

GA²LEN ACARE and UCARE

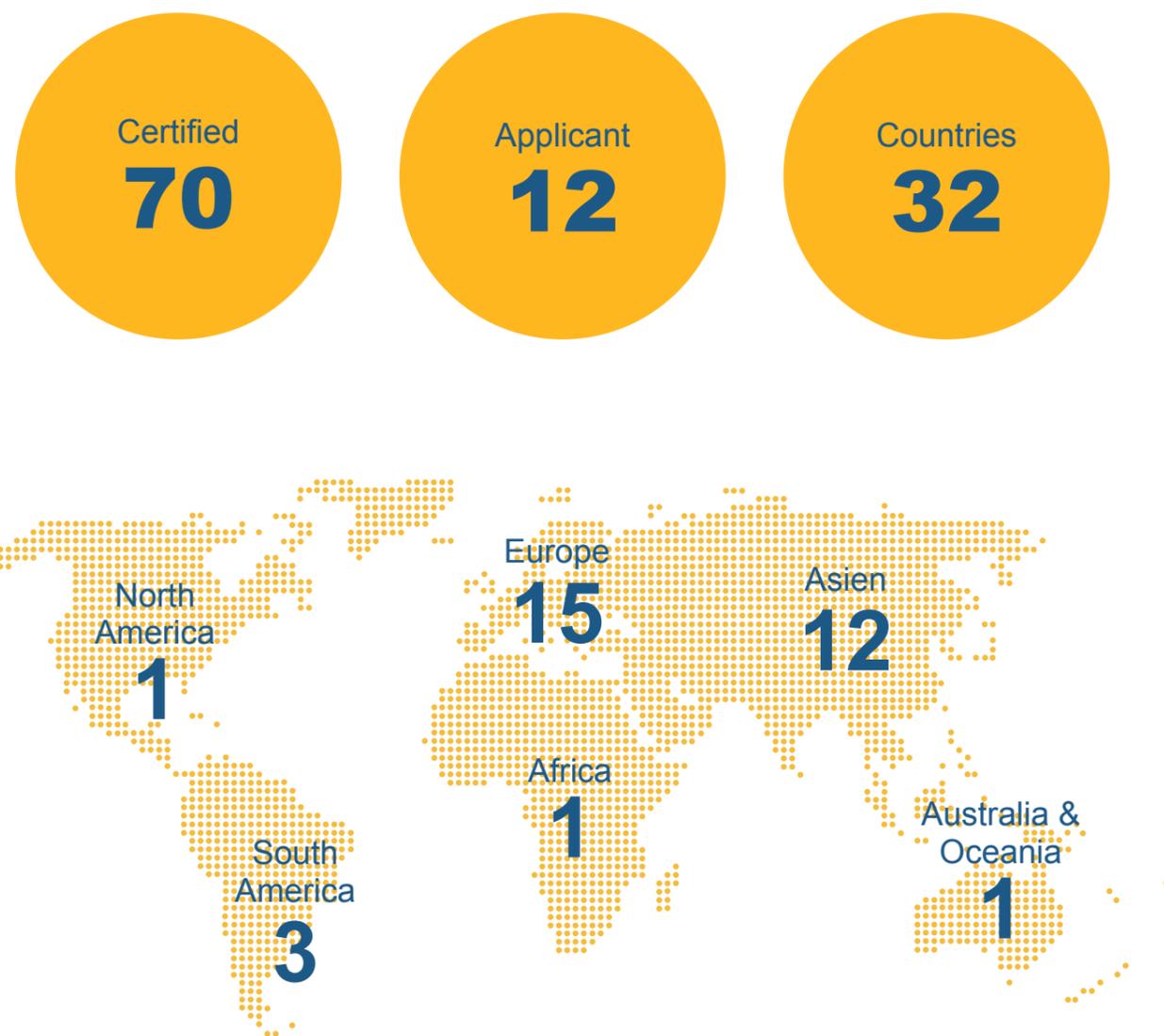
ANNUAL REPORT 2021



Network of Excellence



MEMBER OVERVIEW

ACARE CENTERSStatus as of December 31st 2021In 2021 the following **11 Centers** have joined the ACARE network.

Center	City	Country	Continent	First audit
Department of Dermatology Medical University of Vienna	Vienna	Austria	Europe	02.02.2021
Department of Dermatology University of Erlangen	Erlangen	Germany	Europe	15.03.2021
Department of Asthma and Immunology, Penn State University	Hershey, PA	USA	North America	04.05.2021
Centro Médico Vitae	Buenos Aires	Argentina	South America	05.05.2021
Kepler Universitätsklinikum Universitätsklinik für Dermatologie und Venerologie	Linz	Austria	Europe	26.05.2021
Dermatology Department and the Pediatric Allergy Unit at Koc University Hospital	Istanbul	Turkey	Europe	04.06.2021
Department of Immunology and Allergy and Department of Psychodermatology at the Central Teaching Hospital, Medical University of Lodz	Lodz	Poland	Europe	24.06.2021
Seoul National University Hospital	Seoul	South Korea	Asia	25.08.2021
Alergoskin Alergia e dermatologia	Sao Paulo / Santo André	Brazil	South America	21.10.2021
Department of Otorhinolaryngology, Department of ORL, Head and Neck Surgery, Ulm University Medical Center	Ulm	Germany	Europe	23.11.2021
Box Hill Hospital, Eastern Health	Melbourne	Australia	Australia	15.12.2021

MEMBER OVERVIEW

UCARE CENTERSStatus as of December 31st 2021In 2021 the following **13 UCARE Centers** have joined the network.

Center	City	Country	Continent	First audit
Department of Dermatology, Venereology, and Allergology, Goethe-Universität Frankfurt am Main	Frankfurt	Germany	Europe	14.01.2021
Medical University of Vienna, Department of Dermatology	Vienna	Austria	Europe	02.02.2021
Kepler Universitätsklinikum, Universitätsklinik für Dermatologie und Venerologie	Linz	Austria	Europe	26.05.2021
Department of Dermatology and the Pediatric Allergy Unit at Koç University Hospital	Istanbul	Turkey	Europe	04.06.2021
Urticaria Center at the Clinic of Internal Diseases, Asthma and Allergy, Barlicki Memorial Hospital, Medical University of Lodz	Lodz	Poland	Europe	10.06.2021
Servico de Imunoalergologia, Patologia Cutânea Centro Hospitalar Vila Nova de Gaia/Espinho/EPE	Vila Nova de Gaia	Portugal	Europe	15.06.2021
Cliniques universitaires Saint-Luc, Department of Dermatology	Brussels	Belgium	Europe	24.06.2021
Department of Dermatology, Pediatric Dermatology and Oncology, Medical University of Lodz	Lodz	Poland	Europe	30.06.2021
PERUCARE, Alergia e Inmunología clínica at Clinica Anglo Americana	Lima	Peru	South America	05.07.2021
Department of Allergy and Immunology at Gaffrée and Guinle University Hospital of Federal University of the State of Rio de Janeiro (UNIRIO)	Rio de Janeiro	Brazil	South America	14.07.2021
Sakarya University, Training and Research Hospital, Department of Dermatology	Sakarya	Turkey	Europe	18.08.2021
Department of Dermatology, Re-Medika General Hospital	Skopje	North Macedonia	Europe	30.11.2021
Box Hill Hospital, Eastern Health	Melbourne	Australia	Australia	15.12.2021

ACARE PROGRAMS

Power of Prophylaxis Series of webinars



“Power of Prophylaxis” (POP) was a three-part international live webinar series on the burden of HAE, the goals of treatment, and the role and importance of prophylaxis. The aim of this webinar series was to discuss the impact of HAE on patients and their families, the goals of HAE treatment and guideline recommendations, strategies for assessing and responding to treatment needs, and the tools that can help. In addition, the webinars reviewed the effectiveness and safety of prophylactic treatment options and shared real-life experiences.

Webinar	Topic	Speaker	Date	Participants	Countries
POP 2 <i>CME accredited</i>	Setting goals and achieving them in the management of HAE	Anna Sala-Cunill, Maria Staevska, Marcus Maurer, Markus Magerl	27.01.2021	172	32
POP 3 <i>CME accredited</i>	Current and evolving approaches to complete control in HAE	Margarida Goncalo, Marcus Maurer, Markus Magerl, Sorena Kiani	23.02.2021	116	32

Scientific director:

Marcus Maurer

Guest appearances by HAEi leadership:

Anthony J. Castaldo and Henrik Balle Boysen

Technical agency:

Materia Prima srl

Sponsor:

Takeda – Silver Level

MAKE A DIFFERENCE

Series of webinars



“Make a Difference” (MAD) is a direct continuation of the live webinar series “The Power of Prophylaxis”.

