

ACARE LevelUp MAGAZINE



WWW.GA2LEN-ACARE.COM

October 19, 2023

Content

New centers

Current events

- GA²LEN UCARE Conference 2023
- UCARE and ACARE LevelUp Preceptorships

Past events

- EADV
- EMEA

Educational Activities

- Preceptorships
- Webinars
- Podcast

Current Scientific Projects

- Interview with Thomas Buttgerit on DANCE - a global consensus on the definition, acronyms, nomenclature, and classification of angioedema
- CARE

Top News

Interview with a Physician from ACARE network

New Podcast about Angioedema

New Project - CARE

GA²LEN 2023
UCARE
CONFERENCE

December 07-09, 2023
Rebouças Convention Center
Sao Paulo - Brazil

Register NOW!

New Centers

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

DATE OF JOINING	NAME OF CENTER	COUNTRY
24.08.2023	Azienda Ospedale Università di Padova	Italy
15.09.2023	Institute for Asthma and Allergy	USA
27.09.2023	University of Alberta	Canada

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

Number of countries on the continents	
Africa	1
Asia	13
Australia	1
Europe	17
North America	2
South America	3
Total	36

ACARE CENTERS
audited centers worldwide

90

Current Events

1. GA²LEN UCARE Conference 2023
2. UCARE and ACARE LevelUp Preceptorships

Details



GA²LEN UCARE Conference 2023, **December 7 to 9**,
Rebouças Convention Center, São Paulo, Brazil

Less than two months to go until the great GA²LEN UCARE Conference 2023 in **São Paulo** on **December 7 to 9**.

Let's make this conference as momentous and diverse as possible!

We are counting on you – your participation in the most important urticaria event of the year is crucial for the UCARE network and for you!

There will be sessions on angioedema as well, in addition to a HAE preceptorship before the conference ([see page 4 on details](#))

So, register, spread the word and share this e-mail with your colleagues.

And please support the UCARE conference by sharing our Social Media posts:

- [Instagram](#)
- [LinkedIn Event](#)
- [Facebook](#)

Please find more information regarding the registration, scientific program and the venue on our [conference website](#).

Please click [here](#) to get to the registration!

Because we want to encourage all our members to be active participants in the network, registration is free of charge for all UCARE and ACARE members as well as applicant centers.

For general inquiries please reach out to us via info@ga2len-ucare.com.



Current Events

1. GA²LEN UCARE Conference 2023
2. UCARE and ACARE LevelUp Preceptorships

Details

1

Save-The-Date: UCARE and ACARE LevelUp Preceptorships in Sao Paulo on December 7, 9:00 a.m. to: 12:30 PM

On the morning of the 1st day of the conference, we invite all interested physicians to join us for the following free preceptorships:

1. UCARE Preceptorship on Mastocytosis - "Updates on Classification, Diagnosis and Patient Management."
[Register here](#)
2. ACARE LevelUp Preceptorship on Recurrent Angioedema with a special focus on HAE
[Register here](#)

Please note the date and check out the [agendas](#). We hope to see many of you there!

2

Save-The-Date: ACARE LevelUp Preceptorships in Abu Dhabi on February 2, 2024

State of the art management of recurrent angioedema and hands-on training intended for health care professionals from the Arabian Gulf.

ACARE will host a one-day live preceptorship in Abu Dhabi within the ACARE LevelUp program. This initiative follows the consensus reached on the diagnosis and management of Hereditary Angioedema (HAE) in the Middle East. The goal is to educate healthcare practitioners in the region and promote a unified approach to diagnosing and managing HAE.

The target audience is specialist physicians including Allergists, Dermatologists, Paediatricians, Gastroenterologists and ENTs but also family physicians. Speakers planned for this event will be some of the KOLs on angioedema including, Marcus Maurer, Markus Magerl, Mohamed Abuzakouk, Iman Nasr and more.

Past Events

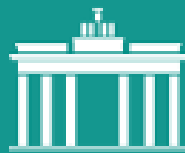
1. GA²LEN at EADV Congress
2. UCARE at EADV Congress
3. ACARE at EMEA

Details

GA²LEN had two sessions at EADV in Berlin this year.

