidence-based pharmacoepidemiological perspective. Through REG I have been fortunate to work with colleagues around the world to explore several areas of uncertainty including:

1. What is the best step up for a child on low dose inhaled corticosteroids (ICS) and poorly controlled asthma? The answer may be that that addition of long acting beta agonist (LABA) is more effective than leukotriene receptor antagonist (LTRA) for achieving control, although these two treatment options seem equally effective in preventing exacerbations.
2. Are fixed dose combination (FDC) inhalers superior to separate inhalers? FDC may be more effective at achieving control but as above both options are equally effective in preventing exacerbations.
3. In preschool children with asthma-like symptoms, is asthma treatment effective in reducing symptoms? We were not able to find evidence of effectiveness.

Inevitably this REG activity has not completely answered the questions, but it has provided an important perspective. Looking forwards, as we try to match the right treatment to the right patient, complementary perspectives should include real-life REG-like data, randomised clinical trial data and lab-based data. Asthma is a heterogenous condition and REG can help shape the key to unlock the enigma of asthma across the life course.



**Steve Turner**

Child Health, Royal Aberdeen Children's Hospital, Aberdeen, UK, AB25 2ZG

The Respiratory Effectiveness Group (REG) and myself crossed paths some years ago when we started to evaluate real-life implementation of FeNO as a tool in the management of patients with asthma. Being trained as translational researcher, pulmonologist and clinical pharmacologist, I oversee different aspects of chronic respiratory disease: i.e., from the pathophysiological roots to real-life daily clinical practice. From this "holistic" point of view, I like to support the translational fate of biomarkers: firstly developed as a tool to reflect underlying pathways, subsequently applied to confirm efficacy of treatment interventions in pathophysiological processes of airway disease, and subsequently progressing into real-life clinical practice.

Obviously, in early drug development and subsequent clinical trials, including highly selected study populations, potentially different biomarkers may be necessary than in real-life situations. Within REG working groups, biomarkers as real-life tools get a new dimension: the actual applicability across wide patient populations as we see in daily clinical practice, hence adding to the clinical applicability of a biomarker. Apart from being

reliable, point-of-care and cost-effective, this also means that a clinically applicable biomarker combines the properties of being predictive of efficacy of a new treatment modality while also predicts the treatment's actual effectiveness in real-life - i.e. across the vast spectrum of the disease.

The REG offers a platform for both translational researchers, scientists and clinicians to exchange ideas and to facilitate transitions from basic science into daily practice and to define unmet needs.

**Professor Zuzana Diamant**

Past guest professor, Dr Researcher at Dept of Respiratory Medicine & Allergy, Institute for Clinical Science, Skane University Hospital, Lund University, Lund, Sweden;

Honorary Affiliate at Department of Respiratory Medicine, First Faculty of Medicine, Charles University and Thomayer Hospital, Prague, Czech Republic

Trainer Clin Pharmacology at Dept Clin Pharm & Pharmacol, Univ Groningen, Univ Med Ctr Groningen, Groningen, Netherlands



# WORKING GROUP UPDATE



## COPD WORKING GROUP

The COPD Working Group have published the results from the prospective, observational study on the concept of control in COPD; the manuscript published in *Respirology* concludes that control status, defined by easy-to-obtain clinical criteria, can be used at each clinical visit as a complement to the current recommendations and is predictive of future exacerbation risk. A further manuscript accepted in *Archivos de Bronconeumologia* provides evidence of the short-term predictive value of COPD control, with an increased risk of moderate or severe exacerbations seen during the following 6 months in patients who are classified as uncontrolled.

Study set up is currently underway for a new prospective, observational multicentre study that will assess the prevalence of suboptimal peak inspiratory flow in patients with COPD and assess the predictive value of peak inspiratory flow in COPD exacerbations. If a centre is interested to participate in this study, please contact Sarah Lucas who is the researcher leading this project ([sarah@regresearchnetwork.org](mailto:sarah@regresearchnetwork.org))

The Real-Life WISDOM project is a database study to assess the implications of ICS withdrawal in the management of COPD. The project found, using data from the Optimum Patient Care Research Database, that in a primary care population of patients with COPD, composed mostly of infrequent exacerbators, withdrawal of ICS in those on triple therapy was associated with a significant reduction of the risk of COPD exacerbations and pneumonia; a manuscript currently in preparation.

The working group is currently seeking funding for a comprehensive study into the epidemiology and natural history of alpha-1 antitrypsin deficiency in the UK.



## ALLERGY WORKING GROUP

The Allergy Working Group, chaired by Moises Calderon and Pascal Demoly, have been building foundations and seeking funding for a new project looking to build a global registry of patients receiving allergy immunotherapy (AIT) to assess the effectiveness of the treatment in airways disease. The objectives, methodology and funding strategy are being finalised and a research proposal has been disseminated to gauge interest of companies.



