

Dear UCARE members,

We are happy to send you a short update from our network and a preview of what is to come in the next months. The newsletter will contain info on: New centers, upcoming educational activities, current scientific projects, CRUSE and patient advocacy.

We will continue to send you these short newsletters in regular intervals going forward. Please share them with your network as well, and as always, we look forward to your feedback, ideas and engagement. For more up-to-date UCARE info, please subscribe to our <u>event calendar</u>.

With best wishes,

The UCARE office team

# 1. New Centers June-July:

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

Date of joining	Name of center	Country
06.06.2023	University of Health Sciences Prof. Dr. Cemil Taşçıoğlu City Hospital	Turkey
16.06.2023	UOC Medicina 2, AORN Cardarelli	Italy
11.07.2023	Osaka Medical and Pharmaceutical University	Japan
11.07.2023	University Hospital LMU Munich	Germany
13.07.2023	Clínica Universidad de Navarra	Spain

You can find more information on our UCARE centers here.

### 2. Educational Activities:

### >> Save the Date: UCARE LevelUp Journal Club August 31, 12.00 to 12.45 CET

João Marcelino from Centro Hospitalar de Setúbal will be presenting at the upcoming Journal Club meeting.

If you are a UCARE or ACARE physician and would like to present a paper, please contact Julia Föll at <a href="mailto:julia.foell@ga2len.berlin">julia.foell@ga2len.berlin</a> or Niklas Mahnke at niklas-amadeus.mahnke@charite.de.

Click here for the rotation list, there are still empty slots.

Click here to join the meeting

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.

### >> Save the Date: 7<sup>th</sup> UCARE LevelUp webinar on September 27, 17.00-18.00 CET

**Topic:** Urticaria and Allergy: when to suspect allergy in an urticaria patient?

**Target audience:** Every physician treating urticaria patients

**Description/Aim:** This webinar defines the association of urticaria and allergy. The

audience will learn about the clues in patient history, physical examination and clinical characteristics that may guide clinicians on ruling out as a cause of allergy in acute and chronic urticaria patients.

#### **Speakers/subtopics:**

1. Introduction and moderation – Emek Kocatürk Göncü (5 min)

- 2. When to suspect allergy in acute urticaria patients Désirée Larenas-Linneman (15 min)
- 3. When to suspect allergy in chronic urticaria patients Jonathan Bernstein (15 min)
- 4. Immediate contact reactions, contact urticaria syndrome Ana Gimenéz-Arnau (15 min)
- 5. Questions and Answer Session all faculty (moderator: Emek) (10 min)

>> Save the Date: 8th UCARE LevelUp webinar on November 15, 16.00-17.00 CET

**Topic:** Urticaria: the mind and body interactions **Target audience:** Every physician treating urticaria patients

**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)

>> <u>Invitation: GA<sup>2</sup>LEN UCARE Conference 2023, December 7 to 9, Rebouças Convention</u> Center, São Paulo, Brazil



On behalf of the International Scientific Committee and the National Scientific and Organizing Committee, we would like to invite you once again to the GA<sup>2</sup>LEN UCARE Conference 2023 in São Paulo on December 7 to 9, 2023.

Please find more information regarding the registration, scientific program and the venue on our conference website. Also, please bear in mind that conference is an in-person event.

Additionally, please note that the first day of the conference, December 7th, 2023, is only for UCARE and ACARE members and dedicated to these networks. If you have questions, please reach out to info@ga2len-ucare.com.

Don't miss the chance to be part of this important event and contribute to the improvement of the worldwide treatment of urticaria. We are looking forward to seeing you there!

# >> UCARE LevelUp Podcast 'All Things Urticaria'

The **66.** Episode "Urticaria and the CRUSE app" of the 'All Things Urticaria' podcast series was recently launched.

Listen and subscribe to the podcast on...

<u>Spotify</u> <u>Apple Podcasts</u> <u>Medthority</u>

We look forward to your feedback and topic ideas for future episodes.

# 3. Current Scientific Projects:

**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: <u>karlaroblesvelasco@gmail.com</u>

#### 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: <u>karlaroblesvelasco@gmail.com</u>

## PREVALENCE-D (Recruitment extended until October 31)

To know the prevalence of dermographism in a large and representative sample of general population

For more information please contact: kanokvalai.kul@mahidol.ac.th.

## **CSUplus**

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

For more information please contact: polina.pyatilova@charite.de

#### **CU-Tiger**

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**

Risk factors and Lifestyle in Chronic Urticaria

For more information please contact: <a href="mailto:dremekozgur@gmail.com">dremekozgur@gmail.com</a>

## **FAMLI-CU**

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

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

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

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

Please kindly use this link to complete the

quick questionnaire: https://www.surveymonkey.com/r/PREG-AD

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### **Publications from our UCARE physicians**

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

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

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

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

### 4. CRUSE:

We have just had our 4,000<sup>th</sup> download of CRUSE! CRUSE has already been launched officially in 17 countries and has 2 international version (English and Ukrainian) and we are planning to launch in 8 more countries making big waves in Asia and North America in Q3 of 2023. Our latest launches have made CRUSE available in **Denmark, Latvia, Poland and Ukraine** in their national languages and reflecting the medication that is available there.

Get it here: www.cruse-control.com

To learn more on how to use CRUSE: https://youtu.be/Kpw1QztnEJU

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.

### 5. Patient Advocacy:

### >> Save the Date: UDAY 2023, October 1

We are more than happy to announce the **Urticaria Day (UDAY)** with its theme for this year: **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.

Make a difference on Urticaria Day 2023 by actively participating in or organizing an <u>UDAY event</u>. Whether you host a small or big gathering, start a local support group, or find unique ways to raise awareness about urticaria, every contribution counts towards making a long-lasting change!

Spread the word, get involved and make October 1st a memorable day!

## **Supported by Novartis**



# >> Conversation with Sarah Lepsy and Marcus Maurer on Chronic Urticaria (for patients)

This video conversation on Sarah Lepsy's YouTube Channel "<u>Thrive with hives</u>" is a great resource for patients on how to manage their Chronic Urticaria. Have a look or feel free to share it with your patients: <a href="https://www.youtube.com/watch?v=fbEJSYLT-Bk">https://www.youtube.com/watch?v=fbEJSYLT-Bk</a>