



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, and new cooperations.

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 take a look at our [event page](#).

With best wishes,
The ACARE office team

1. New Centers 2023:

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

Date of joining	Name of center	Country
08.05.2023	University Hospital of Zürich	Switzerland
14.04.2023	Ankara University, School of Medicine, Department of Chest Diseases	Turkey
14.04.2023	Saint Antoine Hopital	France
03.04.2023	Erciyes University School of Medicine	Turkey
03.04.2023	Icahn School of Medicine, Mount Sinai	USA
30.03.2023	HAE Center Denmark	Denmark
26.02.2023	Bnai Zion Medical Center	Israel
12.02.2023	Remedika General Hospital	North Macedonia
17.01.2023	Showa University Hospital	Japan

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

2. Educational Activities:

>> **ACARE LevelUp:**

Based on the success of the UCARE *LevelUp* program the ACARE network will launch the ACARE *LevelUp* program within the next weeks. The program comprises of seven formats, among those are:

- Webinars
- Master Classes
- Journal Clubs
- Podcast series

Every format has a scientific taskforce consisting of ACARE physicians and is coordinated by one of the ACARE program managers.

At the moment, we are finalizing our content planning and scheduling. More information on this can be found on our website, our social media channels and in the next newsletter.

>> **10 questions:**

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

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

>> **Make a Difference (MAD) webinar series:**

With **8 webinars** already taken place with **almost 1,000 participants** learning about 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, the Make a Difference series continues with 3 more webinars.

MAD 9 will take place in **September 2023**,

MAD 10 will be in **November 2023**,

MAD 11 in **February 2024**.

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 July 31)**

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

To learn more about this project, please get in touch with: Ivan Cherrez (ivancherrez@gmail.com)

or Karla Robles (karlaroblesvelasco@gmail.com).

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. Cooperations:

>> **APAAACI:**

We are proud to announce that **UCARE and ACARE have partnered with [APAAACI](#)**. This partnership includes the development and implementation of joint activities, developing educational and advocacy programs, joining forces in research efforts and working together to increase disease awareness and develop better approaches to disease management.

>> **CREAK:**

We are also very pleased to **partner with [CREAK](#)**. We believe that by joining forces with CREAK, we can make significant strides in improving the care and outcomes for those affected by these conditions. Our partnership will involve collaboration on research projects, joint educational initiatives and the sharing of knowledge and expertise.

>> **ITACA:**

We are no less proud to inform you that **ACARE has entered a cooperation with [ITACA](#)**. ACARE and ITACA share common interests, and members of both networks are expert centers for all forms of angioedema and can diagnose, certify and treat HAE as well as angioedema due to acquired C1INH-deficiency, contact system activation and mast cell degranulation.

We are looking forward to these undoubtedly fruitful collaborations!