



Dear ACARE members,

We are happy to send you a short update from our network and a preview of what is to come in the next months. The newsletter will contain info on:

New centers, educational activities, current scientific projects, CARE registry and scientific developments.

We will continue to send you these short newsletters in regular intervals going forward. Please share them with your network as well, and as always, we look forward to your feedback, ideas, and engagement. For more up-to-date ACARE info, please our [event page](#).

With best wishes,

The ACARE office team

1. New Centers July:

It is our great pleasure to welcome the following centers to the ACARE family:

Date of joining	Name of center	Country
11.07.2023	Osaka Medical and Pharmaceutical University	Japan
13.07.2023	Clínica Universidad de Navarra	Spain
20.07.2023	Hospital Universitario La Paz	Spain

You can find more information on our ACARE centers [HERE](#).

2. Educational Activities:

>> Coming in August: ACARE *LevelUp* Podcast 'All Things Angioedema'

The goal is for the audience of the podcast to gain deeper understanding of all forms of angioedema and their pathophysiology, disease burden, management, and treatment options. For this purpose, the host of the podcast, Thomas Buttgereit, will exchange knowledge and discuss novel research findings in each episode with angioedema specialists from all over the world.

Please find more information regarding the podcast on our [website](#).

Follow us on social media to not miss the launch!

>> Make a Difference 9 - Management Of HAE Patients On Modern Long-Term Prophylaxis

The overall aim of this webinar series is to help to provide the optimal therapy to all patients with recurrent angioedema as early as possible, especially patients with HAE. The webinars will cover strategies for achieving earlier diagnosis and lower rates of misdiagnoses, approaches for family screening in patients with HAE, the implementation of close-meshed therapy control, and guidance on how to continuously optimize therapy methods.

Date: 7 September 2023 (possible change in date)

Topics: Moderation - Prof. Dr. Marcus Maurer, Germany

Shared decision making in HAE - Dr. Stephen Betschel, Canada
New challenges in adherence - Prof. Susan Waserman, Canada
LTP: How long is long term? - Dr. Marta Ferrer Puga, Spain

>> **10 questions**

We are proud to introduce our new ACARE tool 10 questions.

10 questions can help you determine the exact cause and find the correct treatment. You can find the questionnaire under the Resources tab, or just click [here](#).

So far, the ACARE 10 questions tool is available in 5 languages (English, German, Czech, Chinese and Turkish). Would you like to help us translate this important tool into your language? Reach out to [Felix Aulenbacher](#) or [Julia Föll](#), we would love to have you on board.

3. Current Scientific Projects:

SHAERPA (Recruitment until December 31)

Stopping androgen treatment in patients with HAE – characterization of reasons and protocols and development of advice for patients and physicians

For more information please contact: carolina.vera@charite.de

IMAGINE 2.0

Identification of mutations in genes of patients with recurrent idiopathic and hereditary angioedema

For project-related documents, please see our member area or contact the project lead: thomas.buttgereit@charite.de

PROMUSE PAT (Recruitment extended until December 31)

Knowledge, attitudes, perceptions, experiences and satisfaction about the use of Patient Reported Outcomes Measures (PROMs) by patients with chronic urticaria

For more information please contact: karlaroblesvelasco@gmail.com

>> **PREG-AD: Systemic Treatment of Atopic Dermatitis in Pregnancy**

The treatment of atopic dermatitis during pregnancy remains a challenge for clinicians. In order to better understand real world practices regarding systemic treatment of choice for atopic dermatitis during pregnancy, we invite you to participate in a questionnaire study directed at physicians.

Please kindly use this link to complete the quick questionnaire: <https://www.surveymonkey.com/r/PREG-AD>

>> **Publications from our ACARE physicians**

Newly published journal *touchREVIEWS in RMD* Volume 2, Issue 1 – 2023

Click here to access: <https://www.touchimmunology.com/journals/touchreviews-in-immunology/touchreviews-in-rmd-volume-2-issue-1-2023/>

Congrats to our UCARE experts Luis, Marcus and Emek who were part of the editorial board!

4. CARE Registry is coming soon:

The chronic angioedema registry (CARE) is a prospective, international, multicenter, observational (non-interventional), open-ended disease registry being developed and managed by GA²LEN ACARE and UNEV e.V.

The aim of this project is to establish and to run a global registry for all patients with angioedema, i.e. patients with MMAE, BMAE, and other types. The results of the registry will be published and should help to improve the medical care for patients. We aim to have all ACARE centers partake in the CARE registry.

5. Scientific Developments:

>> Hereditary angioedema (HAE) in Belgium: results from a national survey

Van der Poorten et al present the **first nation-wide epidemiological study regarding HAE I and II in Belgium**. Their data, on 112 patients, show that median delay between first symptoms and diagnosis was 7 years and that the morbidity of HAE is not to be underestimated (51% of patients had experienced pharyngeal or tongue swelling and 78% had experienced abdominal symptoms).

60% of symptomatic patients reported to receive long term prophylactic treatment. Human plasma-derived C1-esterase inhibitor concentrate was used by 56.3% of patients. Knowledge and dissemination of these data is critical in raising awareness, encouraging development of therapies and optimising nationwide management.

Please click the link for more information:

[http://journal.frontiersin.org/article/10.3389/falgy.2023.1143897/full?&utm_source=Email_to_authors&utm_medium=Email&utm_content=T1_11.5e1_author&utm_campaign=Email_publication&field=&journalName=Frontiers in Allergy&id=1143897](http://journal.frontiersin.org/article/10.3389/falgy.2023.1143897/full?&utm_source=Email_to_authors&utm_medium=Email&utm_content=T1_11.5e1_author&utm_campaign=Email_publication&field=&journalName=Frontiers%20in%20Allergy&id=1143897)

>> New HAE TrackR app: HAEi's app by patients, for patients

HAE TrackR allows you to download a comprehensive report of your treatments (preventative and on-demand) and attacks to be used as a tool for you and your physician. HAE TrackR also has a reminder function to help you remember to take your medication.

Get it [here!](#)

If you would like to share some of the research and publications from your ACARE center with the whole network, please reach out us!