

# UCARE LevelUp MAGAZINE

WWW.GA2LEN-UCARE.COM

March, 2024

## Content

### New Centers

### Past Events

- UCARE Conference
- UCARE DACH Tag

### Educational Activities

- UCARE LevelUp
  - Journal Club
  - Webinars
  - Podcast
- UCARE 4U
  - UDAY 2024
  - 100 Questions

### Scientific Projects

- CRUSE: Whats new?
- CRUSE around the world: Interview with CRUSE Champions
- Current and Upcoming Scientific Projects
- CURE: Whats new?

## Top News

UCARE Conference 2023

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100 Questions

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DACH-Tag

 **CRUSE**  
CONTROL

CRUSE Champions

# New Centers

September 2023 to March 2024

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

DATE OF JOINING	NAME OF CENTER	COUNTRY
08.09.2023	Food & Drug Allergy Clinic by Dr. Ghada E. Fouda	Egypt
20.10.2023	Miami Itch Ctr - Dr Phillip Frost	USA
06.11.2023	Sakarya University Training and Research Hospital	Turkey
12.12.2023	Urticaria Outpatient Clinic (HCFMUSP)	Brazil
18.12.2023	Vilnius University Hospital Santaros Klinikos	Lithuania
01.02.2024	Emedic Salud SAC	Peru
02.02.2024	Universitätsklinikum Hamburg-Eppendorf (UKE)	Germany
14.02.2024	Corporate Fund "University Medical Center"	Kazakhstan
17.02.2024	Medical Center Hospital of the President's Affairs Administration of the Republic of Kazakhstan	Kazakhstan
22.02.2024	City General Hospital "8th September"	North Macedonia

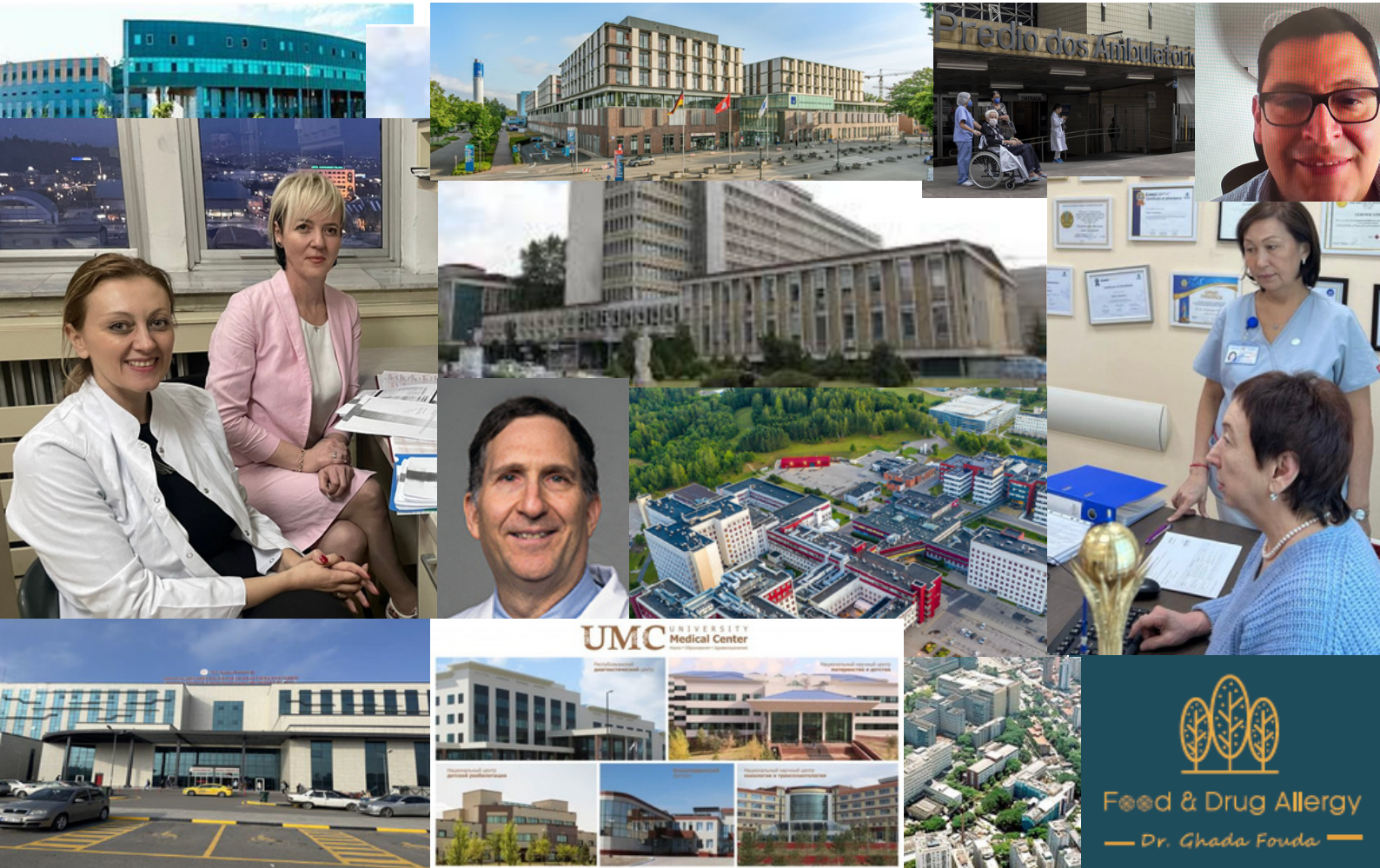
You can find more information on our UCARE centers [here](#).

# New Centers

**UCARE CENTERS**  
audited centers worldwide

# 172

Number of countries on the continents	
Africa	2
Asia	16
Australia	1
Europe	19
North America	3
South America	5
Total	46



**UMC** UNIVERSITY Medical Center



**Food & Drug Allergy**  
— Dr. Ghada Fouda —

# Past Events

1. GA<sup>2</sup>LEN UCARE Conference 2023
2. UCARE DACH Tag

## Details

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The 4th GA<sup>2</sup>LEN UCARE Conference took place in São Paulo on **December 7 to 9**.

*Thank you to everyone who travelled to Brasil, submitted an abstract, gave a presentation and attended lectures. All of you are what made this conference a great success.*

You can view the programme and more information on this [website](#).