Aim:

This series of five webinars, of which 3 webinars were held in 2021, explored how clinicians can best proceed to provide optimal diagnosis and treatment to all HAE patients as early as possible. The webinars addressed the strategy of earlier and more comprehensive diagnostics that reduce delays in diagnosis, as well as close monitoring of therapy that enables continuous optimisation of therapeutic procedures.

Webinar	Topic	Speaker	Date	Participants	Countries
MAD 1	HAE and the pandemic	Anete S. Grumach, Laurence Bouillet, Marcus Maurer, Markus Magerl	18.05.2021	78	36
MAD 2 <i>CME accredited</i>	Where are the guidelines taking us?	Henrik Boysen, Marcus Maurer, Markus Magerl, Stephen Betschel, Timothy Craig,	27.09.2021	106	25
MAD 3 <i>CME accredited</i>	No attacks, normal life, complete control – the aims of angioedema treatment	Hilary Longhurst, Karsten Weller, Marcus Maurer, Markus Magerl	29.11.2021	108	33

Scientific director: Markus Magerl
Technical agency: Materia Prima srl
Sponsor: Takeda – Gold Level

INTERACT

Series of preceptorships



With the INTERACT Preceptorship series, held in the second, third and fourth quarters of 2021, ACARE reached out to physicians treating patients with recurrent angioedema with a series of region-specific, web-based educational programs. The four-hour INTERACT training courses did not only address the clinical spectrum, burden, differential diagnosis and diagnostic work-up in patients with recurrent angioedema, but also the management of recurrent angioedema, with a particular focus on new evidence and treatment options that have recently become available. Each course included interactive elements, case discussions and lectures, with additional material available online for download and was designed for around 20 participants.

Webinar	Topic	Speaker	Date	Participants	Countries
INTERACT 1	STATE OF THE ART MANAGEMENT OF RECURRENT ANGIOEDEMA AND HANDS ON TRAINING with special focus on the Commonwealth of Independent States	Daria Fomina, Marcus Maurer, Markus Magerl, Thomas Buttgereit,	17.06.2021	17	8
INTERACT 2 <i>CME accredited</i>	STATE OF THE ART MANAGEMENT OF RECURRENT ANGIOEDEMA AND HANDS ON TRAINING with special focus on South America	Anete S. Grumach, Marcus Maurer, Markus Magerl, Thomas Buttgereit	01.09.2021	18	3
INTERACT 3 <i>CME accredited</i>	STATE OF THE ART MANAGEMENT OF RECURRENT ANGIOEDEMA AND HANDS ON TRAINING with special focus on China	Marcus Maurer, Markus Magerl, Thomas Buttgereit, Xue Wang, Yuxiang Zhi, Zuotao Zhao	17.11.2021	33	11

Scientific director: Marcus Maurer
Technical agency: Materia Prima srl
Sponsor: Takeda – Gold Level

UCARE PROGRAMS

In the efforts to educate the world about Urticaria UCARE has decided to make 2021 and 2022 the years of education. With this as the network's goal two educational programs have been launched:

UCARE LEVELUP

UCARE LevelUp

The free physician information and education program is an enduring educational program, creating an interactive, virtual, and comprehensive environment where healthcare professionals worldwide can learn, network, and share best clinical practices in chronic urticaria (CU).

Aim:

The program launched in July 2021 with 8 Digital formats with the following aims:

- Update physicians on recent developments in urticaria,
- Establish a platform for interaction among physicians who treat patients with CU,
- Help health care professionals involved in the management of urticaria to network, on a regional, national, and global level
- Improve the interaction of general practitioners and specialists
- Build strategic therapeutic plans for patients
- Improve the use of patient-reported outcome measures (PROMs)
- Streamline the CU patient journey to disease control.

Project Steering Committee:

Ana Maria Giménez-Arnau, Spain
 Désirée Larenas-Linnemann, Mexico
 Emek Kocatürk, Turkey
 Iman Nasr, Oman
 Luis Felipe Chiaverini Ensina, Brazil



The following section will contain details on the programs' digital formats



LevelUp Webinars:

Deals with different questions and topics, which include but are not limited to guideline recommendations and updates, recent insights from publications, results from UCARE projects, a year in review webinar towards the end of 2021 and 2022, advances in the diagnostics of urticaria, the history of urticaria, advances in our understanding of chronic urticaria (CU) comorbidities, the UCARE and ACARE network interaction, the CU patient burden and how to assess it, biomarkers in CU and mast cell biology.

All webinars are **1-hour programs** with 45 minutes of presentations by one or more UCARE physician with 15 minutes for questions and answers. **Recordings of the webinars are available on the website and youtube.**

Taskforce:

Aisté Ramanauskaitė – Germany, Aleksandra Lesiak – Poland, Ana Maria Giménez-Arnau – Spain, Bahar Sevimli Dikicier – Turkey, Désirée Larenas-Linnemann – Mexico, Iman Nasr – Oman, Joanna Narbutt – Poland, Lea Alice Kiefer – Germany, Maryam Ali Al-Nesf – Qatar, Michael Rudenko – United Kingdom, Ramzy Mohammed Ali – Qata, Rosaly Vieira dos Santos – Brazil, Koremasa Hayama – Japan, Larissa Brandão – Brazil, Kiran Godse – India, Chris Rutkowski – United Kingdom, Jason Fok – Australia, Sahil Sethi – India

EVENT OVERVIEW:

Event	Topic	Date	Registrations	Countries involved	Online Views (as of July 2022)
Webinar 1	Solar Urticaria and its differential diagnoses	22/09/2021	136	22	170
Webinar 2	CU Patient Burden of the Disease	25/11/2021	43	11	185



LevelUp Newsletter:

Features hot topics in urticaria, news from the network, serves to inform physicians about upcoming UCARE LevelUp activities, provide advice on urticaria management, review the results of studies and projects published and inform physicians about clinical trial opportunities at UCAREs and beyond.

Taskforce:

Bahar Sevimli Dikicier – Turkey, Emek Kocatürk – Turkey, Fragkiski Tsatsou – Greece, Iman Nasr – Oman, Iris Medina – Argentina, Joanna Narbutt – Poland, Michael Rudenko – United Kingdom, Natasa Teovska Mitrevska – North of Macedonia, Roberta Fachini Jardim Criado – Brazil, Rosaly Vieira dos Santos – Brazil, Sérgio Dortas Junior – Brazil, Solange Valle – Brazil, Oscar Calderon – Perú, Jason Fok – Australia, Sahil Sethi – India

PUBLICATION OVERVIEW:

Newsletter 1:

Release Date:

14 October 2021

Main Topics:

- COVID-19 Vaccination in Chronic Spontaneous Urticaria
- Treatment advice: H1 antihistamines
- Project CURICT
- SoIU-CE and COVAC-CU
- The new urticaria guidelines

Newsletter 2:

Release Date:

7 December 2021

Main Topics:

- EAACI Guideline for the Definition, Classification, Diagnosis and Management of Urticaria
- Machine Learning based algorithms may be used to identify chronic urticaria (CU) subtypes
- How to Manage Omalizumab treatment in CSU patients
- Project COLD-CE
- UCARE conference 2021

UCARE LEVELUP



LevelUp Podcast:

The UCARE LevelUp podcast series, “All things urticaria”, aims to address important questions on urticaria and its management. In 2021, we produced and aired 23 episodes, which are available for download from various podcast providers including Spotify and Apple Podcasts.

The podcast is hosted by Marcus Maurer and features UCARE urticariologists from all over the world.

