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UDAY AROUND THE WORLD

New Centers

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

DATE OF JOINING	NAME OF CENTER	COUNTRY
24.08.2023	Azienda Ospedale Università di Padova	Italy
30.08.2023	Asfendiyarov Kazakh National Medical University-KazNMU Professors' Clinic	Kazakhstan
08.09.2023	Food & Drug Allergy Clinic by Dr. Ghada E. Fouda	Egypt

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

Number of countries on the continents	
Africa	2
Asia	16
Australia	1
Europe	18
North Africa	3
South America	5
Total	45

UCARE CENTERS
audited centers worldwide

163

Current Events

1. **GA2LEN UCARE Conference 2023**
2. UCARE and ACARE LevelUp Preceptorships
3. GA2LEN at EADV Congress
4. UCARE at EADV Congress

Details



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

Only 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!

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.

Please note that we have extended the **abstract submission deadline to Sunday, October 15th**. All information regarding the abstract submission process and requirements can be found [here](#).

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**
3. GA2LEN at EADV Congress
4. UCARE at EADV Congress

Details

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



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

- UCARE Preceptorship on Mastocytosis - "Updates on Classification, Diagnosis and Patient Management."
- ACARE LevelUp Preceptorship on Recurrent Angioedema with a special focus on HAE
- Please note the date. Further information and the registration link will follow next week in a separate mailing.

04/27

Current Events

1. GA2LEN UCARE Conference 2023
2. UCARE and ACARE LevelUp Preceptorships
3. GA2LEN at EADV Congress
4. UCARE at EADV Congress

EADV CONGRESS



BERLIN
11-14 OCTOBER 2023

Details

GA²LEN will have two sessions at EADV in Berlin this year.



goes



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

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

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



goes



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

05/27



Educational Activities

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

UCARE LevelUp Journal Club

Save the Date: UCARE LevelUp Journal Club October 26, 12.00 to 12.45 CET

Would you like to present on this date? Reach out to us!

[Click here to join the meeting](#)



Save the Date: UCARE LevelUp Journal Club November 11, 12.00 to 12.45 CET

Would you like to present on this date? Reach out to us!

[Click here to join the meeting](#)

Save the Date: UCARE LevelUp Journal Club November 23, 12.00 to 12.45 CET

Ozge Sevil Karstarlı Bakay, MD from Pamukkale University Department of Dermatology, Turkey will present:

>> *Karstarli Bakay OS, Demir B, Cicek D, Erol D, Aşçı Toraman Z, Gural Y, Maurer M. In chronic spontaneous urticaria, IgE and C-reactive protein are linked to distinct microRNAs and interleukin-31. Clin Transl Allergy. <<*

2023 Aug;13(8):e12290. doi: 10.1002/ctt2.12290. PMID: 37632245; PMCID: PMC10405150.

[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 at julia.foell@ga2len.berlin or Niklas Mahnke at 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.

06/27



Educational Activities

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

UCARE LevelUp Webinars

Save the Date: 8th UCARE LevelUp webinar on November 15, 4:00 to 5:00 pm CET

Register [here](#)



Topic: Urticaria: the mind and body interactions

Target audience: Every urticaria- treating physician

Description/Aim: This webinar defines the association between mental disorders and psychological conditions. The audience will learn about the common psychological disorders and character traits/sleep disorders accompanying chronic urticaria and the effect of psychological interventions on disease activity.

Speakers/subtopics:

1. Introduction and moderation – Emek Kocatürk Göncü (5 min)
2. Prevalence of psychological comorbidities and how to recognize them in CU patient – Ann Zalewska-Janowska (15 min)
3. Alexithymia and sleep disorders in CSU – Ivan Cherrez (15 min)
4. The effects of psychological treatments and interventions focused on wellbeing on urticaria – Indrashis Podder (15 min)
5. Questions and Answer Session – all faculty (moderator: Emek) (10 min)

Save the Date: 9th UCARE LevelUp webinar on January 23rd, 2024, 4:00 to 5:00 pm CET

Topic: Recalcitrant Urticaria: What to do when guidelines fail?