### Thank you to the International Scientific Committee:

Prof. Dr. Luis Felipe Ensina

Alergoalpha/CPAlpha – Clinical Research Center Federal University of São Paulo

Prof. Dr. Marcus Maurer

Charité – Universitätsmedizin Berlin, Institute of Allergology IFA, Fraunhofer ITMP, Immunology and Allergology IA Berlin

Prof. Dr. Ana Giménez-Arnau

Hospital del Mar Universal Autònoma Barcelona

Prof. Dr. Torsten Zuberbier

Charité – Universitätsmedizin Berlin, Institute of Allergology IFA, Fraunhofer ITMP, Immunology and Allergology IA, Berlin

Prof. Dr. Emek Kocatürk Göncü

Koç University School of Medicine, Istanbul, Türkiye; Charité – Universitätsmedizin Berlin, Institute of Allergology, Fraunhofer ITMP, Allergology and Immunology IA, Berlin

# Past Events

1. GA<sup>2</sup>LEN UCARE Conference 2023
2. UCARE DACH Tag

## Details

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### And also to the local organizing committee:

Prof. Dr. Luisa Karla Arruda  
University of São Paulo

Prof. Dr. Solange Valle  
Federal University of Rio de Janeiro

Prof. Dr. Régis Albuquerque Campos  
Complexo Hospitalar Universitário, Universidade Federal da Bahia

Prof. Dr. Roberta Fachini Jardim Criado  
ABC School of Medicine, São Paulo

Prof. Dr. Rosana Camara Agondi  
UCARE Hospital das Clínicas, University of São Paulo

Prof. Dr. Luis Felipe Ensina  
Alergoalpha/CPalpha – Clinical Research Center Federal University of São Paulo

Dr. Paulo Ricardo Criado  
Full Researcher at Centro Universitário FMABC.

**Your hard work and dedication made the UCARE Conference the fantastic event that it was.**

# Past Events

1. GA<sup>2</sup>LEN UCARE Conference 2023
2. UCARE DACH Tag

## Details



### The 4th GA<sup>2</sup>LEN UCARE Conference 2023 in numbers:

- 431 participants hailing from 37 countries
- 126 abstracts submitted
- 116 posters presented
- 10 oral presentations
- 16 scientific sessions
- 39 presentations

### Some impressions from the conference:



Don't miss *episode 81* of our **All Things Urticaria** podcast with Luis Ensina and Marcus Maurer.



See the highlights in one video:



## Abstract Review



### Prof. Dr. Emek Kocatürk Göncü:

- Professor of Dermatology,
- Department of Dermatology,
- Koç University School of Medicine, Istanbul, Türkiye
- Clinical Researcher,
- Charité - Universitätsmedizin Berlin, Institute of Allergology,
- Fraunhofer Institute for Translational Medicine and Pharmacology ITMP, Allergology and Immunology, Berlin, Germany

*“There were many great sessions and interesting abstracts in Sao Paulo UCARE Conference that it was difficult for me to pick, however I tried to give a brief summary of what I have learned from the poster presentations in this comprehensive conference in urticaria. I hope you benefit from my highlights from the UCARE Posters.”*

- Patients with solar urticaria who require omalizumab have lower baseline UCT in comparison with those treated only with antihistamines. All omalizumab-treated patients presented a fast reduction of FcεRI levels and FcεRI was inversely correlated to the improvement of UCT. This observation highlights the pathogenic importance of IgE-mediated pathways in solar urticaria in real clinical practice and it emerges as a possible biomarker of response to omalizumab.
- Results from DRuSO-CU study showed in 2,325 CU patients that overall median omalizumab survival rate is 3.3 years and the main reason for discontinuation is mostly due to well-controlled disease. Ineffectiveness and side effects are minor reasons for discontinuation. Immunosuppressive co-treatment at start of omalizumab and autoimmune disease predicted a higher risk of discontinuation due to ineffectiveness. CInDU patients show complete or good response to omalizumab in majority of the patients (73%) and major reason for discontinuation well-controlled disease.

- CSU gut microbiota displays low diversity and low short-chain fatty acids in mice. Transplantation of *Roseburia hominis* and caproate administration protected recipient mice from MC-driven skin inflammation. Gut microbiome alterations may facilitate MC-driven skin inflammation in CSU patients.
- Dupilumab demonstrated clinically meaningful and statistically significant improvements in patients with H1 antihistamine-resistant CSU regardless of baseline IgE level and was consistent with the known dupilumab safety profile. Dupilumab treatment also led to decreased median total serum IgE over time from baseline to Week 24.
- Female patients with CSU shows higher rates of angioedema, systemic symptoms, positive family history, concomitant diseases (obesity, asthma, thyroid disorders, autoimmune diseases, gastrointestinal diseases and depression), elevated ESR and use of immunosuppressive medications as well as higher quality of life impairment
- CSU patients more often had autoallergic (aa)CSU (58%) than autoimmune (ai)CSU (8%) and almost all patients with aiCSU also had aaCSU. aaCSU tended to be younger where patients with aiCSU were more often female and had higher levels of thyroid peroxidase autoantibodies and a more severely impaired quality of life
- The majority of solar urticaria patients develop symptoms within 10 minutes after exposure to light and most patients rated their condition as severe with a substantial impact on their quality of life. The available therapeutic options including off-label treatments are insufficient to achieve complete control of the disease in most cases.
- Insomnia and obstructive sleep apnea are the most common sleep disorders in chronic urticaria patients and uncontrolled urticaria patients had more cases of sleep disorders
- CSU patients experiencing higher levels of psychosocial stress and reduced well-being may benefit from attention-based therapy program that provides enhanced psychosocial well-being and reduction CSU symptomatology
- Angioedema, emergency referrals, need for systemic steroids, comorbid systemic disorders are more frequent and baseline urticaria control test scores are lower in CSU plus CIndU patients compared to isolated CIndU patients.
- Personality disorders are common in CSU patients, the most common being histrionic (43%), followed by obsessive (31%) and depressed (16%).
- A new autoantibody, anti-HSP10 IgG was found in CSU patients, which showed a significant correlation with UAS7 scores. A decreased serum HSP10 level was related with upregulated miR-101-5p due to incretion of IL-4 and PAF in CSU patients. Modulation of miR-101-5p and HSP10 may be a novel therapeutic approach for CSU.