Have a look to the review on [Social Media](#).

EADV CONGRESS



BERLIN
11-14 OCTOBER 2023

GA²LEN
Global Allergy and Asthma Excellence Network
Network of Excellence

goes

EADV Congress Berlin

Save the date

When: Wednesday 11 October 2023, from 8:30 to 11:45

Where: Messe Berlin, Room: M1 +2

Speakers: Torsten Zuberbier, Marcus Mauer, Manuel Pereira, Antonella Muraro, Charlotte Mortz, Holger Schünemann

**Wednesday, 11 Oct,
08:30 - 11:45 CEST**

UCARE
Urticaria Centers of Reference and Excellence
A GA²LEN NETWORK

goes

EADV Congress Berlin

Save the date

Symposium: How to manage chronic urticaria – Clinical tips and tricks from experts

When: Thursday 12 October 2023, from 11:15 to 12:00

Where: Messe Berlin, Industry Experts Hub 2

Moderator: Prof. Dr. Marcus Maurer

Speakers: Emek Kocatürk, Margarida Gonçalo, Christian Vestergaard, Clive Grattan

**Thursday, 12 Oct,
11:15 - 12:00 CEST**

05/18

Past Events

1. GA²LEN at EADV Congress
2. UCARE at EADV Congress
3. **ACARE at EMEA**

Details



The **HAEi Regional Conference EMEA** covered Europe, the Middle East, and Africa and took place in Munich on **1-3 September 2023**. The ACARE network was more than happy to be part of this important and interesting event, providing patients, caregivers and physicians with information on current ACARE studies and tools as well as other scientific and educational activities. As always, it was an inspiring meeting and we look forward to many more wonderful HAEi conferences.

Get the 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!](#)

HAE TrackR has recently been update with two more languages, Bahasa Melayu and Korean, which means the app is now available in 36 languages!



Educational Activities

1. ACARE Make a Difference Webinar
2. ACARE LevelUp Podcast

ACARE Make a Difference Webinar

Save the Date: 9th Make a Difference webinar on November 9, at 5:00 pm CET

Register [here](#) and tell your patients!

Target audience: Patients, caregivers, physicians

Description/Aim: The overarching goal of this webinar series is to facilitate the provision of optimal therapy to all individuals afflicted with recurrent angioedema, particularly those affected by HAE, at the earliest possible stage.

Throughout these webinars, various topics will be explored, including strategies to expedite the diagnosis process and reduce instances of misdiagnosis, methods for family screening in HAE patients, the implementation of closely monitored therapy control measures, and guidance on the continual refinement of therapeutic approaches.

This specific webinar will place special emphasis on the updated and comprehensive classification and terminology of angioedema presented by three expert speakers from Charité – Universitätsmedizin Berlin Institute of Allergology IFA & Fraunhofer ITMP Immunology and Allergology IA.

Speakers/Topics:

1. Angioedema nomenclature and classification. – Prof. Dr. Markus Magerl
2. Finding consensus in angioedemology. – Dr Thomas Buttgereit
3. Unmet needs in angioedema classification. – Prof Dr Marcus Maurer



MAKE A DIFFERENCE

ACARE Make A Difference is an eleven-part webinar series with a primary focus

9TH DATE

NOVEMBER 9TH, 2023 - 5:00 pm CET

**UPDATED AND COMPREHENSIVE
CLASSIFICATION AND
TERMINOLOGY OF ANGIOEDEMA**

07/18



Educational Activities

1. ACARE Make a Difference Webinar
2. ACARE LevelUp Podcast

NEW ACARE LevelUp Podcast

'All Things Angioedema'



ACARE LevelUp Podcast 'All Things Angioedema'

Listen and subscribe to our 'All Things Angioedema' podcast series:



We are proud to announce that the **ACARE LevelUp Podcast 'All Things Angioedema'** (ATAE) has been launched in August. 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, **Dr. Thomas Buttgerit**, 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.