Target audience: Predominantly specialists

Description/aim: The global guidelines on urticaria are a marvelous document, but there are always exceptions: patients who do not fare well with the proposed therapies, new treatment options not yet covered by the GLs and when resources are a restriction to apply the GLs fully. This webinar addresses these three topics.

Speakers/sub topics:

1. Introduction and moderation – Prof. Dr. Désirée Larenas-Linnemann (5 minutes)
2. Approach to patients who fail conventional (guideline) therapy (focus on the diagnosis) – Prof. Dr. Jorge Sanchez (15 minutes)
3. Treatment option beyond guidelines – Prof. Dr. David Khan (15 minutes)
4. Management of urticaria in resource limited setting – Prof. Dr. Kiran Godse (15 minutes)
5. Questions & Answers moderated by Prof. Dr. Désirée Larenas-Linnemann (10 minutes)

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

07/27



Educational Activities

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

UCARE UCARE4U Webinar

Save the Date: 6th UCARE 4U webinar on October 24, 6:00 to 7:00 pm CET

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



Topic: Patient Organizations: The Bridge between Patient and Physician

Target audience: Patients, caregivers, physicians

Description/Aim: Patient organizations are a vital bridge between the patient and the physician, especially for conditions like urticaria that are often under-diagnosed. In this webinar, participants will learn all about the ins-and outs of patient organizations, hear of the patient (advocate) journey of someone affected, and understand how patient organizations also help physicians in offering the best care to their patients.

Speakers/subtopics:

1. Introduction and moderation – Dr. Aiste Ramanauskaite
Patient organizations: What, How, Why - Tonya Winders (President of Global Allergy & Airways Patient Platform (GAAPP) – USA)
3. Patient Advocacy: An empowering journey – Arzoo Ahmed (Head of Ethics at Our Future Health – UK)
4. How Patient Organizations can help physicians – Dr. Aiste Ramanauskaite (Universitätsmedizin Berlin Institute of Allergology, IFA& Fraunhofer ITMP Immunology and Allergology IA, Berlin – Germany)
5. Questions & Answers moderated by Dr. Aiste Ramanauskaite

08/27



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 67: Angioedema and artificial intelligence

Professor Markus Magerl joins Professor Marcus Maurer in this episode to explore the significance of differential diagnosis in the identification of angioedema in chronic spontaneous urticaria (CSU). Professor Magerl takes a deep dive into the prospective use of artificial intelligence (AI) in the analysis of data derived from a questionnaire utilizing algorithmic models. Both professors, Maurer and Magerl, discuss the implications AI can have in enhancing the diagnostic accuracy of angioedema.

Episode 68: Angioedema and CSU

Dr Régis de Albuquerque Campos joins Professor Marcus Maurer to discuss the implications of angioedema and its impact on people living with chronic spontaneous urticaria (CSU). Dr Campos highlights diverse aspects of the burden of CSU and the impact misdiagnosis has on quality of life. Professor Maurer provides an overview of the current treatment landscape, differential diagnosis, unmet needs in angioedema clinical trials and the utilization of omalizumab in managing angioedema associated with CSU.

Episode 69: The burdens of angioedema

Professor Marcus Maurer is joined by Professor Paula Busse to explore the multifaceted burdens of angioedema for patients and physicians. They discuss issues surrounding timely diagnosis, interpreting ambiguous symptoms, patient concerns about medications, and enhancing quality of life monitoring.

Episode 70: Urticaria management in resource-poor settings

Dr Désirée Larenas-Linnemann and Professor Marcus Maurer delve into best practices for urticaria management in resource-poor settings, underlining the crucial role of accurate diagnosis and adherence to established guidelines. They also address trending topics in angioedema and urticaria treatment, such as antihistamine up-dosing and the complexities surrounding triple-combination therapies and the need for better education.

Episode 71: The patient perspective (UDAY Special)

Professor Marcus Maurer is joined by the president of Global Allergy & Airways Patient Platform (GAAPP), Tonya Winders, for a special Urticaria Day (UDAY) episode to discuss the role patient advocacy groups play in supporting individuals with chronic spontaneous urticaria. Both experts explore patient unmet needs and highlight methods clinicians can use to help overcome these barriers.