- C5aR expression is significantly increased in skin lesions of CSU patients, this may indicate the involvement of complement activation in the pathogenesis of CSU and a potential role of anti-C5 and anti-C5aR therapies as novel treatment for CSU patients.
- CSU shows changes in disease features by age. Decrease in isolated CINDU frequency, increase in the prevalence of elevated CRP, positive anti-TPO antibodies, and comorbid systemic disorders and longer disease duration by the advancement of age suggests a change in disease processes in CU.
- Early responders to omalizumab are associated with a higher initial omalizumab dose ( $\geq 300$  mg), higher basophil counts, total IgE levels exceeding 798 kU/L and lower platelet-to-lymphocyte ratio.
- The usage of oral tofacitinib significantly improves the clinical picture in refractory CSU. Tofacitinib's effectiveness in CSU raises the possibility that it could represent a novel therapeutic option for individuals with refractory CSU.
- Many CSU patients have autoantibodies to TPO, and most have either IgE or IgG autoantibodies but not both. Anti-TPO IgE was related with the atopic status and favorable response to antihistamine treatment, whereas anti-TPO IgG was associated with angioedema and poor response.



Prof. Dr. Emek Kocatürk Göncü



*Get in touch!*

# Past Events

1. GA<sup>2</sup>LEN UCARE Conference 2023
2. UCARE DACH Tag

## Details

### UCARE DACH Tag 2024

On **March 6, 2024**, physicians from DACH region UCAREs (Germany, Austria, Switzerland) as well as patient organization and pharma representatives gathered in quaint Buxtehude near Hamburg, Germany, to discuss the UCARE network and all its activities, including **CRUSE**, **CURE**, and **CARE** and **UDAY**.



The participants had many insightful questions and great suggestions on how to improve recruitment and enhance the user experience for both the registries and the app. They also discussed strategies for deepening engagement and participation with our educational programs as well as UDAY. In the afternoon, the floor was opened to the patient organization representatives.

They introduced their organizations, gave testimony on living with urticaria and shared their perspectives. After that, the topics were the **Patient Charta** and developing it in German, as well the connection and collaboration between UCAREs and regional physician associations and other dermatology networks.

Lastly, there was a round table discussion on UCARE Tools (CRUSE APP, CURE etc.) and how to improve recruitment for **clinical studies**.

It was a day full of networking, insightful discussions, as well as lofty ideas and hopes for the future – all with the goal of improving the lives of urticaria patients in the DACH region.

The UCARE team is grateful for the Buxtehude UCARE under Dr. Andreas Kleinheinz for hosting this event, all participants for their engagement and of course our event sponsors.

We are already looking forward to our meeting next year!

# Past Events

## UCARE DACH Tag 2024

1. GA<sup>2</sup>LEN UCARE Conference 2023
2. UCARE DACH Tag



The UCARE Dach Tag 2024 was sponsored by



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# Educational Activities

1. UCARE LevelUp Journal Clubs
2. UCARE LevelUp and UCARE4U Webinars
3. UCARE LevelUp Podcast



## UCARE LevelUp Journal Club

**1 Save the Date: UCARE LevelUp Journal Club April 18, 12.00 to 12.45 CET**

Nicole Nojarov (IFA Berlin) will speak on

*“Hereditary alpha tryptasemia is not associated with specific clinical phenotypes”*

– Chollet and Akin, 2021, JACI

[Click here for the paper](#)

[Click here to join the meeting](#)

**2 Save the Date: UCARE LevelUp Journal Club May 2, 12.00 to 12.45 CET**

Zhuoran Li (Berlin) will speak on

*“DOCK2 regulates MRGPRX2/B2-mediated mast cell degranulation and drug-induced anaphylaxis”*

– Kunimura et al, 2023, JACI

[Click here for the paper](#)

[Click here to join the meeting](#)

**3 Save the Date: UCARE LevelUp Journal Club May 16, 12.00 to 12.45 CET**

Nian Liu (Berlin) will speak.

[Click here to join the meeting](#)

If you are a UCARE or ACARE physician and would like to present a paper, please contact [Julia Föll](mailto:julia.foell@ga2len.berlin) at [julia.foell@ga2len.berlin](mailto:julia.foell@ga2len.berlin) or [Niklas Mahnke](mailto:niklas-amadeus.mahnke@charite.de) at [niklas-amadeus.mahnke@charite.de](mailto:niklas-amadeus.mahnke@charite.de).

Do you have a Journal Club at your own UCARE center that you would like to open for other UCARE members? Let us know, we are happy to facilitate this.



# Educational Activities

1. UCARE LevelUp Journal Clubs
2. UCARE LevelUp Webinars
3. UCARE LevelUp Podcast



## UCARE LevelUp Webinars

**Save the Date:** 10th UCARE LevelUp webinar on Tuesday, April 23rd, 12:00 to 1:00 pm CET

**Topic:** Urticaria in special populations  
**Target audience:** Every urticaria treating physician  
**Learning Objectives:** - To understand the philosophy in treating urticaria in special populations  
- To apply current knowledge to urticaria management in special population

### Speakers/subtopics:

1. Introduction & Moderation – Jason Fok (5 minutes)
2. Urticaria in children -- Petra Staubach-Renz (15 minutes)
3. Urticaria in elderly and people with complex medical needs -- Kanokvalai Kulthanan (15 minutes)
4. Urticaria in pregnant and lactating women -- Emek Kocatürk (15 minutes)
5. Questions and Answers -- Moderated by Jason Fok (10 minutes)



Accredited with 1 European CME credit (ECMEC®) by the European Accreditation Council for Continuing Medical Education (EACCME®)

**Save the Date:** 11th UCARE LevelUp webinar on Tuesday, June 25th, 2024, 4:00 to 5:00 pm CET

**Topic:** Acute urticaria – current perspective and what key points to consider  
**Target audience:** Every urticaria treating physician/GPs  
**Description/aim:** This webinar focuses on the most frequent presentation of urticaria: acute urticaria. The speakers will highlight how it is defined, where it comes from, how to manage it, and how we may suspect it will evolve into chronic urticaria.

### Speakers/sub topics:

1. Introduction + Moderator: Ana Giménez-Arnau, Spain (5 minutes)
2. Causes of acute urticaria - Ümit Şahiner, Turkey (15 minutes)
2. Management of acute urticaria – Joao Marcelino, Berlin (15 minutes)
3. When does acute urticaria evolve into chronic urticaria? –
4. Martin Metz, Germany (15 minutes)
5. Questions and Answer Session – all faculty, moderated by Ana Giménez-Arnau, Spain (10 minutes)



If you've missed a past webinar, you can watch them on our [website](#) or our [youtube](#) channel.