08/18

We look forward to your feedback and topic ideas for future episodes. Please use the feedback form [here](#)



Educational Activities

1. ACARE Make a Difference Webinar
2. **ACARE LevelUp Podcast**

ACARE LevelUp Podcast

'All Things Angioedema'



ACARE LevelUp Podcast 'All Things Angioedema'

Listen and subscribe to our 'All Things Angioedema' podcast series:



1 Episode 1: What "angioedemologists" do and what motivates them

Dr Thomas Buttgerit welcomes the renowned urticaria specialist, Professor Marcus Maurer. Professor Maurer is the founding force behind both ACARE and UCARE, and spearheads the popular podcast, All Things Urticaria. The pair delve into the significance of angioedema across all areas of medicine and offer insights into the role and responsibilities of angioedemologists. They also shed light on the complexities of tackling angioedema, highlighting the invaluable role of the ACARE global network in tackling these challenges.

2 Episode 2: What is angioedema and what is not?

Dr Thomas Buttgerit is joined by Professor Markus Magerl, leader of the angioedema clinics at ACARE Berlin. Their conversation explores the clinical features of recurrent angioedema and the essential differential diagnoses that dermatologists must bear in mind when encountering facial swellings.

3 Episode 3: Angioedema and EAACI 2023

Professor Jason Fok joins Dr Thomas Buttgerit to discuss angioedema updates from the European Academy of Allergy and Clinical Immunology (EAACI) Congress 2023 and the role EAACI has in disseminating novel insights in angioedema treatment and diagnosis. Dr Buttgerit takes a deep dive into how data presented at EAACI congresses can be implemented into specialist ACARE clinics and the benefits the congress has in aiding clinicians to implement the latest guidelines for the benefit of patients.

4 Episode 4: Androgens in hereditary angioedema

Dr Thomas Buttgerit is joined by Dr Carolina Vera to discuss the use of attenuated androgens in the treatment of hereditary angioedema and their associated risks and side effects. Both experts delve into the safety, ethical considerations and alternative treatment options to using androgens for the treatment of hereditary angioedema. Dr Vera concludes the discussion with an in-depth explanation of the SHAERPA project, focusing on the discontinuation of androgen use in individuals with angioedema, and the benefits this project can have in providing guidance on alternative medications.

09/18

We look forward to your feedback and topic ideas for future episodes. Please use the feedback form [here](#)



Current Scientific Projects

Interview with Dr. Thomas Buttgereit on DANCE – a global consensus on the definition, acronyms, nomenclature, and classification of angioedema

Dr. Thomas Buttgereit:

- Angioedema Center of Reference and Excellence (ACARE), Institute of Allergology, Charité – Universitätsmedizin,
- corporate member of Freie Universität Berlin and Humboldt-Universität zu Berlin, Berlin, Germany
- Allergology and Immunology, Fraunhofer Institute for Translational Medicine and Pharmacology ITMP, Berlin, Germany

What drove the idea of this study?

I think that Avner Reshef (Barzilai University Hospital, Israel) and Marcus Maurer (Charité Berlin, Germany) had the crucial idea for the project. The basic idea was that, unfortunately, different abbreviations and terms are currently used in the medical literature and technical language for the same clinical picture, and this can lead to confusion/misunderstandings.

In addition, this is unfavorable for literature searches in the absence of standardization. Avner used the metaphor of the Tower of Babel: everyone knows a lot and is diligent, but does not speak a uniform language, which makes progress difficult and ultimately leads to failure. He also finds the term HAE with normal C1INH inappropriate for a disease where nothing is actually normal if you always develop swelling attacks and you may have a rare mutation as the cause.

Why do we need this project?

It is needed that all experts agree on a common standard to be able to compare and analyze results and publications more easily.

What are the main questions to be answered with this project?

The main goal has been achieved, certain terms, categorizations and classifications have been agreed upon, even if of course not everyone is happy with what has come out. But that's how it is when the majority decides and at least 75% are needed.