09/27

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



Current Scientific Projects

Interview with Emek Kocatürk Göncü on COVAC-CU

The results of the COVAC-CU study are published in The Journal of Allergy and Clinical Immunology!

Here are some insights about the study from the project lead.

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

What drove the idea of this study?

There is a concern in chronic urticaria patients that vaccines might trigger immune responses that could exacerbate their urticaria symptoms or induce new skin reactions. Also, they fear that potential allergens are present in vaccines.

These concerns not only existed in the patients but also in the physicians treating urticaria patients during the massive COVID-19 vaccination period so that we needed to find answers to many questions on the safety of COVID-19 vaccines in chronic urticaria patients. The need to answer these questions as well as the lack of information based on real life experiences prompted us to perform the COVAC-CU study among the UCARE Network. The study aimed to investigate the rates and risk factors for CU exacerbation and the frequency of adverse reactions including allergic reactions in CU patients vaccinated against COVID-19 in a world-wide, large, and diverse patient population.

What was the participation rate from UCAREs? And how is the patient population?

First of all, the high participation rate among UCARE Centers was very pleasing for us: 50% of the UCAREs worldwide participated in the study, which shows a high enthusiasm on answering the study question.

The study included a diverse population of almost three thousand chronic urticaria patients from all over the world who received mainly two doses of different types of COVID-19 vaccines.

The high rate of patients with good control of urticaria (more than 50% reported complete control) highlighted the importance of specialized patient care centers, as becomes clear when we look at previous studies showing that almost 80% were not controlled.



What questions can physicians answer through the results of this study?

Our study is published in a very high impact allergy journal: The Journal of Allergy and Clinical Immunology (JACI) which is read by a wide range of physicians and scientists all over the world. We believe it will provide answers to many questions that urticaria treating physicians faced during the vaccination campaign. Some of these questions and answers are below:

What is the risk of getting disease exacerbation after COVID-19 vaccination in chronic urticaria patients?

9%. But even if the exacerbations occur, they respond to antihistamines in more than 70% of the patients and they lasted for a few weeks or less.

Which chronic urticaria patients are at risk for getting disease exacerbations after vaccination?

Female patients and patients with chronic spontaneous urticaria rather than chronic inducible urticaria are more prone to having disease exacerbations as well as patients with NSAID intolerance and who have concern about getting vaccinated.

Adenovirus viral vector vaccines were associated with higher risk of CU-exacerbation while being on omalizumab treatment and Latino/Hispanic ethnicity lowered the risk.

Can I have further vaccine doses if I had disease exacerbation at the first dose?

There is a 50% possibility that CU patients who had disease exacerbation at the first dose will have exacerbation at the second dose

Though we did not report in the manuscript, the risk of CU-exacerbation seemed to decrease when a switch to another type of vaccine was made in the following dose.

Is good disease control and effective treatment important before vaccination?

In our study we found that the rate of adverse reactions (43.5%) was lower than the reported adverse effect rate in observational studies and also in clinical trials (around 60%), we believe this is linked to the effects of CU treatment received by the patients, either antihistamines, omalizumab or others. Additionally, omalizumab lowered the risk of CU exacerbation after COVID-19 vaccination. Therefore, it is recommended to keep disease under control before vaccination.



What is the mechanism of chronic urticaria exacerbations after COVID-19 vaccination?

Since CU-exacerbations were more common in patients who had constitutional symptoms after vaccination, we proposed that disease exacerbations are not due to a hypersensitivity reaction but possibly associated with nonspecific immune response triggered by the vaccine components.

What is the most important message for the physicians?

Since our study found that having concern about getting vaccinated increased the risk of post vaccine CU exacerbation, it is crucial to discuss with the patients possible adverse effects of the vaccines and ensure them that the risk of disease exacerbation and systemic adverse reactions is low.



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

Our study could give information about the rates of disease exacerbation and factors associated with this while also presenting the rates of other adverse effects including systemic reactions. However, we could not identify the mechanisms underlying disease exacerbations and what is happening in the cellular level.