Applied for 1 European CME credit (ECMEC®) by the European Accreditation Council for Continuing Medical Education (EACCME®)



# Educational Activities

1. UCARE LevelUp Journal Clubs
2. UCARE LevelUp and UCARE4U Webinars
3. UCARE LevelUp Podcast



## UCARE LevelUp Podcast

# 'All Things Urticaria'

### UCARE LevelUp Podcast 'All Things Urticaria'

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



Since our last newsletter the following episodes have been launched:

#### Episode 72: IL-9, IL-10 and CSU pathogenesis

Dermatologist Professor Kiran Godse joins Professor Marcus Maurer to explore the use of JAK and STAT inhibitors in the management of chronic urticaria and how these drugs may impact quality of life for people with this condition.

#### Episode 73: Urticaria and stress

Professor Marcus Maurer is joined by Professor Eduardo Souza Lima to explore the relationship between stress and urticaria, and the implications of mast cells and neuropeptides in chronic spontaneous urticaria.

#### Episode 74: Non-steroidal anti-inflammatory drugs in CSU

Professor Riccardo Asero joins Professor Marcus Maurer to offer advice on the use of non-steroidal anti-inflammatory drugs (NSAID) in people with chronic spontaneous urticaria (CSU). The experts discuss risk assessment and strategies to avoid respiratory and cutaneous hypersensitivity reactions in people who require these common medications to manage comorbidities.

#### Episode 75: Urticaria in a veterinary setting

Professor Ralf Mueller to discuss how urticaria affects animals, including similarities and differences with the condition in humans and the challenges of treating performance animals.

#### Episode 76: Clinical nurse specialists: Leading collaborative care

Professor Marcus Maurer is joined by Clinical Nurse Specialist Lorena Lorenzo to discuss the responsibilities of the nurse's role, and the potential benefits it brings for people living with urticaria.

#### Episode 77: Antihistamines and urticaria

"We treat until it's gone." Professor Marcus Maurer is joined by Professor Gordon Sussman to discuss the use of antihistamines in people with urticaria, covering the history, side effects, safety and best practices.



# Educational Activities

1. UCARE LevelUp Journal Clubs
2. UCARE LevelUp and UCARE4U Webinars
3. UCARE LevelUp Podcast



## UCARE LevelUp Podcast

# 'All Things Urticaria'

### 78 Episode 78: What is cold urticaria?

"Wouldn't it be nice to find a cure?" Professor Marcus Maurer is joined by Dr Aurélie Du-Thanh to discuss cold urticaria, covering risk factors, diagnosis journey, and the most suitable treatment options.

### 79 Episode 79: Apps, refugees, and the future of digital healthcare

"This is only the beginning of making use of this technology." Professor Marcus Maurer is joined by asthma and allergic rhinitis expert Professor Jean Bousquet to discuss the collaboration that produced the MASK-Air and CRUSE apps, how they are helping Ukrainian refugees and the possibilities for future development.

### 80 Episode 80: Living with CSU: The patient's voice

"It doesn't just affect one part of your life." Arzoo Ahmed joins Professor Marcus Maurer to discuss the patient perspective, covering the reality and challenges of living with chronic spontaneous urticaria.

### 81 Episode 81: UCARE Conference 2023

"It's really a catalyst to what the network does." Professor Marcus Maurer asks Dr Luis Felipe Ensina to reflect on the UCARE Conference 2023, covering personal highlights and expectations for future meetings.

### 82 Episode 82: Managing autoimmune CSU

"There's still so much we need to learn." Dr João Marcelino joins Professor Marcus Maurer to discuss autoimmune chronic spontaneous urticaria, including indicative test results and hopes for the future.

### 83 Episode 83: Chronic Angioedema Registry (CARE)

"I think CARE will grow and grow." Dr Thomas Buttgerit joins Professor Marcus Maurer to discuss the recently launched Chronic Angioedema Registry (CARE), including benefits for patients, current capabilities and how to get involved.

### 84 Episode 84: Does country make a difference?

"We treat until it's gone." Professor Marcus Maurer is joined by Professor Gordon Sussman to discuss the use of antihistamines in people with urticaria, covering the history, side effects, safety and best practices.

15/36

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

UCARE LevelUp Podcast 'All Things Urticaria'

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



## Educational Activities



1. UDAY 2024
2. 100 Questions

## Details

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### Getting ready for



1<sup>st</sup> OCTOBER 2024

**urticaria**  
**day** *your journey*

*The theme of this year is YOUR Journey – The patient's perspective.*

The key messages will relate to the area of "handling and management of urticaria".

As always, there are many ways to be a part of UDAY:

- Share and like our social media posts
- Tell your patients about UDAY
- Download assets such as posters, social media profile pictures, guidelines for organizing
- an urticaria awareness walk and so much more on our website
- Plan your own UDAY events and share them with us

Find more info on <https://urticariaday.org/> and get in touch with [Rebekka Locke](#) or [Sandra Bednareck](#).



# Educational Activities



1. UDAY 2024

2. 100 Questions

## Details

### 100 questions and answers



An example for

*“What are the common causes of acute urticaria?”*



- New format in the UCARE 4U program, comprised of 100 short video clips (20 - 30 sec.)
- UCARE physicians from all over the world answer the most frequently asked and most important questions about urticaria
- In English and native language where applicable
- Videos will be shared via our [4U website](#) and our [social media](#) channels

Would you like to be featured? Reach out to us!

# Current & Upcoming Scientific Projects



## CRUSE CONTROL Details

On March 19, **CRUSE** reached a big milestone: **10.000 downloads!**

Since the last newsletter, we have launched in the USA, Oman and Japan in December 2023 and in Thailand, Ireland, Mexico and Australia in March 2024.

CRUSE is now available in **28 countries** and three additional **global versions in English, Ukrainian and Arabic.**

**Also new:** a patient education section that launched in German and English on March 22nd, allowing all patients that use CRUSE to truly understand what urticaria is, therapies available, how PROMs are used and it also shares the latest news in the urticaria world.

**CRUSE** lets patients take control of their Chronic Urticaria by recording their symptoms and impact on their quality of life in just a few minutes each day. CRUSE then allows them to share these results with their treating physician, track how they respond to treatment and ideally with this information allow for better control.

If you are not yet using CRUSE for your patients, now is the perfect time to start! To give you some inspiration and insight into the life and work of our CRUSE champions, please enjoy the interview below with our champions from Argentina, Denmark, Ecuador and the US.

