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COMMUNICATION







SHARP

Severe Heterogenous Asthma
Research collaboration
Patient-centered

Wishes from the Chairs for the New Year_ Progress on SHARP Projects in Programmes 2 and 3, and the COVID-19 Research response – Newsletter 7.

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Dear SHARP colleagues,


Thank you very much for your continued and enthusiastic participation in SHARP.


To begin, please accept our very best wishes for 2022!

Our CRC has made much progress over the past year despite the COVID-19 pandemic and its impact on communications and availability of the SHARP Stakeholders, and this is thanks to you. We are, therefore, very pleased to circulate this seventh issue of the SHARP Newsletter so as to share our achievements and to remind ourselves of the plans for 2022.

This issue also includes an interview of 2 engaged leaders from different stakeholder groups in SHARP!

Interview of 2 engaged leaders from the different Stakeholder groups

Name & Stakeholder group	Questions	Answers
Dóra Paróczai, Rising Star 	Why did you get involved in SHARP?	<i>My involvement in SHARP started with the COVID-19 research response project to represent the perspectives of young clinicians and to increase the understanding of the impacts of COVID-19 on both physicians' and severe asthma patients' perceptions. Previously, I started to include Hungarian patients to SHARP Central registry and my national leader, Zsuzsanna Csoma recommended participating in further projects as a Rising star.</i>
	What does the SHARP vision mean to you?	<i>SHARP offers new opportunities to connect the European standards and to collaborate with highly recognized asthma experts. The SHARP vision inspired me to rethink the way I treat severe asthma patients, emphasizing the centrality of the patients in my daily work. Moreover, SHARP enabled me to be open for further new projects</i>

		<i>and taught me how I can work effectively as a member of a great workgroup.</i>
	Which SHARP project excites you the most and why?	<i>I work on the COVID-19 research response and, on its extension, the vaccination study, so they are the most exciting projects for me. To pick up the most important strength in these studies, I would choose patient involvement. Patients’ representatives are heard and reflect the actual thoughts of severe asthma patients; thus, we can adjust our work to physicians and patients, as well. I have never worked on this kind of study before, so it is a real new challenge for me.</i>
	Why is patient centricity of SHARP important?	<i>Our ultimate goals are to make our patients’ life easier, provide them a better quality of life and treat them in a personalized way. Researchers need to understand the burdens and fears of their patients, bridging the gap between physicians and patients. Including patients’ perceptions can lead to relevant studies and results that would provide further innovative treatment options.</i>
<p>Namhee Kwon, Pharma Partner</p> 	Why did you get involved in SHARP?	<i>SHARP came to me as an interesting and exciting collaboration opportunity, fortunately, when I was responsible for external collaborations in the GSK global medical. I knew that being truly collaborative was a big commitment as it was not just about financial support but, more importantly resource commitment. SHARP made that expectation clear from the beginning and I was excited with such an open opportunity that requested expertise as well as time commitment.</i>
	What does the SHARP vision mean to you?	<i>It has always been the same when I was a clinician and when I am a researcher now. This is naturally linked to the ‘P’ in SHARP that stands out and explains by itself where the SHARP vision is heading for. For me, this is a continuous journey of my career.</i>
	Which SHARP project excites you the most and why?	<i>The answer is simple - the BIPAR study. It excites me most as I am leading it 😊. Seriously, I believe the BIPAR study is an excellent example of how SHARP does prioritise patient centricity. One more point that I am excited about is that SHARP is a multidisciplinary team with various stakeholders involved. Based on the vision and the aims, people from the different stakeholder groups continuously feed into SHARP with insights and ideas. This keeps SHARP alive and evolving</i>
	Why is patient centricity of SHARP important?	<i>The fundamental reason for the existence of healthcare is for patients. Patients justify the value of relevant activities like SHARP. As it is impossible just to ignore the fundamentals, SHARP cannot exist without patients being centred. SHARP is exemplary in embedding the value into the vision and projects.</i>

 **General Progress of SHARP**

Our CRC has made substantial progress over the past months and here is a summary of our current projects:

The most Bothersome aspects In patients with severe Asthma and availability in the severe asthma Registries: the BIPAR Study

The main objective: to identify discrepancies between patients and physicians regarding the patient’s most bothersome symptoms or problems and to assess whether they are well reflected in the registries.