Also, in our study we focused on the exacerbation of existing CU by COVID-19 vaccination, however there are also cases of new onset urticaria following COVID-19 vaccination and these cases also warrant future studies to be clarified. Recently, the UCARE network has started the UNITACT study, which aims to characterize new onset urticaria after COVID-19 vaccination or infection with SARS-CoV-2.

Current Scientific Projects

Interview with Kanokvalai Kulthanan on [PREVALENCE-D](#)

The PREVALENCE-D study is ending recruitment on **October 31!** Here are some insights about the study from the project lead.

Prof. Dr. Kanokvalai Kulthanan:

- Department of Dermatology,
- Faculty of Medicine Siriraj Hospital,
- Mahidol University, Bangkok, Thailand



What prompted the project?

The prevalence of physiological dermographism, simple urticarial dermographism (SUD), and symptomatic dermographism (SD) remain ill-defined, and previous studies have produced inconsistent results. Importantly, very little is known about differences in the rates of the different types of dermographism between males and females, across countries and genetic backgrounds, or between different age groups.

Why do we need this project?

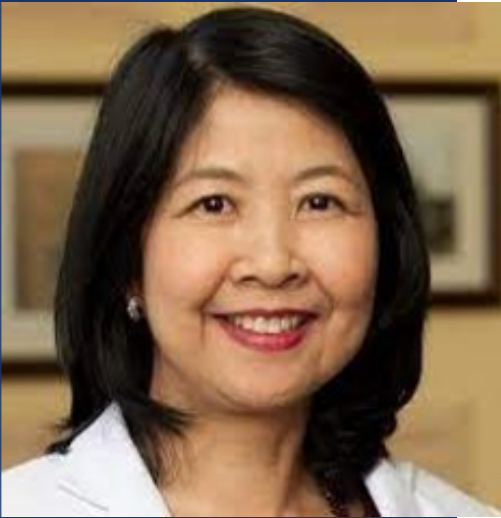
Knowledge of symptomatic dermographism patient numbers can help to allocate healthcare resources, promote the development of treatments, plan and run clinical trials, and serve to detect changes in follow up studies. To address these gaps of knowledge, we perform the present PREVALENCE-D (Prevalence estimation of dermographism).

Which countries are participating?

Thirty-four urticaria centers of reference and excellence (UCAREs) from 27 countries are participating in this study, including Argentina, Australia, Brazil, Bulgaria, China, Ecuador, France, Georgia, Germany, India, Iran, Japan, Kuwait, North Macedonia, Oman, Peru, Poland, Portugal, Russian Federation, Saudi Arabia, South Korea, Spain, Switzerland, Thailand, Turkey, the United Kingdom, and the United States of America.

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

The primary objective of this study was to determine the overall prevalence of SD in participants aged 18 years or older from geographically diverse areas and of different age groups by an internet-based survey. The secondary objectives were to compare i) overall prevalence of SD and SUD among participants, ii) the prevalence of SD and SUD stratified by age groups and countries, and iii) the prevalence of SD and SUD in males and females.



What is the methodology of the project in brief?

This international, cross-sectional internet-based study was conducted as a collaboration of the UCAREs. The PREVALENCE-D questionnaire was developed to assess the prevalence of different types of dermographism, including physiologic dermographism, simple urticarial dermographism, and symptomatic dermographism. Digital versions (google form) were developed and used.

Participating UCAREs were requested to include at least 3,000 individuals, with at least 1,000 individuals each across three age groups: the student age group (18-24 years old), the working age group (25-60 years old), and the elderly age group (>60 years). After recruiting all participants, UCAREs forwarded the data to the principal investigator for statistical analyses.

Are there any findings you can already share?

Based on a preliminary analysis of 3,144 participants from Thailand, the point prevalence of SD is 9.8%. This prevalence varied across age groups: 6.9% among students (18-24 years old), 12.9% among working-age individuals (25-60 years old), and 9.4% among the elderly (>60 years old). Additionally, point prevalence of SUD is 5.7%, with rates of 2.1% in students, 6.7% in the working-age population, and 4.0% in the elderly.

Current Scientific Projects

Article review by Associate Professor Jason Fok

Enjoy this review of the latest CURE publication by Associate .