Get CRUSE [here](#) and [learn more](#) on how to use CRUSE!

# Current & Upcoming Scientific Projects



## Details

### CRUSE around the world: Interview with CRUSE Champions



**Prof. Claudio Parisi, Argentina**  
Hospital Italiano de Buenos Aires  
Pediatrics and Adults Allergy Sections



**Prof. Simon Francis Thomsen and Jennifer Astrup Sørensen**  
(PhD Student) at Bispebjerg Hospital Department of Dermatology in  
Denmark



**Prof. Dr. Manuel Ivan Cherrez-Ojeda, Ecuador**  
Respiralab Research Center, Guayaquil  
Universidad Espiritu Santo, Samborondon



**Prof. Jonathan Bernstein, USA**  
University of Cincinnati College of Medicine and Bernstein,  
Allergy Group, Cincinnati, Ohio

# Interview with CRUSE Champions



## 1. What are the advantages you see in incorporating the CRUSE app into your practice?

It is a practical tool that facilitates consultations, allows patients to understand what controlling the disease means, how it affects their quality of life, what the options are and the needs for treatment modification.

On the other hand, it generates complete feedback with the patient, where language and common objectives are managed. - *Prof. Claudio Parisi, Argentina*

**The CRUSE app is the first step towards creating a fully virtual outpatient clinic, so we, in time, can help patients with CU in real-time.** Since CU is a fluctuating disease with symptoms usually present when the patient is at home, e.g. at night, and not present when the patient is in the hospital outpatient clinic, we can create the best possible outcome for the patient.

- *Prof. Simon Francis Thomsen and Jennifer Astrup Sørensen, Denmark*

The advantages I perceive in incorporating the CRUSE app into my daily medical practice are that it allows patients to achieve better control of their symptoms, leading to an improved quality of daily life. With this app, **I can access real-time data** on the progression of the disease in my patients, facilitating more informed and personalized decision-making. It enables closer patient monitoring, even at a distance, which is beneficial in situations where in-person visits are limited.

By providing educational information and resources within the app, there is potential for an enhanced understanding among patients about their condition, fostering active participation in the management of urticaria. - *Prof. Dr. Manuel Ivan Cherrez-Ojeda, Ecuador*

See question 2 from Prof. Jonathan Bernstein

# Interview with CRUSE Champions

## 2. What advice do you have for other CRUSE champions or those who want to become one?

Be persistent in the search for possibilities to increase the number of patients with CSU, starting from the workplace and insisting on the search for resources that allow the generation of paper and/or digital material, taking advantage of every possibility of participation in conferences or other scientific events to present slides. Share knowledge and disseminate it to residents/fellows in different specialties. - *Prof. Claudio Parisi, Argentina*

See the potential to become fully aligned with your patients' symptoms when they are present instead of only being able to retrospectively **help patients**. Also see the potential to engage with physicians around the world jointly creating real-time real-world evidence as we manage our patients. - *Prof. Simon Francis Thomsen and Jennifer Astrup Sørensen, Denmark*

Joining the CRUSE application can be beneficial for three reasons:

### 1.Improvement of Doctor-Patient Communication:

The CRUSE app provides an interactive platform that can enhance communication between doctors and patients. It facilitates monitoring and understanding of the evolution of urticaria, thereby strengthening the doctor-patient relationship.

### 2.Construction of a Knowledge Base:

Participating in the CRUSE app contributes to the construction of a knowledge base regarding disease activity in a specific country. This not only benefits individual patients but can also provide valuable insights into epidemiological patterns and the development of treatment strategies.

### 3.Generation of Scientific Evidence:

By contributing data to the CRUSE app, doctors can be part of generating scientific evidence. The collection and analysis of large-scale data can contribute to the scientific understanding of urticaria and improve clinical practices. - *Prof. Dr. Manuel Ivan Cherrez-Ojeda, Ecuador*

I think we are living in an age with **artificial intelligence** that can advance patient care. Tools like CRUSE do this for CSU. It provides an opportunity to do real world research for those treating hives to better understand CSU and CIndU prevalence, epidemiology, natural cause, comorbid illnesses, treatment utilization and patient response among other clinical characteristics that will advance our knowledge of this complex inflammatory skin disorder and other mast cell related conditions.

- *Prof. Jonathan Bernstein, USA*

# Interview with CRUSE Champions

## 3. How are you promoting the app to patients?

In our UCARE center at the Italian Hospital of Buenos Aires, in each consultation, once the diagnosis has been established, we dedicate a part of the consultation demonstrating and describing CRUSE. We have the QR code in our office so that patients can download the application as well as some brochures and images that describe it. **The concept is not to miss the opportunity.**

We explain to patients the usefulness and advantages of CRUSE and then in subsequent consultations we review the results and ask if there are questions regarding its use.

On the other hand, through the Hospital's **social networks** (Instagram @alergia.hospitalitaliano) and the personal networks of each doctor on the team (Linkedin, IG, Facebook, X) we are making monthly posts. - *Prof. Claudio Parisi, Argentina*

We hand printouts with QR code to all new CU patients and follow-up patients in our outpatient clinic. We also demonstrate the app on a phone for the patients. - *Prof. Simon Francis Thomsen and Jennifer Astrup Sørensen, Denmark*

The RESPIRALAB Medical Center is promoting the CRUSE APP among patients through two main channels:

Social Media Promotion: The center is using social media platforms to reach younger patients. They are leveraging these channels to create awareness about the CRUSE APP, emphasizing its capability to help patients with urticaria effectively manage and control the condition.

Medical Consultation Recommendations: During each medical consultation, patients are being actively encouraged to use the CRUSE APP. This **direct recommendation from healthcare professionals** at RESPIRALAB reinforces the importance of the application for managing and controlling urticaria. - *Prof. Dr. Manuel Ivan Cherez-Ojeda, Ecuador*

**The CRUSE app is a tool that should be used by any physician managing urticaria and by any patient with urticaria.** It is an efficient way of monitoring severity and control of patient's hives. I currently provide the link to every patient I treat with hives and promote it to my colleagues at meetings and other events. I am currently looking for a sponsor of the app in the US which will further promote the value of this app. - *Prof. Jonathan Bernstein, USA*

# Interview with CRUSE Champions

## 4. How are you promoting the app to fellow doctors and healthcare professionals?

With respect to other doctors (clinicians, dermatologists, allergists, family medicine doctors, paediatrics etc.), do we describe and teach the APP in each presentation or class, both at the hospital level and in Allergy Associations and national or regional congresses. Also, when the opportunity for **interviews on radio or television** is given, we achieve greater dissemination of the application in the general population. - *Prof. Claudio Parisi, Argentina*

Not doing much here, sorry...we can do better here. - *Prof. Simon Francis Thomsen and Jennifer Astrup Sørensen, Denmark*

We promote the CRUSE app among medical colleagues and healthcare professionals through medical events. The latest event where CRUSE app was promoted was our RESPIRAR 2023 CONGRESS held in November, with an attendance of over 300 physicians.