Taskforce:

Aleksandra Lesiak - Poland, Fragkiski Tsatsou – Greece, Jason Fok – Australia, Joanna Narbutt - Poland, Larissa Brandão – Brazil, Luis Felipe Chiaverini Ensina, Brazil, Marcus Maurer – Germany, Michael Rudenko – United Kingdom, Natasa Teovska Mitrevska – North of Macedonia, Rosaly Vieira dos Santos – Brazil, Chris Rutkowski – United Kingdom

EVENT OVERVIEW:

Episode 9 - Chronic Urticaria in Pregnancy and COVID-CU	05.01.2021
Episode 10 - All Things Angioedema	19.01.2021
Episode 11 - When doctor becomes patient	02.02.2021
Episode 12 - Mastocytosis, MCAS and Beyond the Skin in CSU	16.02.2021
Episode 13 - Symptomatic Dermographism	02.03.2021
Episode 14 - COLD-CE: Insights from a UCARE Project	16.03.2021
Episode 15 - All Things UCARE	12.05.2021
Episode 16 - Exploring the CSU spectrum: pure angioedema	25.05.2021
Episode 17 - Acute urticaria: not so cute after all?	08.06.2021
Episode 18 - The Patient Voice	22.06.2021
Episode 19 - Unanswered Questions in CSU	06.07.2021
Episode 20 - Not Just Small Adults: Managing Paediatric CSU	20.07.2021
Episode 21 - Let's talk comorbidities	03.08.2021
Episode 22 - What's new in CU?	17.08.2021
Episode 23 - The Truth About T Cells	01.09.2021
Episode 24 - Communication technology meets urticariology	14.09.2021
Episode 25 - Improving sleep quality in urticaria: more than just a dream?	28.09.2021
Episode 26 - All Things ACARE	12.10.2021
Episode 27 - Gender differences in chronic urticaria	26.10.2021
Episode 28 - The pathogenesis of CSU: when will we have a cure?	09.11.2021
Episode 29 - Paediatric Urticaria: Challenges and Solutions	23.11.2021
Episode 30 - Shining a Light on Solar Urticaria	07.12.2021
Episode 31 - The Role of PAF and Urticaria in Adults	21.12.2021

UCARE LEVELUP



LevelUp Fireside Chats:

Fireside chats is an interactive online format, 45 minutes, with 4 UCARE physicians, on predefined topics. The setting is a discussion between these 4 colleagues, no slides and free flowing conversation on CU along different topics, e.g. chronic inducible urticaria, the use of patient reported outcome measure, the optimization of response to treatment with omalizumab, the recruitment and retention of patients in clinical trials. Participants can ask questions and the fireside chatters will bring them on board in their discussion. Fireside chats will be held four times per year and recordings of the fireside chats will be posted after the event, which is live, on the UCARE platform.

Taskforce:

Aleksandra Lesiak – Poland, Fragkiski Tsatsou – Greece, Jason Fok – Australia, Joanna Narbutt – Poland, Larissa Brandão – Brazil, Luis Felipe Chiaverini Ensina – Brazil, Marcus Maurer – Germany, Michael Rudenko – United Kingdom, Natasa Teovska Mitrevska – North of Macedonia, Rosaly Vieira dos Santos – Brazil, Chris Rutkowski – United Kingdom

EVENT OVERVIEW:

Event	Topic	Date	Registrations	Countries involved	Online Views (as of July 2022)
Fireside Chat 1	The next generation: What do junior urticariologists expect from the UCARE network, what do seniors expect from juniors?	01/12/2021	62	18	129

UCARE LEVELUP



LevelUp Educational Videos:

The UCARE network is producing 7 videos, 15 min each, to be launched (e.g. YouTube, UCARE website) every other month starting in 2022, on how to confirm chronic urticaria (CU) and exclude differential diagnoses, the search for relevant conditions that modify disease activity, as well as the causes, comorbidities, consequences, components, and course of CU (“the seven Cs of the diagnostic workup of CU).

Taskforce:

Aleksandra Lesiak – Poland, Andac Salman – Turkey, Bahar Sevimli Dikicier – Turkey, Emek Kocatürk – Turkey, Fragkiski Tsatsou – Greece, Iman Nasr – Oman, Joanna Narbutt – Poland, Jörg Scheffel – Germany, José Ignacio Larco – Peru, Maryam Ali Al-Nesf – Qatar, Michael Rudenko – United Kingdom, Natasa Teovska Mitrevska – North of Macedonia, Rosaly Vieira dos Santos – Brazil, Salma Taha – Qatar

UCARE LEVELUP



LevelUp Journal Club:

The Ucare LevelUp journal club is an online format of 30 minutes where junior UCARE physicians will present recent publications on chronic urticaria for subsequent discussion with participants. The journal club is held every 2 weeks with rotating presentations and rotating moderators.

Taskforce:

Aleksandra Lesiak – Poland, Fragkiski Tsatsou – Greece, Jason Fok – Australia, Joanna Narbutt – Poland, Larissa Brandão – Brazil, Luis Felipe Chiaverini Ensina – Brazil, Marcus Maurer – Germany, Michael Rudenko – United Kingdom, Natasa Teovska Mitrevska – North of Macedonia, Rosaly Vieira dos Santos – Brazil, Chris Rutkowski – United Kingdom

Event Number	Topic	Date
Journal Club 1		26/08/2021
Journal Club 2		09/09/2021
Journal Club 3		23/09/2021
Journal Club 4		07/10/2021
Journal Club 5		21/10/2021
Journal Club 6		11/11/2021
Journal Club 7		25/11/2021
Journal Club 8		09/12/2021

UCARE LEVELUP



LevelUp Grand Rounds:

With the grand rounds format the UCARE LevelUp program will provide an online live opportunity for physicians to share their cases and to receive feedback from two senior urticariologists. Grand rounds will be 1 hour with up to 4 cases presented by participants followed by expert feedback and discussion. This online format will allow participating physicians to ask questions and to get answers on difficult to treat patients. It also allows for the presentation of didactic cases, patients treated by physicians who are suited to teach other physicians important insights on CU management. Recordings of the grand rounds will be made available on the UCARE website.

Taskforce:

Aleksandra Lesiak – Poland, Désirée Larenas-Linnemann – Mexico, Fragkiski Tsatsou – Greece, Joanna Narbutt – Poland, Luis Felipe Chiaverini Ensina – Brazil, Maryam Ali Al-Nesf – Qatar, Michael Rudenko – United Kingdom, Natasa Teovska Mitrevska – North of Macedonia, Rosaly Vieira dos Santos – Brazil, Tayseer Ibrahim – Qatar



LevelUp Poster sessions:

Poster sessions are 1-hour online formats where early stage urticaria researchers present the results of their projects for feedback by two senior urticariologists and discussion with participants.

Taskforce:

Aleksandra Lesiak – Poland, Désirée Larenas-Linnemann – Mexico, Fragkiski Tsatsou – Greece, Joanna Narbutt – Poland, Luis Felipe Chiaverini Ensina – Brazil, Maryam Ali Al-Nesf – Qatar, Michael Rudenko - United Kingdom, Natasa Teovska Mitrevska – North of Macedonia, Rosaly Vieira dos Santos – Brazil, Tayseer Ibrahim – Qatar



UCARE 4U

The patient information and education program brings extensive information directly to patients affected by urticaria. It aims to update patients on recent developments in urticaria and help them understand causes, triggers, comorbidities, and treatment of Chronic Urticaria (CU) and it wants to unite patient and physician efforts to improve the treatment of CU and to uphold interaction and cooperation.

Aim:

The program launched in July 2021 with 4 Digital formats with the following aims:

- Bringing extensive information directly to patients affected by urticaria
- Update patients on recent developments in urticaria.
- Help patients understand causes of Chronic Urticaria (CU).
- Improve patients' understanding of triggers.
- Educate patients on the effects of simultaneous presence of comorbidities with CU.
- Uphold interaction between patients and physicians.
- Unite patient and physician efforts to improve the treatment of CU
- Expand the knowledge of treatment options for patients with CU.

Project Steering Committee:

Alicja Kasperska-Zajac, Poland
 Kanokvalai Kulthanan, Thailand
 Luis Felipe Chiaverini Ensina, Brazil
 Maryam Ali Al-Nesf, Qatar
 Mojca Bizjak, Slovenia

Following, the programs will be broken down to its components with details about each digital format it consists out of.



4U Website:

The UCARE 4U website is specifically developed by world leading experts in the urticaria to be first point of reference for patients that suffer from urticaria. It features a page where patients from around the world can find patient organisations that are focussed on urticaria.

The website features detailed information to learn about:

- Definitions
- Diagnosis
- Triggers and types of urticaria
- Treatment advice
- Tools for urticaria sufferers

It features a page where patients from around the world can find patient organisations that are focussed on urticaria.

The website will also feature all the UCARE 4U activities and resources including on demand content.

Taskforce:

Aleksandra Lesiak – Poland, Fragkiski Tsatsou – Greece, Iman Nasr – Oman, Joanna Narbutt – Poland, Maryam Ali Al-Nesf – Qatar, Michael Rudenko – United Kingdom, Rabia Oztas Kara – Turkey, Ramzy Mohammed Ali – Qatar, Rosaly Vieira dos Santos – Brazil, Sérgio Dortas Junior – Brazil, Solange Valle – Brazil, Koremasa Hayama – Japan, Oscar Calderon – Perú



4U Webinar:

The UCARE network offers participation in regular patient education webinars, initially held every 6-8 weeks starting in 2022. These 1-hour webinars will deal with different questions from patients. Patients will be able to ask questions and will get answers. Each webinar will address one specific aspect or question, and patients can suggest what aspects should be covered and what questions should be addressed. Recordings of the webinars will be made available on the UCARE website. The UCARE patient webinars bring on board suggestions for topics and areas of interest based on patient feedback. The webinars are free of charge for patients to participate.