Professor Jason Fok:

- Allergist/Immunologist
- Box Hill Hospital, Melbourne, Australia.
- Monash Medical Centre, Melbourne, Australia



“Patients with chronic spontaneous urticaria who have wheals, angioedema, or both, differ demographically, clinically, and in response to treatment

– Results from CURE

Thomas Buttgereit, MD , Carolina Vera, MD , Felix Aulenbacher, et al Published online in JACI In Practice in August 2023

I have enjoyed reading this landmark paper which explores the demographic and clinical characteristics, comorbidities, disease burden and treatment response for three chronic spontaneous urticaria (CSU) phenotypes, i.e., wheals, angioedema, or both. The study recruited data from a sizeable cohort of 3,698 CSU patients based on an ongoing, prospective, international, multicentre and observational registry [Chronic Urticaria Registry (CURE)] involving numerous UCARE centres around the world.

There are several key findings from this paper, and I have highlighted a few below.

- 1. CSU patients with wheals and angioedema have longer-lasting wheals than patients with wheals alone, but shorter-lasting swellings than patients with angioedema alone.**
- 2. The tongue is more commonly affected in CSU patients with angioedema only.**
- 3. Concomitant symptomatic dermographism is more common in CSU patients without angioedema.**
- 4. The occurrence of angioedema in CSU is linked to comorbid metabolic disease, e.g., higher rate for hypertension and obesity being observed.**
- 5. Comorbid psychiatric disease, autoimmune disease (especially Hashimoto thyroiditis), and nonsteroidal anti-inflammatory drug hypersensitivity are mostly reported by CSU patients with wheals and angioedema.**
- 6. CSU patients with wheals and angioedema more often have systemic symptoms (e.g., malaise, musculoskeletal pain and recurrent unexplained fever). They also have higher disease activity than CSU patients with wheals alone (based on assessment by various patient reported outcome measures).**
- 7. Antihistamines and omalizumab are most effective in CSU patients with recurrent angioedema without wheals.**

The article also provides important rationales as to why angioedema itself should be regarded a CSU subtype given this being a heterogenous disease, based on key findings presented above. Other important aspects explored in the article include CSU patients with wheals and angioedema have higher rates of features seen in type IIb autoimmune CSU, and whether or not vascular changes may influence the spectrum of presentation of CSU. The latter was based on the observation that there is higher association for hypertension, obesity and more frequent tongue swellings in patients with angioedema compared to those with both wheals and angioedema.

This study paves way for future research that potentially could explore endotypes, phenotypes and biomarkers in CSU in the face of precision medicine.

Current & Upcoming Scientific Projects

1. **CU-SLEEP**
2. **PROMUSE PAT**
3. **CSUplus**
4. CU-Tiger
5. RIFA-CU
6. FAMLICU
7. UNITACT
8. WOW – Wheals of the World (upcoming)

Details

We need YOUR participation!

CU-SLEEP (Recruitment extended until December 31)

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

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

CSUplus (currently recruiting)

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. Please note that ethics approvals from Germany, Brazil, Thailand, Oman and Greece are already available. If you have obtained ethics approval, we kindly ask you to provide it to us.

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

Current & Upcoming Scientific Projects

1. CU-SLEEP
2. PROMUSE PAT
3. CSUplus
4. **CU-Tiger**
5. RIFA-CU
6. FAMLI-CU
7. UNITACT
8. WOW – Wheals of the World (upcoming)

Details

We need YOUR participation!

CU-Tiger (currently recruiting)

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

For more information please contact: yi-kui.xiang@charite.de and pavel.kolkhir@charite.de

RIFA-CU (currently recruiting)

Risk factors and Lifestyle in Chronic Urticaria.

For more information please contact: dremekozgur@gmail.com

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

UNITACT (upcoming)

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

For more information please contact aiste.ramanauskaite@charite.de

WOW – Wheals of the World (upcoming)

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 or sophia.neisinger@charite.de

If you have issues with accessing the UCARE member area, please reach out to Emilia Zimmermann at 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 September 2023, 60 centres from 29 countries worldwide have joined the registry and have entered baseline data on more than 5,000 CU patients. The first analyses of CURE data resulted into three publications and there are at least three more under development.