-but in any case, I think the new classification and the consensus statements give physicians some guidance and a basis on how to classify the different forms of angioedema.



Interview with Dr. Thomas Buttgerreit on DANCE

What was the methodology of the project in brief?

In brief, statements were written by a committee of experts and presented to a panel of other experts for voting in 3 rounds using the scientific method Delphi. Three rounds, because after the first two rounds no consensus could be reached for all statements and therefore, they had to be reformulated and revised taking into account the feedback/suggestions of all experts.

What are the areas of future research and are there any upcoming projects on this topic?

Here I clearly see a confirmation of the individual classifications by further research results. Why has ACE inhibitor-induced angioedema not made it into the bradykinin category (AE-BK)? There should be a project that definitively proves that AE-ACEI is an AE-BK. This would make a lot of things easier. In addition, we need projects that investigate the pathomechanisms of the development of AEs in very rare AE forms such as HAE-HSST, AE-MYOF in more detail, in order to be able to assign them more clearly to a category. The same applies to Gleich syndrome.

Are there any findings you can already share?

Sure: There are 3 endotypes and 2 additional subclasses of angioedema: AE-MC (mast cell), AE-BK (bradykinin), AE-endothelial dysfunction, AE-DI (drug induced) and AE of unknown origin/mechanism.

However, I won't tell you yet which angioedema has ended up in which class. You will need to wait for the publications to find out!

DANCE is supported by HAEi and HAEA



Current Scientific Projects

1. [SHAERPA](#)
2. [IMAGINE 2.0](#)
3. [PROMUSE PAT](#)
4. [HAPY](#)
5. [MENTALIST](#)
6. [CARE](#)
7. [10 questions \(that can save lives\)](#)

Details

We need YOUR participation!

[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 project-related documents, please see our member area or contact the project lead:
carolina.vera@charite.de

[IMAGINE 2.0](#) (recruitment ongoing)

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 project-related documents, please see our member area or contact:
karlaroblesvelasco@gmail.com

Current Scientific Projects

1. [SHAERPA](#)
2. [IMAGINE 2.0](#)
3. [PROMUSE PAT](#)
4. [HAPY](#)
5. [MENTALIST](#)
6. [CARE](#)
7. [10 questions \(that can save lives\)](#)

Details

We need YOUR participation!

[HAPY](#) (recruitment ongoing)

Hereditary Angioedema in Pregnancy

A questionnaire for patients with HAE and their physicians will be used to retrospectively collect and evaluate details on the influence of pregnancy on HAE. The time period surveyed will cover the periods before, during and after the pregnancies/breastfeeding periods and should include, among other things, disease activity, medication, contraception, concomitant diseases and outcome of the pregnancies.

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

[10 questions](#) (that can save lives)

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 6 languages (English, German, Czech, Chinese, Turkish and Russian). 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.

[MENTALIST](#)

Unmet needs in hereditary angioedema – a global physician perspective

This project had the aim to identify and rank unmet needs in hereditary angioedema (HAE) including HAE due to C1INH deficiency and HAE with normal C1INH values with known or unknown causative mutations.

Thank you to the 52 physicians from all continents that participated, we appreciate your engagement!

Current Scientific Projects



Details

After a very successful Kick-Off Meeting with the CARE Steering Committee at the end of September, the CARE Management team is very excited and looking forward to the project start, the first patient inclusion and to all the information that will be collected and analyzed in the coming years!

As you already know, CARE is the global registry for all forms of recurrent angioedema, i.e. patients with mast cell-mediated angioedema (AE-MC), bradykinin-mediated angioedema (AE-BK) and other types of angioedema (AE). The Project is driven by the GA²LEN network of Angioedema Centers of Reference and Excellence (ACAREs) and the Urticaria Network e.V. (UNEV) and planned to be gold-sponsored soon by CSL Behring, Kalvista, BioCryst, Pharvaris and Takeda. The registry will collect real life data during normal routine patient visits and assessments with the objective to improve the knowledge on chronic angioedema.