Taskforce:

Aleksandra Lesiak – Poland, Aisté Ramanauskaitė – Germany, Chris Rutkowski – United Kingdom, Michael Rudenko – United Kingdom, Rosaly Vieira dos Santos – Brazil, Kiran Godse – India, Iman Nasr – Oman, Sahil Sethi – India, Fragkiski Tsatsou – Greece, Jason Fok – Australia, José Ignacio Larco – Peru, Maryam Ali Al-Nesf – Qatar , Désirée Larenas-Linnemann – Mexico, Natasa Teovska Mitrevska – North of Macedonia, Rabia Oztas Kara – Turkey, Ramzy Mohammed Ali – Qatar



4U Social Media:

The UCARE network has taken this opportunity to get create an online presence with creating social media channels as to engage patients and physicians. The social media channels also allows invitations and posts to be share farther and wider by allowing reposting from 3rd parties.

Taskforce:

Aleksandra Lesiak – Poland, Alicja Kasperska-Zajac – Poland, Andac Salman – Turkey, Bahar Sevimli Dikicier – Turkey, Carla Ritchie – Argentina, Fragkiski Tsatsou – Greece, Joanna Narbutt – Poland, Luis Felipe Chiaverini Ensina, Brazil, Michael Rudenko – United Kingdom, Natasa Teovska Mitrevska – North of Macedonia, Rabia Oztas Kara – Turkey, Roberta Fachini Jardim Criado – Brazil, Rosaly Vieira dos Santos – Brazil, Sarah Hahn / Alexandra Bredigkeit – Germany, Sérgio Dortas Junior – Brazil, Solange Valle – Brazil, Koremasa Hayama – Japan, Larissa Brandão – Brazil, Oscar Calderon – Perú

Channels	Link	Launch	Hits 2021
4U Twitter	https://twitter.com/UCARE_4U	Nov 2021	25059
LevelUp Twitter	https://twitter.com/UCARE_LevelUp	Nov 2021	14079
YouTube	https://www.youtube.com/channel/UCVny6D9xPqrDMiSTkLfMc3Q/featured	Dec 2021	2229
LinkedIn	https://www.linkedin.com/company/ga%C2%B2len	Dec 2021	212
Reddit	https://www.reddit.com/user/UCARE_4U	planned for 2022	
TikTok	https://www.tiktok.com/@ucare_4u	planned for 2022	
Instagram	https://www.instagram.com/ga2len_acare_ucare/	planned for 2022	



Urticaria Day:

Urticaria day (UDAY) remains a day where urticaria patients are the focus of attention. Since 2014, UDAY is the opportunity to raise awareness of urticaria among patients, their families, doctors, politicians, the press and the rest of the world. With incorporating UDAY into 4U it gives the opportunity for a structured plan to be built by some of the world's leading physicians.

Taskforce:

Aleksandra Lesiak – Poland, Andac Salman – Turkey, Anna Zalewska-Janowska – Poland, Carla Ritchie – Argentina, Désirée Larenas-Linnemann – Mexico, Fragkiski Tsatsou – Greece, Iman Nasr – Oman, Joanna Narbutt – Poland, José Ignacio Larco – Peru, Kanokvalai Kulthanan – Thailand, Lea Alice Kiefer – Germany, Maryam Ali Al-Nesf – Qatar, Michael Rudenko – United Kingdom, Natasa Teovska Mitrevska – North of Macedonia, Rabia Oztas Kara – Turkey, Rosaly Vieira dos Santos – Brazil, Sérgio Dortas Junior – Brazil, Solange Valle – Brazil, Koremasa Hayama – Japan, Kiran Godse – India, Chris Rutkowski – United Kingdom, Jason Fok – Australia, Sahil Sethi – India, Chuda Rujitharanawong – Thailand

TASKFORCE CREATED VIDEOS:

Uday Video	Topic	Release Date	Online Views (as of July 2022)
Uday video 1	Urticaria medication during COVID 19 pandemics	October 2021	243
Uday video 2	Stress, anxiety and urticaria flares during COVID 19 pandemics	October 2021	509
Uday video 3	Omalizumab for urticaria during COVID 19 pandemics	October 2021	352
Uday video 4	COVID 19 vaccines in urticaria patients	October 2021	1400



UDAY EVENT OVERVIEW:

Organizer	Country	Event
Kepler University Hospital	Austria	Celebrating our acceptance as UCARE Center and our first participation at the urticaria day.
rubra	Brazil	Expert Roundtables
Federal University of Paraná	Brazil	Informieren Sie sich über die Neuerungen bei der Aktualisierung der Internationalen EAACI/GA2LEN/EuroGuiDerm/APAAACI-Leitlinie für die Definition, Klassifizierung, Diagnose und Behandlung von Urtikaria-2021
Joao Pessoa/PB Brasil Hospital Universitário Lauro Wanderley (HULW)	Brazil	UDay - Webinário Urticária Crônica Espontânea "Quem se importa? Você se importa: an event will be held in order to raise awareness among the population, train health professionals and students, highlighting its main aspects: diagnosis, treatment and prejudice .
Rosaly Vieira dos Santos	Brazil	chat online to general population by instagram
Sandra Mitie Ueda Palma	Brazil	UDAY celebration
Hospital Universitário Clementino Fraga Filho Universitário Clementino Fraga Filho	Brazil	Dia Mundial da Urticária no Serviço de Imunologia HUCFF-UFRJ
ASBAIRJ YouTube Channel	Brazil	"LIVE" Urticária ASBAIRJ on YouTube
Elaine Dery	Canada	Video lectures by Canadian physicians on several topics related to chronic urticaria. The lectures are in English with French subtitles or in French with English subtitles.
Maia Gotua	Georgia	early meeting with colleagues, to discuss progress in the treatment of urticaria and future perspectives. We will have an educational webinar for patients and medical students to broaden their knowledge about urticaria. Furthermore, social media events throughout the whole week are planned to raise awareness of the disease.
DAAB	Germany	Online Urticaria Week for patients
Sherezade Monino-Romero	Germany	Stream about Urticaria (in Spanish) on Twitch
Mainz Clinical Research Center	Germany	UDAY celebration with patients
UMG - Klinik für Dermatologie, Venerologie und Allergologie	Germany	Dermatologists and Patientgroups inform on the disease and encourage patients to seek treatment.
UDAY 4U Taskforce	Global	Videos on the topic of urticaria and COVID 19 & live Q&A on UDAY
D Y Patil Hospital	India	Celebration of World Urticaria Day at Dr. D Y Patil Hospital with Dr. Kiran Godse

Pgimer	India	Cme program was conducted touching all important aspects of urticaria. Dr hillary loghurst gave a comprehensive talk on hae
Mashhad university	Iran	Webinar held by the members of the allergy research center of mashhad university (ucare center) about updates on pathogenesis, classifications, diagnosis, approach and treatment of urticaria.
Perucare	Peru	"Dia internacional de la urticaria. Charla a pacientes por perucare": members of perucare will help you understand your urticaria unase a nosotros en el zoom: tema: dia internacional de la urticaria: charla a pacientes por perucare
Katedra i klinika dermatologii, wenerologii i dermatologii dziecięcej spsk1 w lublinie	Poland	Open consultation day where you will be able to register for a consultation appointment with a specialist dermatologist and allergologist
University of lodz	Poland	Understanding urticaria: webinar with lectures on urticaria & live q&a session
Hamad general hospitalamad general hospital	Qatar	Awareness campaign about urticaria in particular and allergy in general directed toward all the community of qatar. Will provide education from 27th to 30th sep and from 3rd-7th oct during working hours (7 am-3 pm).
Rcci republic clinical hospital	Russia	Round table meeting
Siriraj hospital, mahidol university	Thailand	Online virtual meeting of "world urticaria day 2021" during the covid-19 pandemic. Many people were interested in the event including patients, their family members, and physicians. Essential knowledge about urticaria and how the covid-19 pandemic affects this disease were discussed which participants had engaged in the meeting by sharing their doubts and concerns. In the end everyone was satisfied. This opportunity has raised awareness of urticaria among patients.
Kirsehir medical school	Turkey	Meeting with students
Sakarya university training and research hospital	Turkey	Urticaria patients meeting: the relationship and interaction between urticaria and today's covid-19 pandemia
Sakarya university training and research hospital	Turkey	Live stream on instagram: came together with our urticaria patients and went live on the @seahdermatology instagram page to raise awareness of urticaria on october 1, urticaria day, and told our patients about the effects of the covid-19 pandemic on the treatment and course of urticaria disease.
The istanbul faculty of medicine	Turkey	The istanbul faculty of medicine celebrated uday on october 1st, 2021. Staff wore t-shirts as well as rozzettes to celebrate the day and distributed rozzettes on which "never give up" is written to patients.
Emek kocatürk	Turkey	Youtube video: how urticaria patients feel and live: urticaria is a serious disease; it should not be perceived as a simple itch! Watch the youtube video!