The first publication shed light on the rationale, methods and initial implementation of the CURE (Weller K, et al. J Eur Acad Dermatol Venereol. 2021 Mar;35(3):721-729). The following study analyzed baseline and follow-up data of 2,078 CSU patients to assess factors associated with complete response to CSU treatment (Kolkhir P, et al. J Allergy Clin Immunol Pract. 2023 Feb;11(2):610-620.e5).

The latest CURE publication assessed CSU patients with wheals, angioedema or both regarding demographics, disease characteristics, comorbidities, disease burden, and treatment response (Buttgereit T, et al. J Allergy Clin Immunol Pract. 2023 Aug 19:S2213-2198(23)00924-8). [Read a review of this last article by Dr. Jason Fok in this newsletter!](#)

Current & Upcoming Scientific Projects



Details

Further CURE-based publications will include comparisons in terms of symptom patterns, risk factors, treatment responses, costs to the health system and deeper analysis of some of the rarer subtypes of CU.

Patient data including the results from the use of PROMs, collected by using CRUSE app, can be sent directly to treating physician and can be included in the CURE using a common identifier (ID). This allows improving current CU management of a specific patient as well as keeping the data for scientific analyses within CURE. We are also working on implementing novel questions in the CURE, e.g. to collect data on patients with urticarial vasculitis.

You are interested in joining the chronic urticaria registry (CURE)? All urticaria-treating physicians and centers are highly welcome to contribute to this important effort. However, before you can start entering data into the registry some steps need to be taken:

- 1. Obtain approval for taking part in the CURE registry from your responsible ethics committee (institutional review board - IRB) and your responsible data protection officer/unit.**
- 2. Date and sign a collaboration agreement with the urticaria network e.V. (UNEV) that is hosting CURE**
- 3. Send copies of both documents to: cureoffice@urtikaria.net.**

Please also check the CURE website to get additional information and download the collaboration agreement template and other documents.

You can find more information and project documents in the UCARE member area or on our website.

Current & Upcoming Scientific Projects



Details

We have broken the **5.000 downloads** mark for CRUSE in September 2023 and are seeing some real momentum in implementation.

We have also launched 4 new countries, just in time for UDAY this year on the 1st of October.

We welcome, **India, the Netherlands, South Africa and South Korea** to the CRUSE community. For Q4 we are aiming for at least 4 more launches including USA and Mexico to make some waves for the North Americans to CRUSE on. The first publication for CRUSE has also been submitted to the Allergy Journal and will probably be published this year. If you are not yet using CRUSE for your patients, now is the perfect time to start!

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

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.

Current & Upcoming Scientific Projects



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We welcome, **India, the Netherlands, South Africa and South Korea** to the CRUSE community. For Q4 we are aiming for at least 4 more launches including USA and Mexico to make some waves for the North Americans to CRUSE on. The first publication for CRUSE has also been submitted to the Allergy Journal and will probably be published this year. If you are not yet using CRUSE for your patients, now is the perfect time to start!

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

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.

Current & Upcoming Scientific Projects

1st OCTOBER 2023



urticaria day

Details

This year's Urticaria Day (UDAY) had the theme **Access to Care**.

Urticaria Day is an opportunity to raise **awareness of Urticaria** across the world, to help improve the lives of patients and to progress understanding amongst professionals, media and the general public.

Thank you to all those who organized events for UDAY 2023, who shared, reposted, counted steps, took photos, or found a unique way to share information and raise awareness about urticaria. Every contribution counts towards making a long-lasting change!

Check out the hashtags #UDAY2023 and #UrticariaDay2023 to see more photos of UDAY events from around the world.

And even though October 1 is past, it does not stop there: Many events are still taking place in the month of October. Check the [UDAY website](#) or our [social media channels](#) for more information.

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urticaria day



The UCARE Team with Dr. Marcus Maurer

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urticaria day



The Charité/IFA Team



UCARE Team Mainz on the first Urticaria Patient Congress with head Petra Staubach-Renz and guest from UCARE Berlin UCARE September 26.



Current & Upcoming Scientific Projects

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urticaria day



A special thank you to

Emek Kocatürk, Kanokvalai Kulthanan, Jason Fok and the CURE office for their contributions.



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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