Additionally, we have showcased the app during **international conferences** where our Respirolab Director, Dr. Iván Cherrez, has been a speaker, recommending its use.

On social media, we actively encourage fellow doctors and healthcare professionals to consider the app, emphasizing how it can enhance patients' control and management of urticaria. - *Prof. Dr. Manuel Ivan Cherrez-Ojeda, Ecuador*

See question 3. The **CRUSE app slide** should be at the end of every talk given by a physician on urticaria whether it is to physicians, nurses, or laypersons. - *Prof. Jonathan Bernstein, USA*

# Interview with CRUSE Champions

## 5. What challenges do you face within your country's health system?

We need to achieve greater knowledge of CRUSE outside the UCARE centers. In Argentina, we have some difficulties regarding **economic aspects** that limit the support of the industry to be able to promote it. - *Prof. Claudio Parisi, Argentina*

**Long waiting times** to see office-based dermatologists/allergologists. This halts the patients' immediate access to highly specialised hospital-based care, where advanced therapies are available. Last year, however, it became possible for general practitioners to refer CU patients via fast-track to dermatologists to be seen within one month. - *Prof. Simon Francis Thomsen and Jennifer Astrup Sørensen, Denmark*

The implementation of the CRUSE app in Ecuador's healthcare system may face several challenges. These include ensuring universal access to technology, addressing connectivity issues, raising awareness and providing education to healthcare professionals and patients, establishing trust and data security, providing effective training for healthcare staff, integrating with existing systems, accommodating diverse user skills, addressing cultural acceptance, ensuring financial sustainability, and promoting patient compliance. **Proactive measures and stakeholder involvement are crucial** for a successful implementation and realizing the benefits of the CRUSE app in the Ecuadorian healthcare system. - *Prof. Dr. Manuel Ivan Cherrez-Ojeda, Ecuador*

There is more of a concern with obtaining RVUs than there is for delivering quality care. **Physicians still do not follow guidelines** which reflects in their management of complex conditions like CSU and CIndU. They certainly do not assess severity or control of hives. The other issue is access and prior authorization for advanced therapeutics.

This is very time consuming, and many physicians do not want to take the time to do this.

**The CRUSE app can help address both problems.** Documenting longitudinally patients CSU severity and control should make it easier to demonstrate the need for advanced therapeutics when indicated. It should also help to educate physicians about implementation of appropriate treatment algorithms and for assessing severity and control which helps determine whether treatment needs to be stepped up or down. - *Prof. Jonathan Bernstein, USA*



# Interview with CRUSE Champions

## 6. How well do patients and healthcare professionals in your country generally adopt apps and new technologies?

In general, **new technologies are very well accepted in Argentina**, a significant percentage of the population has cell phones and CRUSE is easy to use and friendly.

Health professionals require that we show them that this is an app that facilitates consultations so that they can adapt to them and do not feel that it is something that overloads their daily work.

- Prof. Claudio Parisi, Argentina

Very well, **Denmark is one of the most digitized countries in the World.** - Prof. Simon Francis Thomsen and Jennifer Astrup Sørensen, Denmark

The adoption of health applications and new technologies in the healthcare sector in Ecuador is underway but faces challenges. Acceptance of these technologies varied among patients and healthcare professionals and was influenced by **factors such as accessibility, awareness, and trust in technology.**

In the Ecuadorian context, factors influencing the adoption of applications like CRUSE include:

- Connectivity and Internet Access: The availability and accessibility of reliable internet connections could impact the effective use of mobile applications by patients and healthcare professionals.
- Awareness and Education: Lack of awareness about health applications and the need for education on their benefits could influence adoption by both patients and healthcare professionals.
- Trust in Technology: Trust in the safety and efficacy of health applications was crucial. Concerns about data privacy or the accuracy of provided information could pose obstacles.
- Healthcare Culture and Practices: The willingness of healthcare professionals to integrate new technologies into their daily practices and the overall culture toward technology-based healthcare were important factors.
- Patient Acceptance: Patients' willingness to use mobile applications for health management could depend on various factors, including age, comfort with technology, and the severity of their medical condition

- Prof. Dr. Manuel Ivan Cherez-Ojeda, Ecuador

# Interview with CRUSE Champions

## 6. How well do patients and healthcare professionals in your country generally adopt apps and new technologies?

AI is slowly being adapted by patients more so in the younger generation than older populations. However, **the CRUSE app is so easy that anyone can master it.** It just takes some discussion between the treating physician and patient on why it is important to use – it's like giving homework to the patient before their next appointment.

If they are good students using the CRUSE app will be a snap. If they have struggled in the past with homework, a caring physician that reinforces positive behavior by tutoring them about the importance of monitoring their condition, will result in increased use of CRUSE and adherence with office visits and treatment ultimately leading to very good clinical outcomes.

- Prof. Jonathan Bernstein, USA



Get CRUSE [here](#) and [learn more](#) on how to use CRUSE!

# Current Scientific Projects

1. **CU-SLEEP**
2. **PROMUSE PAT**
3. **CSUplus**
4. CU-Tiger
5. RIFA-CU
6. FAMLI-CU
7. To'SOLU
8. HURDLE

## Details

**We need YOUR participation!**

### **CU-SLEEP** (Recruitment extended until June 30th, 2024)

Assess the frequency of sleep disorders in patients with spontaneous and inducible chronic urticaria through the Global Sleep Assessment Questionnaire (GSAQ).

**For more information please contact: [karlaroblesvelasco@gmail.com](mailto:karlaroblesvelasco@gmail.com)**

### **PROMUSE PAT** (currently recruiting)

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](mailto:karlaroblesvelasco@gmail.com)**

### **CSUplus** (currently recruiting until June 2024)

Characterizing the spectrum, prevalence, frequency, and relevance of ANDSiSys in CSU.

The aim of the project is to assess additional signs and symptoms in adult patients with CSU regarding demographics, disease characteristics, comorbidities, disease burden, and treatment response.