After receiving great input from the Steering Committee and ACARE Centers, the CARE Management Team has been able to finalize the variables and is in the final stages of programming the CARE eCRF and database. The questionnaire covers the following areas:

Core variables:

- Demographic data
- Duration of disease
- Course of the disease
- Frequency of angioedema
- Comorbidities
- Triggering factors
- Treatment response
- Disease activity
- Disease control
- Quality of life impairment
- Direct health care costs
- Absence from work/school
- Underlying causes

Current Scientific Projects



Details

The coordinating center at the Charité has already received a positive ethics vote for the project and provided the necessary documents to submit to the Ethics Committee to all ACARE Centers. Now it's your turn! If you have any questions, please do not hesitate to contact the [CARE Office](#). You are also welcome to visit the [CARE Homepage](#), which is continuously growing and will soon provide all the important information and documents.

To all ACARES: Please spread the word, since all angioedema treating physicians are highly welcome to participate and to contribute to this important project. Let's bring our combined efforts together towards improving treatment and positively impacting the lives of those affected by angioedema.

The CARE management team manages, oversees, and directs the operation of CARE:

Dr. Thomas Buttgereit
- Chief Scientific Coordinator

Dr. Pavel Kolkhir
- CURE liaison officer

Prof. Dr. Marcus Maurer
- HAEi liaison officer

PD Dr. med. Karsten Weller
- Principal Investigator

PD Dr. Frank Siebenhaar
- ACARE liaison officer

Alexandra Bredigkeit
- CARE Office

Annika Gutsche
- Chief Statisticianwil

Prof. Dr. Markus Magerl
- UNEV liaison officer

Reinhardt Britz
- ACARE Office

Current Scientific Projects



Meet the CARE Team

CARE is academia-driven, international, and peer-governed. Its bodies include the CARE International Steering Committee (ISC) and the CARE Management Team.

The ISC is comprised of CARE investigators, a UNEV delegate, gold sponsor delegates (one per gold sponsor), a non-voting consulting HAEi delegate and all ACARE steering committee members.

Clemens Schöffel, Austria	Ankur Jindal Chandigarh, India	Hilary Longhurst, Auckland, New Zealand	Marcus Maurer, Berlin, Germany
Daria Fomina, Moscow, Russia	Asli Gelincik, Istanbul, Turkey	Inmaculada Martinez-Saguer, Mörfelden, Germany	Markus Magerl, Berlin, Germany
Aharon Kessel, Haifa, Israel	Connie Katelaris, Westmead, Australia	Karsten Weller, Berlin, Germany	Mauro Cancian, Padova, Italy
Andrea Zanichelli, Milan, Italy	Danny Cohn, Amsterdam, Netherlands	Laurence Bouillet, Grenoble, France	Noemi Bara, Sangeorgiu de Mures, Romania
Anete Grumach, Sao Paulo, Brazil	Emel Aygören-Pürsün, Frankfurt, Germany	Marc Riedl, San Diego, USA	Petra Staubach, Mainz, Germany
Timothy Craig, Hershey, USA	Henrik Balle Boysen, Horsens, Denmark	Yu-Xiang Zhi, China	Anthony Castaldo, USA
Thomas Buttgereit, Berlin, Germany	Teresa Caballero, Madrid, Spain	Tamar Kinanciyani, Vienna, Austria	Stephen Betschel, Toronto, Canada
Stefan Cimbollek, Sevilla, Spain	Michihiro Hide, Hiroshima, Japan	Roman Hakl, Brno, Czech Republic	Vesna Grivcheva-Panovska, North Macedonia
Henriette Farkas, Budapest, Hungary			



Sharing is Caring

Coming up in the next newsletter:

- Hot topics in Angioedema
- Treatment Advice

Please share our news 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 see our website or view our [social media channels](#).

A special thank you to

**Thomas Buttgereit and the CARE
office for their contributions.**

CARE  **CHRONIC
ANGIOEDEMA
REGISTRY**



Sponsors

Thanks

We would like to thank the ACARE LevelUp Sponsors:

Gold

Takeda



Silver

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