Chronic Urticaria Self Evaluation App

More than 80 million people worldwide are affected by chronic spontaneous urticaria (CSU) - and the number is rising! This disease brings with it a high level of suffering and a considerable loss of quality of life for patients. Those affected develop itchy wheals, swelling of the skin (so-called angioedema) or both. Only one in ten patients has the disease adequately under control. One of the reasons for this is that the response to treatment is not recorded properly. Renowned dermatologists and allergists have developed the CRUSE app to change this. CRUSE stands for Chronic Urticaria Self Evaluation, and the app can help patients with chronic spontaneous urticaria to gain better control over the disease and, as a result, significantly reduce the level of suffering.

Urticaria can be controlled and treated

The goal of treatment for patients with chronic spontaneous urticaria is complete control until spontaneous remission ("treating the disease until it goes away on its own"). This is possible in most cases with the treatment options available today. However, in many patients, the therapy has to be adjusted several times in order to reach the treatment goal. For this, however, continuous monitoring and documentation of disease activity and control is important.

Digital progress against urticaria

With the CRUSE app, patients now have a tool at their sides that is uncomplicated to use, with which the disease activity and control can be optimally recorded and thus the next doctor's appointment can be optimally prepared. For example, the app offers the possibility to upload photos of skin changes in advance. The doctor treating the patient can then have the app report sent to him/her by email and can see at a glance how well the urticaria is under control. CRUSE Control will be available in Germany from March 2022 and can be downloaded free of charge from the app stores. This is an important step in the fight against chronic spontaneous urticaria and a great relief for patients. By July 2022 it will be available in Austria, Italy, Switzerland, and the United Kingdom.

Developed by a network of experts

The app was developed by UCARE (Urticaria Center of Reference and Excellence) in cooperation with the team of the Institute for Allergy Research of the Berlin Charité under the leadership of Prof. Dr. Marcus Maurer (Professor of Dermatology and Allergology), Sophia Neisinger (Assistant Doctor of Dermatology and Allergology), Anja Lingnau (PROM Coordinator Charité) and Reinhardt Britz (GA²LEN UCARE and ACARE Programme Manager).



ACARE supports HAE TrackR App

In 2021 HAEi has launched HAE TrackR app that enables physicians to improve the collaboration with their patients to better control their HAE. Developed by fellow HAE patients at HAE International (HAEi), HAE TrackR is an easy-to-use electronic diary designed to record patient's HAE attacks, treatments and the impact HAE has on their life and the life of their loved ones. In its first version HAE TrackR was available in the following languages: English, Polish, Norwegian, Swedish, Danish, Portuguese, Spanish, German and French. HAE TrackR is available as a Progressive Web Application (PWA), allowing to access a secure and GDPR compliant electronic diary from any device with a standard internet browser.



ACARE recommend all angioedema treating physicians to advise their patients to use this tool.

More information here: <https://haetrackr.org/>

Download the app here: <https://haei.org/hae-trackr-is-now-live-2/>

SCIENTIFIC PROJECTS

(Status December 2021)

IMAGINE 1.0

Identification of mutations in genes of patients with idiopathic and hereditary angioedema



Type:

Explorative international, multi-center study with questionnaire (physician and patient)

Aim:

Identify genetic mutations and biomarkers in clinically well characterized patients with recurrent idiopathic angioedema in order to gain more insights into the pathomechanisms and genetic drivers of rare forms of angioedema.

Project Lead:

Thomas Buttgereit, Charité Berlin / Institute of Allergology IFA, Berlin, Germany
 Markus Magerl, Charité Berlin / Institute of Allergology IFA, Berlin, Germany
 Marcus Maurer, Charité Berlin / Institute of Allergology IFA, Berlin, Germany

Project Steering Committee:

Anete S Grumach, Faculty of Medicine ABC, São Paulo, Brazil
 Asli Gelincik, Istanbul University/Istanbul Faculty of Medicine, Istanbul, Turkey
 Kiran Godse, Dr D Y Patil Medical College and Hospital, Navi Mumbai, India
 Marc Riedl, University of California, San Diego, USA
 Margarida Gonçalo, University of Coimbra, Faculty of Medicine and University Hospital, Coimbra, Portugal
 Yuxiang Zhi, Peking Union Medical College Hospital & Chinese Academy of Medical Sciences, Beijing, China

Status:

Global Rollout October 2021 until September 2023

Number of participating centers:

5

Number of patients included:

40

Sponsor:

Centogene – Silver Level

DANCE

A global consensus on the definition, acronyms, nomenclature, and classification of angioedema GA²LEN ACARE/EAACI/APAACI/AAAAI/ACAAI/HAEi/HAEA project



Type:

Delphi study with Expert panel

Aim:

Currently, several classifications and several different names, acronyms / abbreviations for the same angioedema type are being used. This makes it difficult to compare the results of studies, to develop multicenter studies, and to harmonize the care for patients with angioedema. Thus this project aims to establish a global consensus on the definition, acronyms, nomenclature, and classification of angioedema (DANCE).

Project Lead:

Avner Reshef, Barzilai Angioedema Center, Ashkelon, Israel
Markus Magerl, Charité Berlin / Institute of Allergology IFA, Berlin, Germany
Marcus Maurer, Charité Berlin / Institute of Allergology IFA, Berlin, Germany

Project Steering Committee:

Anete S Grumach, Faculty of Medicine ABC, São Paulo, Brazil
Ankur Jinda, Post Graduate Institute of Medical Education and research, Chandigarh, India
Henriette Farkas, Semmelweis University, Budapest, Hungary
Hilary Longhurst, Auckland DHB Clinical Immunology and Allergy, Auckland, New Zealand
Jonny Peter, Groote Schuur Hospital | University of Cape Town Lung Institute, Groote Schuur/Mowbray, South Africa
Michihiro Hide, Hiroshima Citizens Hospital, Hiroshima, Japan
Marc Riedl, University of California, San Diego, USA
Stephen Betschel, University of Toronto/ St. Michael's Hospital, Toronto, Canada
Teresa Caballero, Hospital Universitario La Paz, Madrid, Spain
Yuxiang Zhi, Peking Union Medical College Hospital & Chinese Academy of Medical Sciences, Beijing, China

Status: Creation of tools & documents, recruitment of expert panel
Number of participating physicians: 94 (expert panel)
Sponsor: HAEi/HAEA – Gold Level

SHAERPA

Stopping androgen treatment in patients with HAE - characterization of reasons and protocols and development of advice for patients and physicians



Type:

international, multi-center, prospective and partly retrospective, observational, cross-sectional academic study with questionnaire (physician and patient)

Aim:

Determine why, how, and with what consequences androgen treatment is stopped in patients with hereditary angioedema (HAE).

Project Lead:

Carolina Vera, Charité Berlin / Institute of Allergology IFA, Berlin, Germany
Markus Magerl, Charité Berlin / Institute of Allergology IFA, Berlin, Germany
Marcus Maurer, Charité Berlin / Institute of Allergology IFA, Berlin, Germany

Project Steering Committee:

David Launay, University of Lille, CREAK / CHU Lille, Lille, France
Emel Aygören-Pürsün, University Hospital Frankfurt, Clinic for Paediatrics and Adolescent Medicine, Angioedema Outpatient Clinic, Frankfurt, Germany
Henriette Farkas, Semmelweis University, Budapest, Hungary
Isabelle Boccon-Gibod, CREAK / Grenoble, France
Sorena Kiani, Barts Health NHS Trust, London, UK

Status: pilot phase
Number of participating centers: 5
Number of participants included: 59
Sponsor: Takeda – Gold Level; Biocryst – Silver Level

PROMUSE

Knowledge, perceptions and limitations of the use Patient Reported Outcomes Measures (PROMs) by physicians in allergic diseases.

**Type:**

International, multicenter, observational (non-interventional), Online survey for physicians

Aim:

Identify clinicians' perspectives regarding the use of PROMs in clinical contexts and describe the knowledge, perceptions and limitations of the use Patient Reported Outcomes Measures (PROMs) by physicians in allergic diseases in order to increase engagement and uptake of these tools in clinical practice.