The Project is designed as a one-time assessment, which includes a 10-15 minute online Questionnaire and collection of blood samples. Among others, the samples received will be tested for tryptase levels and alpha-tryptase gene copy number. All patients with a physician-verified CSU, regardless of therapy, are eligible for the study. The study includes a patient questionnaire, blood samples (optional) and the provision of laboratory values.

About 100 patients from four centers have been already recruited, and we expect to reach the number of 500 patients this year. Let's make it possible together!

**For more information please contact: [polina.pyatilova@charite.de](mailto:polina.pyatilova@charite.de)**

# Current Scientific Projects

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4. **CU-Tiger**
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## Details

We need YOUR participation!

### **CU-Tiger** (recruitment for new Centers closed)

Characterizing urticaria markers including anti-TPO and IgE in serum.

**Please note that samples must be sent to Charité Berlin by June 1st, 2024!**

**Aims:** To investigate how many IgE-low and IgG-anti-TPO-high CSU patients have functional autoantibodies (IgG and/or IgE) assessed by both BAT and immunoassays; appropriate cut-off values; whether an additional parameter, e.g. basopenia, would increase diagnostic accuracy of using TPO/IgE for diagnosis of aiCSU; patients who have low IgE, high anti-TPO, both, or none for their clinical characteristics; link between IgE/anti-TPO and treatment responses, at least responses to antihistamine treatment (standard and higher than standard dosed treatment) and omalizumab.

**For more information please contact: [yi-kui.xiang@charite.de](mailto:yi-kui.xiang@charite.de) and [pavel.kolkhir@charite.de](mailto:pavel.kolkhir@charite.de)**

### **RIFA-CU** (currently recruiting until June 1st, 2024)

Risk factors and Lifestyle in Chronic Urticaria.

**Background:** CU is a chronic inflammatory disease which has been associated with a female gender, thyroid diseases, infections, pseudoallergens in the diet, drugs and stressful conditions. But life style factors such as diet, physical activity, caffeine intake, alcohol intake and smoking and risk factors such as blood type, occupation, exposure to hazardous substances in the work place, family history has not been thoroughly investigated and compared with healthy individuals.

**For more information please contact: [dremekozgur@gmail.com](mailto:dremekozgur@gmail.com)**

28/36

# Current Scientific Projects

1. CU-SLEEP
2. PROMUSE PAT
3. CSUplus
4. CU-Tiger
5. RIFA-CU
6. **FAMLI-CU**
7. **To'SOLU**
8. HURDLE

## Details

We need YOUR participation!

### **FAMLI-CU** (currently recruiting)

Application of the Family Dermatology Quality of Life Index in families (close relatives) of patients with chronic spontaneous urticaria.

For more information please contact: [bmzabdalla@gmail.com](mailto:bmzabdalla@gmail.com)

### **To'SOLU** (beginning recruitment soon)

Therapies and their outcomes in patients with **Solar Urticaria: *The patients' perspective***

**Aim:** The aim of this questionnaire-based survey is to investigate therapeutic response of solar urticaria therapies from the patient's perspective, as well as to better understand the clinical picture of solar urticaria and its impact on the quality of life of patients.

The study is aiming for **200 patients**.

For more information, please contact Lea Alice Kiefer ([lea-alice.kiefer@charite.de](mailto:lea-alice.kiefer@charite.de)) and Manuel Fernando Lobo Pereira ([manuel.pereira@charite.de](mailto:manuel.pereira@charite.de))

# Current Scientific Projects

1. CU-SLEEP
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3. CSUplus
4. CU-Tiger
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6. FAMLI-CU
7. To'SOLU
8. HURDLE

## Details

We need YOUR participation!

### **HURDLE** – (recruiting until April 2024 for HURDLE-I)

Is it possible that elevated histamine load in CSU might increase the frequency of dysmenorrhea and prolong histamine clearance rate? (HURDLE)

**Background:** HURDLE is a prospective, cross-sectional multicenter study. The first step of the HURDLE project is regional (HURDLE-I) and will only recruit patients from Turkish UCARE centers. The second step (HURDLE-II) will be international.

The primary aim of this study is to investigate the frequency of dysmenorrhea in women of reproductive age diagnosed with CSU and change in dysmenorrhea severity after the diagnosis. Additionally, the histamine clearance rates (measured with histamine-50-prick-test) of the same patient group will be compared with the general population.

Authorship criteria: UCAREs get to nominate one coauthor per 10 patient and control data.

### **HURDLE-II**

After gaining results from HURDLE-I, detailed information about global rollout of HURDLE-II will be announced soon.

For more information, please contact Murat Türk ([mrtrtk@gmail.com](mailto:mrtrtk@gmail.com))

# Upcoming Scientific Projects

1. UNICODE
2. CU-Paper
3. CHAPEAU
4. UNITACT
5. WAOW
6. PREDICT
7. SOLU-CE
8. ChoLU-CE

## Details

We need YOUR participation!

### UNICODE

Unmet Needs In ChrOnic urticaria: A multinational DElphi consensus

**Aim:** Creation of a roadmap, with recommendations on what efforts need to be prioritized in chronic urticaria (CU) research, considering the opinions of all stakeholders. A multinational Delphi consensus process as a part of the UNICODE project can help with this bringing together diverse stakeholders from around the world to identify and rank the unmet needs relating to gaps of knowledge or lack of education.

For more information, please contact Pavel Kolkhir ([pavel.kolkhir@charite.de](mailto:pavel.kolkhir@charite.de))

### CU-PAPER

Physician estimation of prevalence and impact of chronic urticaria

**Aim:** Investigating the estimated prevalence as well as economic and clinical impact of chronic urticaria (CU) by health care professionals

**Background:** Chronic urticaria (CU) is an inflammatory mast cell-mediated skin disease that presents with wheals, angioedema or both occurring for more than 6 weeks. It can be divided into chronic spontaneous urticaria (CSU) and chronic inducible urticaria (CIndU), which is triggered by specific external stimuli. CU is a common and debilitating skin disease with high rates of psychiatric comorbidities, considerable impairment of patient's quality of life, and high healthcare costs. Although some studies assessed disease burden, they were based mostly on the data provided by patients, and little is known about how CU perceived by physicians and their assessment of disease prevalence and impact.

For more information, please contact Berenike Kern ([berenike.kern@charite.de](mailto:berenike.kern@charite.de))

# Upcoming Scientific Projects

1. UNICODE
2. CU-Paper
3. **CHAPEAU**
4. **UNITACT**
5. WAOW
6. PREDICT
7. SOLU-CE
8. ChoIU-CE

## Details

We need YOUR participation!