Current status: Analysis completed and manuscript under writing

Plan: Finalise the manuscript with National leads feedback, submit to the ERJ by the beginning of February.

The Use of Biologics in Europe

The main objective: to compare the current availability and the rules and criteria for prescription of biologics in European countries.

Current status: The manuscript is being finalised.

Plan: Submit the paper to the ERJ in January or February at the latest.

The Health Economics of Severe Asthma

The main objective: to adapt the Italian Budget Impact model for OCS analysis (already published) for use in the wider European context.

Current status: Data collection in the literature for the fifth initial countries (Belgium, Spain, Slovenia, Sweden and Poland) has been done and the model is validated. There are some gaps in the data regarding the costs of comorbidities for some countries.

Plan: Fill the gaps with the help of National Leads and move to the 2nd wave with 5th additional countries.

UNISA: Use of Nucala In Severe Asthma

The main objective: to understand the use of mepolizumab in usual clinical practice (as opposed to clinical trials) and assess the benefits for the mepolizumab-using patient population. The results will help to determine which patients starting treatment would most benefit from mepolizumab to control their disease.

Current status: Data collection is underway via the Federated Analysis Platform (FAP). SHARP Central and Belgium data are ready. We are working on the other registries to collect data.

Plan: End of Summary data collection is expected in the end of January. There will 2 manuscripts: one describing the FAP and data collection system, a second focusing on mepolizumab data across Europe.

Severe Asthma Questionnaire (SAQ): Burden of Asthma

The main objective: to investigate the real-life impact on the quality of life of living with severe asthma across 11 European countries. The study is collecting longitudinal data to assess changes in HRQoL via the PatientCoach app or online questionnaires over 12 months and comparing with other outcome measures such as asthma control and exacerbations in the SHARP registry.

Current status: 6 countries have signed Data Sharing Agreements and are ready to start, while 5 are awaiting approval. The PatientCoach app is under final setting and refinement.

Plan: The launch of the project is expected this February.

COVID-19 research response

The main objective: to understand the impact of COVID-19 on people with severe asthma so as to provide clear, informed guidance to patients, physicians, national societies, and healthcare systems to be prepared for any future waves of COVID-19.

Current status: Manuscript has been submitted to the ERJ and is under review.

Plan: Waiting for the ERJ response and undertake any revision.

COVID-19 research extension: Vaccination study

The main objective: to evaluate patient's perception of COVID-19 vaccination and reveal patient's vaccination status, hesitancy, and impact on asthma.

Current status: Analysis has been completed and the manuscript is under preparation.

Plan: To submit to the ERJ in January or February at the latest.



Forthcoming Projects

- **SHARP Case series of Rare Asthma:** the theme of next session is **Indication for biologics in patients with Comorbidities** and the meeting will be held on Tuesday 15th of February 2022. **DO JOIN!**
- **The Investigator-led Initiative in FAP and SHARP central:**
 - **Real-Life characteristics of Biologicals-treated severe asthma patients across SHARP Central** _ lead Stefania Principe, Netherlands
 - **Use of LAMAs in severe asthma: a real-life assessment through the SHARP network** _ lead Alessandro Marcon & Marco Caminati, Italy
 - **Investigation of the effect of treatment with biologics on clinical asthma outcomes in patients eligible for 'explanatory' RCT vs ineligible** _ lead Jacob Sont & Anneke ten Brinke, Netherland
- **Creation of a new SHARP website:** The website will be hosted and maintained by the ELF. Olivia Fulton (CRC patient co-chair), Thijs Teeling (PAG member), Jacques Buis (TEVA lead) are leading the working group (Bring Awareness Outside of SHARP) created during the last Stakeholder Board Meeting in May 2021. This project will engage a much larger group of SHARP members to reflect our diversity.

We very much look forward to an exciting and successful year working with you all.



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SHARP co-Chair



Prof. Elisabeth Bel
SHARP co-Chair



Prof. Celeste Porsbjerg
SHARP co-Chair



Dominique Hamerlijnck
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