Project Lead:

Ivan Cherrez Ojeda, Respiralab Research Center, Guayaquil, Ecuador
 Karla Robles Velasco, Universidad de Especialidades Espíritu Santo, Guayaquil, Ecuador

Project Steering Committee:

Marcus Maurer, Torsten Zuberbier, Jean Bousquet

Status:

Global rollout, collection of information: 3 months from December 1st 2021 to March 1st 2022



SCIENTIFIC PROJECTS

OVERVIEW

Projekt	Aim	Status	
DruSo-CU	Determinants of omalizumab drug survival in a long-term daily practice multicentre cohort of patients with Chronic Urticaria	Data evaluation	Ongoing
COVAC-CU	To analyze the rates of vaccine associated reactions such as exacerbation of urticaria, angioedema attacks, local reactions, any other systemic reactions and to analyze risk factors associated with vaccine reactions	Presentation of Prel. Results in Hiroshima (6) (UCARE conference) Dec.2021	Ongoing
ChoIU-CE	Cholinergic urticaria - Natural history, disease features and course and response to treatment	Creation of tools and documents (4)	In preparation
CSU Plus	Chronic spontaneous urticaria plus additional extracutaneous symptoms	Applying for ethics approval	In preparation
CU-Sleep	Sleep disorders in patients with chronic urticaria	Creation of tools and documents	In preparation
UCOMB	collect patients worldwide who receive a combined systemic treatment/management for chronic urticaria.	Creation of tools and documents	In preparation
URCHILD	gather and collect data on children undergoing systemic treatment for chronic urticaria worldwide and to shed light on this underestimated patient group	Creation of tools and documents	In preparation
FAMLI-CU	Aim: of this project is to gather and collect data on the quality index of families with chronic urticaria patients	Creation of steering committee	In preparation
SoluCE	Increase Worldwide understanding of solar urticaria and its clinical spectrum, Determination and optimization of evaluation strategies of SolU-patient, genotype-phenotype correlation	Creation of tools and documents	In preparation

Projekt	Aim	Status	
SDOWN CSU	Investigate stepping down approaches of different steps of chronic spontaneous urticaria treatment from global perspective.	Creation of tools and documents	In preparation
Prevalence-D	Prevalence of Dermographism in General Population	Pilot study	Ongoing
Daef-CINDUS	Effects of Preprandial, Postprandial and post-exercise periods on the threshold values of CIndUs	In preparation	In preparation
CU-Style	To define lifestyle factors (sports, diet, caffeine, smoking, alcohol) and risk factors (systemic diseases, medications, BMI, occupation, marital status, family history, sleep problems, psychological problems, allergy, stress) associated with chronic urticaria (CU).	Creation of steering committee	In preparation
PROMUSE	Knowledge, perceptions and limitations of the use Patient Reported Outcomes Measures (PROMs) by physicians in allergic diseases.	Global rollout	Ongoing
UNITACT	Urticaria following infection or vaccination – Assessment of course & treatment responses	Formation of Steering Committee	In preparation
UVERSICU	Assessing differences in the natural history, clinical symptoms, triggers, associated diseases, and treatment effects in patients with urticarial vasculitis compared to chronic spontaneous urticaria patients	Data evaluation	Ongoing
PREG-CU	Analyze both the impact of pregnancy on the course of chronic urticaria as well as the drugs taken during this period and outcomes of the pregnancy	Publication	Concluded
COLD-CE	Improve the understanding of cold urticaria and cold-induced anaphylaxis on the global level	Publication	Concluded
CURICT	Assess the frequency and preference of ICTs use in patients with chronic spontaneous and chronic inducible urticaria. The global reach of this project will strengthen the UCARE Network as a leader in the field of urticaria.	Publication	Concluded



DRUSO-CU

Determinants of omalizumab drug survival in a long-term daily practice multicentre cohort of patients with Chronic Urticaria



Type:

Multi-center daily practice cohort study

Aim:

Investigate the effectiveness and safety of omalizumab in a large multicenter cohort of patients with chronic urticaria (CU; CSU and CindU) by using drug survival analysis.

Project Lead:

Heike Röckmann

Project Steering Committee:

Martijn B.A. van Doorn, Ana Gimenez,
Juil M. P. A. van den Reek, Karsten Weller, André C. Knulst

Status:

Global rollout, data collection planned until June 2022

Number of patients included:

aim 1000

COVAC-CU

Effects of COVID-19 Vaccination on Chronic Urticaria Patients



Type:

Questionnaire

Aim:

To analyze the rates of vaccine associated reactions such as exacerbation of urticaria, angioedema attacks, local reactions, any other systemic reactions and to analyze risk factors associated with vaccine reactions

Project Lead:

Emek Kocatürk Göncü

Project Advisor:

Marcus Maurer

Project Steering Committee:

Marcus Maurer, Simon Francis Thomsen, Torsten Zuberbier, Luis Felipe Ensina, Ted Popov, Martijn van Doorm, Ana Gimenez Arnau, Riccardo Asero, Paulo Ricardo, Romi Saini, Clive Grattan, Niall Conlon, Ivan Cherrez

Status:

Global rollout, preliminary results presented at the 6th. UCARE conference in Hiroshima in December 2021

Number of patients included:

90

CHOLU-CE

Cholinergic urticaria - Natural history, disease features and course and response to treatment



Type:

Questionnaire

Aim:

Assessing 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

Project Lead:

Sabine Altrichter
Eva Maria Grekowitz

Project Advisor:

Torsten Zuberbier

Project Steering Committee:

Sabine Altrichter, Torsten Zuberbier, Michihiro Hide, Chris Rutkowski, Ivan Cherrez, Sofia Cherrez, Michael Makris, Mona Al-Ahmad, Eva Maria Grekowitz

Status:

Creation of tools & documents

Number of participating centers:

tbd

Number of patients included:

aim 1000, at least 10 per center

CSU PLUS

Chronic spontaneous urticaria plus additional extracutaneous symptoms



Type:

Questionnaire, samples

Aim:

To collect cases of such patients, provisionally called “CSUplus”, to investigate whether such patients represent a distinct CSU subpopulation

Project Lead:

Frank Siebenhaar

Project Coordination:

Polina Pyatilova,
Pavel Kolchir

Project Advisor:

Luis Felipe Ensina

Project Steering Committee:

Laurence Bouillet, Niall Conlon, Iman Nasr, Emek Kocatürk, Kanokvalai Kulthanan, Sarbjit Singh Saini

Status:

Application for ethics approval

Number of patients included:

aim 500-1000

CU SLEEP



Type:

tbc

Aim:

Investigate sleep disorders in patients with chronic urticaria

Project Lead:

Ivan Chérrez Ojeda

Project Advisor:

Torsten Zuberbier

Project Steering Committee:

Ivan & Sophie Chérrez, Torsten Zuberbier, Karsten Weller, Tomasz Hawro

Status:

Creation of tools & documents

Number of participating centers:

tbd

Number of patients included:

tbc

UCOMB

**Type:**

Questionnaire (physician)

Aim:

Collect patients worldwide who receive a combined systemic treatment/management for chronic urticaria.

Project Lead:

Petra Staubach-Renz,
Caroline Mann

Project Advisor:

Marcus Maurer

Project Steering Committee:

Petra Staubach-Renz, Marcus Maurer,
Caroline Mann, Karoline Krause

Status:

Creation of tools & documents

Number of participating centers:

tbd

Number of patients included:

tbc

URCHILD

**Type:**

Questionnaire

Aim:

The aim of this project is to gather and collect data on children undergoing systemic treatment for chronic urticaria worldwide and to shed light on this underestimated patient group

Project Lead:

Petra Staubach-Renz
Caroline Mann

Project Advisor:

Marcus Maurer

Project Steering Committee:

Petra Staubach-Renz, Marcus Maurer, Caroline Mann

Status:

Creation of tools & documents

Number of participating centers:

aim 30-50

Number of patients included:

aim 500-1000

FAMLI-CU

**Type:**

Questionnaire including Family Dermatology Life Quality Index (FDLQI)

Aim:

Gather and collect data on the quality index of families with chronic urticaria patients, focusing on how chronic urticaria may affect emotional, physical, and socially families that participate in patient care.

Project Lead:

Beatrice Martinez Zugaib Abdalla
Roberta Fachini Jardim Criado
Ricardo Criado

Project Advisor:

Kanokvalai Kulthanan

Project Steering Committee:

tbc

Status:

Creation of an international steering committee

Number of participating centers:

tbd

Number of patients included:

tbc

SOLU-CE

Solar urticaria and other solar-induced reactions - Comprehensive Evaluation

**Type:**

Questionnaire, optional laboratory/genetic testing

Aim:

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

To perform a comprehensive analysis of patients with historical or physical evidence of reactions to solar radiation and light in various seasons and geographical regions of the world.