### CHAPEAU

Characterization of pathomechanisms in acute and chronic urticaria – a global UCARE initiative

### **CHAPEAU Global**

Characterization of pathomechanisms in acute and chronic urticaria – a global UCARE initiative

**Aim:** This project aims to examine clinical features (via questionnaires) and blood samples of patients with acute urticaria, cured acute urticaria, acute urticaria with transition to csU and cured csU for markers of type I autoimmunity (autoallergy) and type II2b autoimmunität, e.g. basophils, eosinophils, C-reactive protein, auto-IgE antibodies and auto-IgG antibodies against the IgE receptor and FcεRI, total IgE, soluble FcεR, BAT, BHRA etc.

In this project, patients with acute urticaria (baseline) will be assessed for clinical and laboratory features of their urticaria and re-assessed after at least 6 weeks (Follow-up).

If you are interested in this project, please reach out to Hanna Bonnekoh ([hanna.bonnekoh@charite.de](mailto:hanna.bonnekoh@charite.de)) or Thomas Buttgerit ([thomas.buttgerit@charite.de](mailto:thomas.buttgerit@charite.de))

### UNITACT

Urticaria following Covid-19 infection or vaccination – Assessment of course & treatment responses.

For more information please contact [aiste.ramanauskaite@charite.de](mailto:aiste.ramanauskaite@charite.de)



# Upcoming Scientific Projects

1. UNICODE
2. CU-Paper
3. CHAPEAU
4. UNITACT
5. **WAOW**
6. **PREDICT**
7. SOLU-CE
8. ChoLU-CE

## Details

We need YOUR participation!

### WAOW – World of Angioedema and Wheals

Establish a comprehensive online collection of photographs of urticaria and angioedema, develop technological algorithms to evaluate the likelihood and severity of urticaria as well as the photographic quality and to provide guidance on how to take good pictures of wheals.

For more information please contact [ditte.zhang@gmail.com](mailto:ditte.zhang@gmail.com) or [sophia.neisinger@charite.de](mailto:sophia.neisinger@charite.de)

### PREDICT

Predicting the Probability of Relapse Following Omalizumab Dose Reduction in Patients with Chronic Urticaria

**Aim:** Determining the association between purported predictors of relapse and relapse occurrence following Omalizumab dose reduction in patients with Chronic Urticaria. Determining the non-linear effect of predictors of relapse following Omalizumab dose reduction in patients with Chronic Urticaria with the help of machine learning.

Performing a logistic regression analysis to determine which features are independently associated with a lower/higher probability of relapse following Omalizumab dose reduction after remission in patients with Chronic Urticaria

For more information, please contact Maryam Khoshkhui ([khoshkhuim@mums.ac.ir](mailto:khoshkhuim@mums.ac.ir))

# Upcoming Scientific Projects

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3. CHAPEAU
4. UNITACT
5. WAOW
6. PREDICT
7. SOLU-CE
8. ChoIU-CE

## Details

We need YOUR participation!

### SOLU-CE

Solar urticaria and other solar-induced reactions– Comprehensive Evaluation

**Aim:** Increase Worldwide understanding of solar urticaria and its clinical spectrum, Determination and optimization of evaluation strategies of SolU-patient, genotype-phenotype correlation.

**For more information, please contact Lea Alice Kiefer ([lea\\_alice.kiefer@charite.de](mailto:lea_alice.kiefer@charite.de))**

### ChoIU-CE

Cholinergic urticaria – a comprehensive evaluation of natural history, disease features and course and response to treatment

This study **aims** to improve the understanding of cholinergic urticaria and to assess differences in the natural history, clinical symptoms, triggers, sweating behavior, associated diseases, and treatment effects in patients with cholinergic urticaria by using a standardized patient-related questionnaire and an additional physician questionnaire (including medical history and disease specific information) with the aim of 300 patients.

**For more information, please contact Eva Maria Grekowitz ([eva-maria.grekowitz@charite.de](mailto:eva-maria.grekowitz@charite.de))**

*You can find more information and project documents in the [UCARE member area](#) or on our [website](#). If you have issues with accessing the UCARE member area, please reach out to Emilia Zimmermann at [emilia.zimmermann@ga2len.berlin](mailto:emilia.zimmermann@ga2len.berlin).*

# Current & Upcoming Scientific Projects



## Details

The **Chronic Urticaria Registry** (CURE) is an ongoing, prospective, international, multicentre, observational and voluntary registry of patients with chronic urticaria (CU). The main advantage of CURE over national registries is that it includes a very large sample size collected from many centers and physicians around the world. Its results can thus teach us about similarities and differences in different regions of the world.

Any physician dealing with CU patients can participate in CURE and enter the data of their patients. CURE collects baseline and follow-up data on all CU patients including the patient's demographics, history, symptoms, trigger and risk factors, therapies, and healthcare utilization.

As of March 2024, 73 centers from 30 countries worldwide have joined the registry and have entered baseline data on more than 6.600 and follow-up data on more than 2.800 CU patients.

### What is coming in 2024?

In Q2/Q3 of this year, urticarial vasculitis patient data sets as well as additional clinical and laboratory data will be able to be entered into the database. The latter includes total IgE, IgG-anti-TPO, IgE-anti-TPO, D-dimer, BHRA, BAT, ASST, and other parameters. In addition, skin biopsy results can be included.

We are close to facilitating an inclusion of CRUSE generated data into the CURE registry database. As soon as this option becomes available, you will be alerted.

You are interested in joining the chronic urticaria registry (CURE)? Great! Please check the [CURE website](#) or reach out to [cureoffice@urtikaria.net](mailto:cureoffice@urtikaria.net) to find out how to join and to get additional information and download the collaboration agreement template and other documents.



# Last, but not least

A special thank you Emek Kocatürk, Ivan Cherrez, Jonathan Bernstein, Claudio Parisi, Simon Francis Thomsen and Jennifer Astrup Sørensen for their contributions to this newsletter.

Do you want to share something with the network or become a guest contributor?  
Reach out to Julia Föll at [julia.foell@ga2len.berlin](mailto:julia.foell@ga2len.berlin)

Please share our news with your network as well! As always, we look forward to your feedback, ideas and engagement. For more up to date UCARE info, please check our [website](#), subscribe to our [event calendar](#) or view our [social media](#) channels.

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