## SEVERE ASTHMA AND BIOMARKERS WORKING GROUP

The Severe Asthma and Biomarkers group has not had a meeting yet this year, however there have been some ideas around a project to map the patients journey to biologics and another project looking at modifiable risk factors in asthma that the working group is hoping to pursue.

# WORKING GROUP UPDATE



## CHILD HEALTH WORKING GROUP

The Child Health Working Group have submitted a manuscript for publication entitled 'A *real-life comparative effectiveness study into the addition of antibiotics to the management of asthma exacerbations in primary care*' has been submitted for publication. The study highlights the high levels of antibiotic prescribing for asthma exacerbations, despite this being contrary to guidelines, and shows the addition of antibiotics does not appear to have a clinically significant benefit compared to usual treatment of oral corticosteroids alone.

The PaEdiatric Asthma in Real Life (*PeARL*) project, led by Nikos Papadopoulos, which aims to produce evidence-based recommendations regarding controversial aspects of paediatric asthma is progressing. The first manuscript has been published in which 57 unmet clinical need topics were identified by international experts and prioritised using an survey of 412 stakeholders (including leading experts, researchers, clinicians, patients, policy makers, and the pharmaceutical industry) from 60 countries across 5 continents. The PeARL collaborators have also conducted a survey of paediatric asthma clinics to assess the impact of COVID-19 on paediatric asthma services and disease burden, with the results now published in JACI In Practice.

Following a Working Group meeting in May work is in progress on the developing a database project to investigate ICS step-down and cessation in children with asthma.



## ADHERENCE WORKING GROUP

The Adherence Working Group held a meeting in March and decided to write an article discussing the change in GINA guidelines, which now recommend those with asthma should be treated with as-required or daily ICS rather than with SABA alone. A perspectives article has been submitted that discusses the opportunities and challenges of this change in strategy for primary care.

The Working Group have plans for two scoping reviews for which funding is being sought; one will assess how adherence is included within current guidelines and the second review will assess how precision medicine can be used to monitor and manage adherence.



## DATABASES AND CODING WORKING GROUP

The Towards Optimum Reporting of Pulmonary Effectiveness Databases and Outcomes (TORPEDO) project used a 3-phase modified Delphi exercise to propose lists of minimally required variables for retrospective and prospective asthma and COPD studies, and a manuscript has now been submitted. Developing such lists of variables is an important step in facilitating the sharing, comparison and merging of datasets and in standardising data collection and improving research efficiency. The next phase of this work will involve compiling a list of available data sources and determining which of these minimally required variables for asthma and COPD studies they contain, along with a tool to aid the selection of variables for future prospective studies.

The working group also have plans to write an article on the mapping of respiratory variables to the Common Data Model, including the current challenges/issues and recommendations and best practices for going forward.

# WORKING GROUP UPDATE



## SMALL AIRWAYS WORKING GROUP

An extremely topical new project is in development by the Small Airways Working Group, led by Omar Usmani. The project aims to offer expert opinion on the impact of inhaler choice on the environment to put together an opinion piece on priorities of health care professionals when considering prescribing a different inhaler type. The project also aims to assess the impact of inhaler choice on patient care, gathering patients' perspectives of difficulties associated with changing inhalers. This study will provide a structured consensus piece on the impact of switching inhalers and policy on both the environment and patient care, as well as offer potential alternative solutions to balance the needs of the patient and the reduction of environmental cost. Funders have been approached and interest has been expressed.



## TECHNOLOGY WORKING GROUP

The Technology Working Group, chaired by Ron Dandurand, has been developing some exciting new projects. The design for an opinion piece on the utility of oscillometry has been finalised and is currently seeking funding. Additionally, the group is finalising the details for a new project which will assess the impact of using a digital inhaler device and app on patient adherence to medication and correct inhaler usage. Funders have been approached and discussions are underway.



## COUGH WORKING GROUP

The Cough Working Group, chaired by Prof. Lorcan McGarvey have completed phase 1 of the project to assess the burden of chronic cough on adults in primary care in the UK. The final report of the project has been finalised and circulated with the study group for further discussion on the design for next phase of the research. Discussion regarding a manuscript are ongoing.



## INTERSTITIAL LUNG DISEASE/IDIOPATHIC PULMONARY FIBROSIS WORKING GROUP

Last year, the first phase of the project 'The characterisation of interstitial lung disease multidisciplinary team meetings: a global study' was published. The ILD/IPF working group, led by Luca Richeldi, is expanding this research to characterise distanced electronic multidisciplinary team meetings used to diagnose ILD in the post-COVID era, where face-to-face meetings have not been possible. The study will also aim to open dialogue on the prevalence of post-COVID fibrosis to try to ascertain a standardised approach for managing disease progression.