Project Lead:

Lea Alice Kiefer

Project Advisor:

Ana Gimenez-Arnau, Kanokvalai Kulthanan

Project Steering Committee:

Lesley Rhodes, Atsushi Fukunaga, Margarida Gonalo,
Emek Kocatürk Gönü, Heike Röckmann

Status:

Creation of tools & documents

Number of participating centers:

tbd

Number of patients included:

tbc

SDOWN-CSU



Type:

Questionnaire

Aim:

International, multicenter, observational, cross-sectional, survey-based study which aims to investigate stepping down approaches of different steps of chronic spontaneous urticaria treatment from global perspective.

Project Lead:

Murat Türk
Ragıp Ertaş
Emek Kocatürk, Marcus Maurer

Project Advisor:

Ana Giménez-Arnau

Project Steering Committee:

Emek Kocatürk, Ragıp Ertaş, Christian Vestergaard, Clive Grattan, Silvia Ferrucci, Luis Felipe Ensina, Torsten Zuberbier

Status:

Creation of tools & documents

Number of participating centers:

tbd

Number of patients included:

tbc

PREVALENCE-D

Prevalence of Dermographism in General Population



Type:

Cross-sectional questionnaire

Aim:

Find out the prevalence of dermatographism in a large and representative sample of general population.

Project Lead:

Kanokvalai Kulthanan,
Chuda Rujitharanawong

Project Advisor:

Marcus Maurer

Project Steering Committee:

Marcus Maurer, Ana Giménez-Arnau, Melba Munow Roldan, Jonathan Berstein, Paulo Ricardo Criado, Mona Al-Ahmad, Lu Rongbiao, Hae Sim Park, Kiran Godse

Status:

Pilot study completed

Number of participating centers:

tbc

Number of patients included:

tbd, at least 3000 per center

DAEF-CINDUS



Type:

tbc

Aim:

Demonstration of the differences in threshold values of following the exercise and food intake and to explore the possible reasons and correlations of the changes according to food intake and exercise

Project Lead:

Ragıp Ertaş
Murat Türk
Melba Munoz; Marcus Maurer

Project Advisor:

Marcus Maurer

Project Steering Committee:

tbc

Status:

in preparation

Number of participating centers:

tbd

Number of patients included:

tbc

CU-STYLE

Solar urticaria and other solar-induced reactions - Comprehensive Evaluation



Type:

A prospective, multicentre, non-interventional questionnaire study.

Aim:

To define lifestyle factors (sports, diet, caffeine, smoking, alcohol) and risk factors (systemic diseases, medications, BMI, occupation, marital status, family history, sleep problems, psychological problems, allergy, stress) associated with chronic urticaria (CU).

Project Lead:

Emek Kocatürk Göncü

Project Advisor:

Marcus Maurer

Project Steering Committee:

Emek Kocatürk, Marcus Maurer, Torsten Zuberbier, Chris Rutowski, Michael Makris, Romi Saini, Mona Al-Ahmad, Simon Francis Thomsen, Connie Katelaris, Margarida Gonçalves

Status:

applying for ethics approval

Number of participating centers:

tbd

Number of patients included:

tbc

PROMUSE

Knowledge, perceptions and limitations of the use Patient Reported Outcomes Measures (PROMs) by physicians in allergic diseases.



Type:

International, multicenter, observational (non-interventional), Online survey for physicians

Aim:

Identify clinicians' perspectives regarding the use of PROMs in clinical contexts and describe the knowledge, perceptions and limitations of the use Patient Reported Outcomes Measures (PROMs) by physicians in allergic diseases in order to increase engagement and uptake of these tools in clinical practice.

Project Lead:

Ivan Cherrez Ojeda, Respiralab Research Center, Guayaquil, Ecuador

Karla Robles Velasco, Universidad de Especialidades Espíritu Santo, Guayaquil, Ecuador

Project Steering Committee:

Marcus Maurer, Torsten Zuberbier, Jean Bousquet

Status:

Global rollout, collection of information: 3 months from December 1st 2021 to March 1st 2022

UNITACT



Type:

tbc

Aim:

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

Project Lead:

Marcus Maurer, Sophia Neisinger

Project Advisor:

tbc

Project Steering Committee:

tbc

Status:

Formation of steering committee

Number of participating centers:

tbc

Number of patients included:

tbc

UVERSICU

Urticarial vasculitis versus chronic spontaneous urticaria – Natural history, disease course and response to treatment



Type:

Standardized patient-related questionnaire

Aim:

To assess differences in the natural history, clinical symptoms, triggers, associated diseases, and treatment effects in patients with urticarial vasculitis compared to chronic spontaneous urticaria patients

Project Lead:

Hanna Bonnekoh, Karoline Krause

Project Advisor:

Marcus Maurer

Project Steering Committee:

tbc

Status:

Data evaluation and paper in progress, publication very soon

Number of participating centers:

tbd

Number of patients included:

202 (half urticarial vasculitis, half CSU)

PREG-CU

Solar urticaria and other solar-induced reactions – Comprehensive Evaluation



Type:

Questionnaire

Aim:

Analyze both the impact of pregnancy on the course of chronic urticaria as well as the drugs taken during this period and outcomes of the pregnancy.

Project Lead:

Emek Kocatürk Göncü

Project Advisor:

Marcus Maurer

Project Steering Committee:

Emek Kocatürk, Marcus Maurer, Ana Gimenez-Arnau, Laurence Bouillet, Zuotao Zhao, Petra Staubach

Number of patients included:

288 in 13 countries

Publication:

Kocatürk E, Al-Ahmad M, Krause K, Gimenez-Arnau AM, Thomsen SF, Conlon N, Marsland A, Savk E, Criado RF, Danilycheva I, Fomina D, Godse K, Khoshkhui M, Gelincik A, Degirmentepe EN, Demir S, Ensina LF, Kasperska-Zajac A, Rudenko M, Valle S, Medina I, Bauer A, Zhao Z, Staubach P, Bouillet L, Küçük ÖS, Ateş C, Maurer M. Effects of pregnancy on chronic urticaria: Results of the PREG-CU UCARE study. *Allergy*. 2021 Oct;76(10):3133-3144. doi: 10.1111/all.14950. Epub 2021 Jun 12. PMID: 34022061.

COLD-CE

**Type:**

Multi-center prospective study

Aim:

Improve the understanding of cold urticaria and cold-induced anaphylaxis on the global level

Project Lead:

Mojca Bizjak, Dorothea Terhorst-Molawi

Project Advisor:

Kanokvalai Kulthanan, Marcus Maurer

Project Steering Committee:

Mitja Košnik, Kanokvalai Kulthanan, Marcus Maurer, Raisa Meshkova, Simon Francis Thomsen

Number of participating centers:

32 centers (19 countries)

Number of patients included:

551

Publication:

Bizjak M, Košnik M, Dinevski D, Thomsen SF, Fomina D, Borzova E, Kulthanan K, Meshkova R, Ahsan DM, Al-Ahmad M, Altrichter S, Bauer A, Brockstädt M, Costa C, Demir S, Fachini Criado R, Ensina LF, Gelincik A, Giménez-Arnau AM, Gonçalves M, Gotua M, Holm JG, Inomata N, Kasperska-Zajac A, Khoshkhui M, Klyucharova A, Kocatürk E, Lu R, Makris M, Maltseva N, Mijlković J, Pasali M, Paulino M, Pesqué D, Peter J, Ramón GD, Ritchie C, Rodrigues Valle SO, Rudenko M, Sikora A, de Souza Lima EM, Wagner N, Xepapadaki P, Xue X, Zhao Z, Terhorst-Molawi D, Maurer M. Risk factors for systemic reactions in typical cold urticaria: Results from the COLD-CE study. *Allergy*. 2021 Dec 4. doi: 10.1111/all.15194. Epub ahead of print. PMID: 34862605.

CURICT

**Type:**

Questionnaire

Aim:

Assess the frequency and preference of information and communication technologies (ICTs) use in patients with chronic spontaneous and chronic inducible urticaria.

Project Lead:

Ivan Cherrez

Project Advisor:

Marcus Maurer

Project Steering Committee:

Ivan Cherrez-Ojeda, Marcus Maurer

Number of participating centers:

17 UCAREs (17 countries)

Number of patients included:

1841

Publication:

Cherrez-Ojeda I, Vanegas E, Cherrez A, Felix M, Weller K, Magerl M, Maurer RR, Mata VL, Kasperska-Zajac A, Sikora A, Fomina D, Kovalkova E, Godse K, Rao ND, Khoshkhui M, Rastgoo S, Criado RFJ, Abuzakouk M, Grandon D, Van Doorn MBA, Rodrigues Valle SO, De Souza Lima EM, Thomsen SF, Ramón GD, Matos Benavides EE, Bauer A, Giménez-Arnau AM, Kocatürk E, Guillet C, Larco JI, Zhao ZT, Makris M, Ritchie C, Xepapadaki P, Ensina LF, Cherrez S, Maurer M. Chronic urticaria patients are interested in apps to monitor their disease activity and control: A UCARE CURICT analysis. *Clin Transl Allergy*. 2021 Dec;11(10):e12089. doi: 10.1002/ct2.12089. PMID: 34962721; PMCID: PMC8684305.

CURE

The global chronic urticaria registry

**Aim:**

To collect quality, real-life data on chronic urticaria patient characteristics, the course of disease, underlying causes, comorbidities, treatment responses, quality of life impairment and health care costs.

CURE, the Chronic Urticaria Registry is an ongoing, prospective, international, multicenter, observational, voluntary registry of patients with CU. Participation in CURE is open to any physician treating CU patients, regardless of location, medical specialty or type of practice setting. CURE aims to collect data on all CU patients, with no intentional selection or exclusion criteria. It collects baseline and follow-up data on the patient's demographics, history, symptoms, trigger and risk factors, therapies, and healthcare utilization.

Project Lead:

Karsten Weller

Project Steering Committee:

Marcus Maurer, Ana Giménez-Arnau, Karsten Weller, Riccardo Asero, Clive Grattan, Mojca Bizjak, Emek Kocatürk Göncü

Status:

long term project → continuing data collection, evaluation, and publication

Number of participating centers:

52 in 27 countries

Number of patients included:

Baseline 4249

Follow-Up total 2863

CURE office:

Yana Hackler (yana.hackler@urtikaria.net)

EVENTS

UCARE Adboard 2021

The annual meeting of the German UCARE member centers took place on February, 24th 2021. The purpose of this meeting is to take a closer look at the UCARE projects of the past year and discuss them in order to plan for the coming year and to provide an impetus for possible Germany-wide projects. This year, the main focus was on digitalization to optimize patient care through the pandemic. In addition, the promotion of junior scientists in the field of urticaria was also discussed.

MedScape Cooperation - Expert discussions on CSU

In collaboration with the medical knowledge portal Medscape, UCARE has published the three expert discussions as part of the series „Optimizing Outcomes for Patients With Psoriasis, Spondyloarthropathies and Urticaria“:

- 1 Emerging Therapies for Chronic Spontaneous Urticaria – Understanding How They Work** (CME: 0,5) Expert discussion between Dr. Allen P. Kaplan and Dr. Alexander Eggel on the role of IgE in the pathogenesis of CSU and therapies in development.
- 2 Taking control of chronic spontaneous urticaria – A tale of two perspectives** (CME: 0,5) Expert discussion between Dr. Marcus Maurer, Dr. Luis Filipe Ensina and Dr. Ana Maria Giménez-Arnau on key challenges in management of chronic spontaneous urticaria in clinical practice.
- 3 Unfolding the Future of Chronic Spontaneous Urticaria – Emerging Data with Novel Therapies** (CME: 0,5) Drs Martin Metz and Ana Maria Giménez-Arnau discuss the latest data on new treatments in development for chronic spontaneous urticaria.

UCARE Conference 2021

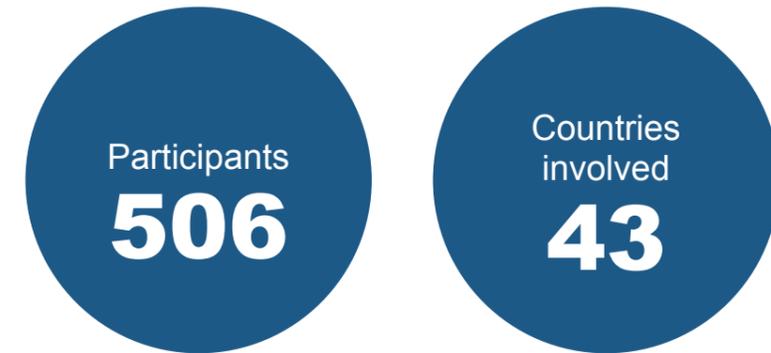
Hiroshima, Japan,
December 9th-11th, 2021



Guided by its theme “A New Era for Urticaria –Advances in its classification and breakthroughs in its treatment”, the third GA²LEN UCARE conference was a three-day international and hybrid event held in Hiroshima, Japan, from 9-11 December 2021 (ON-DEMAND Streaming* December 9, 2021 - January 31, 2022). The program consisted of 9 scientific sessions: oral presentations, review lectures by international experts, as well as 2 workshops and an interactive poster session completed the conference program. Discussions and scientific exchange with other urticaria researchers and physicians treating urticaria and related diseases were the main focus. The latest findings on the pathogenesis of urticaria, its subtypes, biomarkers, comorbidities, diagnostics, the impact of the disease and treatment were discussed, as well as many practical tips for the management of urticaria and other mast cell-related diseases.



UCARE CONFERENCE 2021 IN NUMBERS:



9 distinct sessions **2** oral sessions **1** poster walks **2** workshop sessions

President:
Michihiro Hide, MD, PhD
Director of Hiroshima City Hospital,
Special Advisor of Hiroshima University Hospital

Venue:
Hiroshima Prefectural Medical Association Hall
3-2-3 Futabonosato, Higashi-ku, Hiroshima City,
Hiroshima 732-0057, Japan

ACARE...what are we planning for 2022

2022 is shaping up to be a very exciting year for ACARE. 2021 saw very promising growth of our network, a trend that we certainly want to continue into 2022.

We are planning to deepen the level of partnership with HAEi in order to 1. create more educational programs for physicians, 2. raise the profile of the ACARE network and 3. foster an atmosphere where the patient's voice is front and center.

- 1** In 2022, we will be continuing our successful programs INTERACT and Make A Difference. In addition, we are planning to launch ACARE LevelUP in Q.4., including a new website hosted by HAEi. ACARE LevelUP will comprise of further education programs for physicians such as podcasts, webinars, fireside chats, journal clubs, videos and more. We want to help educate physicians so that patients can receive a fuller range of care.
- 2** Another goal for 2022 is to raise the profile and presence of the ACARE network by attending conferences such as the HAEi Global Leadership forum in Frankfurt on October and participating in events such as HAE day.
- 3** Furthermore, we want to focus on the patients even more in 2022. For this, we are aiming to work closely with patient organizations, become involved with the HAEi advocacy academy and foster a culture of collaboration between patient advocates and our ACARE centers.

UCARE...what are we planning for 2022

For UCARE as well, we have seen a very promising growth of our network, which we of course want to see continuing into 2022 and beyond.

The coming year will see a focus on 1. Physician and patient education, 2. The CRUSE App and 3. Events.

- 1** As with ACARE, one focus in 2022 will be on our websites and social media presence. The new UCARE website will be a twin to the new ACARE website and also encompass our physician education program LevelUp. LevelUp programs will consist of podcasts, webinars, fireside chats, journal clubs, videos and more. The planned launch for both sites is in Q3. For UCARE 4U, our patient education platform, we will launch a separate website in Q2. The focus for this site is to be a comprehensive FAQ on all thing urticaria for patients and patient-adjacent groups, as well as showcase our own patient-education resources such as webinars.
- 2** 2022 will see the launch of CRUSE®, the Chronic Urticaria Self Evaluation App. CRUSE® will enable patients to fill out their Patient Reported Outcome Measure (PROMs) daily on their smart device and will remind patients daily to monitor their quality of life through push notification CRUSE® will allows patients to send a report of their scores (including UAS/AAS, UCT/AECT, WPAI, EQ5D, pictures and current/prior treatment) to their treating physician via Email, WhatsApp or other communication paths. The app will also promote continued monitoring and documentation of CSU disease activity, impact and control that is needed for patients to receive optimal treatment. The launch is planned for Q2 of 2022, beginning with Germany, Austria, Switzerland and the UK.
- 3** After hosting the UCARE conference this year, the 6th GA²LEN Global Urticaria Forum (GUF) will take place on December 7-8 2022 in Berlin. And as every year, October 1 is World Urticaria Day (UDAY).

PARTNERS

We would like to thank our Partners and Sponsors:



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Novartis	UCARE LevelUp and UCARE 4U
Allakos	UCARE LevelUp and UCARE 4U
Courage & Khazaka	UCARE General Support
Medscape	UCARE - Medscape Roundtable
Novartis	UCARE Conference 2021
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