## COST EFFECTIVENESS WORKING GROUP

Moving forwards, the group will work with other working groups to offer collaborative insight to further projects.






## ◆ ISAR Publications in 2020

ISAR continues to focus its efforts on the delivery of high-quality publications, with at least 7 due for submission in 2020. We are also delighted to announce the successful publication of our ISAR protocol within the BMC Medical Research Methodology journal - online release is expected within the coming month!

## ◆ ISAR Abstracts in the ATS 2020 Virtual Conference

We are delighted to announce that 6 ISAR abstracts have been accepted as poster presentations at the ATS 2020 Virtual Conference! Click on the links below to view our published abstracts in the American Journal of Respiratory and Critical Care Medicine, and you can view our main conclusions for all 6 studies summarised below. You may also find the e-Posters uploaded to the ISAR website [HERE!](#)

 <b>ABSTRACT TITLE</b>	<b>KEY FINDINGS</b>
<p>The Impact of Exacerbation Burden on Lung Function Trajectory in a Broad UK Asthma Population: A Large Longitudinal Cohort Study</p>	<p><i>Long term lung function declines significantly faster in asthma patients experiencing exacerbations compared to those who do not.</i></p>
<p>Global Access for Biologics in the Treatment of Severe Asthma: A Challenge to Personalized Medicine</p>	<p><i>Access to biologics depends on patients' geographic location and is dependent upon country specific biological availability, reimbursement and prescription criteria.</i></p>
<p>Biologic Utilization Patterns: Data from the International Severe Asthma Registry (ISAR)</p>	<p><i>Although the majority of severe asthma patients managed around the world continue with their first prescribed biologic therapy, a minority either stop or switch therapy.</i></p>
<p>A Global Survey of Blood Eosinophil Distribution in Severe Asthma Patients: Data from the International Severe Asthma Registry (ISAR)</p>	<p><i>The majority of patients in this severe asthma cohort from 11 countries had a high BEC, and these patients are more likely to have nasal polyps, adult onset asthma and be on long term oral corticosteroids.</i></p>
<p>Characterization of Eosinophilic and Non-Eosinophilic Severe Asthma Phenotypes and Proportion of Patients with These Phenotypes in the International Severe Asthma Registry (ISAR)</p>	<p><i>A clinical algorithm was developed to improve the identification of EOS and non-EOS phenotypes in a real world severe asthma population. Majority of patients seen across severe asthma centers globally have eosinophilic disease.</i></p>
<p>Biomarker Relatability in the International Severe Asthma Registry</p>	<p><i>Most patients were positive for at least one potentially actionable biomarker at baseline, and the overlap appeared to be greater between eosinophil and FeNO positivity than with IgE positivity.</i></p>

## Research Updates

In March 2020, 13 ISAR collaborator research proposals were voted on and ranked to determine the 2020 prioritized research projects. We are pleased to announce the top 3 most voted projects which will be fully delivered by the ISAR team are:

# INTERNATIONAL SEVERE ASTHMA REGISTRY ISAR

### A Define responders and non-responders to biologics and describe their characteristics overall and per biologic.

- **Objective 1:** To operationally define responders and non-responders of biologics by clinical outcomes, such as time spent on biologic after initiation/switch, magnitude of OCS reduction, months of biologic use with asthma controlled, etc.
- **Objective 2:** To describe the demographic and clinical characteristics of the responder and non-responders overall, by biologic class and by race/ethnicity.

### B Describe clinical outcomes before and after biologic treatment by biologic class, by individual biologic, and by subgroups of baseline characteristics.

- **Objective 1:** To describe the proportions of patients by biologic class and drug.
- **Objective 2:** To describe clinical outcomes before and after biologic initiation.
- **Objective 3:** To describe clinical outcomes before and after biologic initiation for demographic/clinical subgroups (e.g. age of onset, nasal polyps).

We would also like to take this opportunity to welcome all collaborators and partners to join us in the above ongoing open research projects. Please register your interest through our **WEBSITE**, or contact your country lead for further details!

### C What is the impact of co-morbidities in severe asthma?

- **Objective 1:** To illustrate the baseline prevalence of all comorbidity types.
- **Objective 2:** To describe the baseline demographic and clinical characteristics of these severe asthma patients with comorbidities.
- **Objective 3:** To investigate the effects of comorbidity (e.g. sleep apnea, nasal polyps) on severe asthma.
- **Objective 4:** To describe possible comorbidity clusters.



### ISAR Website

The ISAR website has had a facelift. It now contains a new "Dissemination" tab for the latest news on ISAR abstracts and publications, and a "FAQ" tab which provides answers to frequently asked questions about ISAR.

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

# ACKNOWLEDGEMENTS

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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