



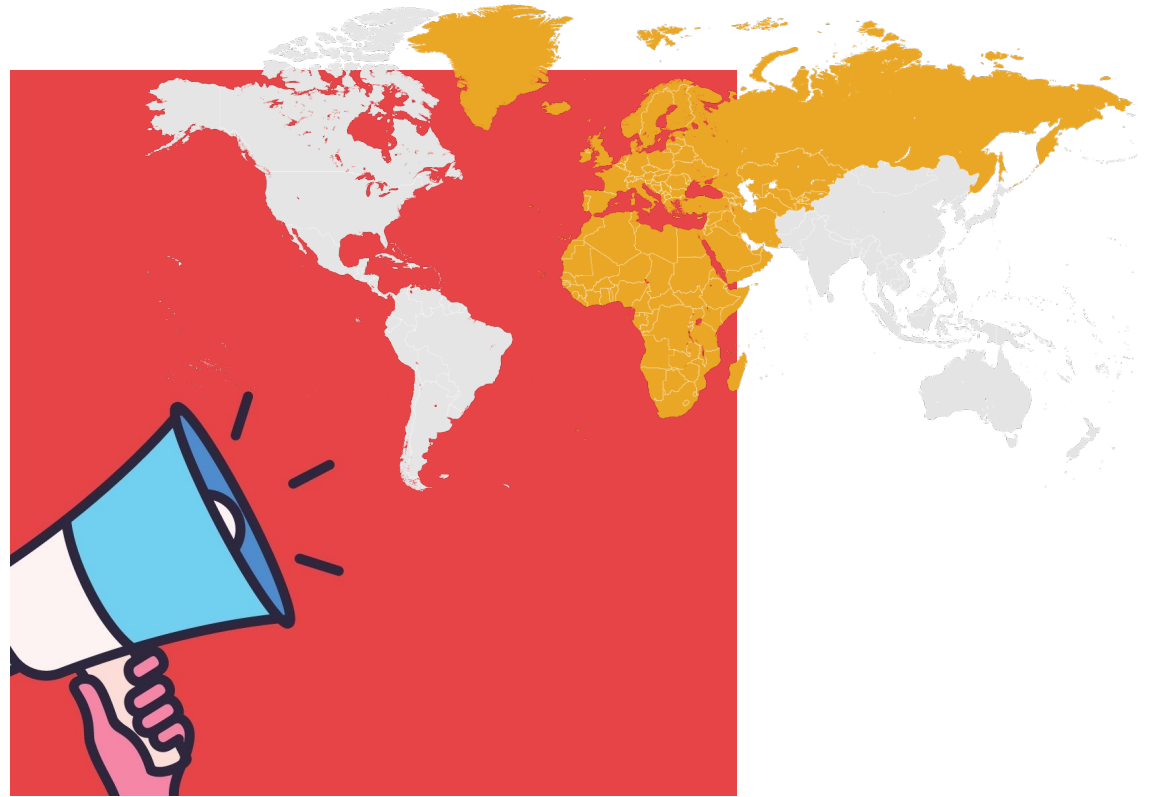
HAEi
REGIONAL
CONFERENCE
EMEA
MUNICH
1-3 SEP 2023

TAKE ACTION



HAE IN THE EMEA REGION

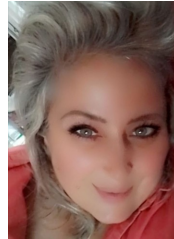
WHAT
MESSAGE
DO YOUR
COUNTRIES
WANT TO
SHARE WITH
THEIR HAE
FAMILY?



WHAT
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HAE Albania



Patient leader:

Silvana Bastri (Alkoci)

Message to patients:

”Stay alert and become your own doctor.”

”Qëndro vigjilent dhe bëhu mjek i vetes!!”

WHAT
MESSAGE
DO YOUR
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HAE Bosnia & Herzegovina

HAE Bosna I Hercegovina



Patient leader:

Miroslav Dragnić

Message to patients:

”Be patient, therapy for HAE patients in Bosnia and Herzegovina should be available soon.”

”Budite strpljivi, uskoro bi trebala biti dostupna terapija za HAE pacijente u Bosni i Hercegovini.”



WHAT
MESSAGE
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HAE Bulgaria



Patient leader:
Danail Dimov

Message to patients:

"Fate loves the brave. Remember that you are not alone."

"Съдбата обича смелите. Помнете че не сте сами."

WHAT
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HAE Algeria



الجمعية الوطنية لمرضى
الوذمة الوعائية الوراثية
HAE ALGERIA



Patient leader:

Mohand Cherif Negrouche

محمد شريف نغروش

Message to patients:

”Together we will continue to fight for
better care and a brighter future for our patients.”

معًا سنواصل النضال من أجل رعاية أفضل ومستقبل أكثر إشراقًا لمرضانا.

WHAT
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HAE France

AMSAO



Patient leader:
Michel Raguet

Message to patients:

”If HAE is still a rare disease, it is not
an orphan disease anymore”

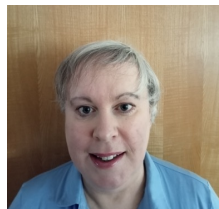
”Si l’AOH est toujours une maladie rare,
ce n’est plus une maladie orpheline”



WHAT
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HAE Ireland



Patient leader:
Bettina Carty

Message to patients:

"The future of HAE medications are getting better all the time – and we look forward to living the most normal life we can"





WHAT
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HAE Armenia

Ժառանգական անգիոայտուց պացիենտական կազմակերպություն



Patient leader:
Armen Ghukasyan



Message to patients:

”Our mission is to stand unwaveringly beside our patients, leaving no one unturned in our pursuit of optimal medical care. Additionally, we strive to provide invaluable support to medical professionals in the adoption of new treatment options.”

”Մեր նպատակն է ամուր կանգնած լինել մեր պացիենտների կողքին, անել անհնարինը պատշաճ բուժական օգնություն ստանալու համար, օգնել մեր բժիշկներին նոր դեղորայք ներմուծելու գործընթացում:”



WHAT
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HAE Bahrain

جمعية الودمة الوراثية بمملكة البحرين



Patient leader:

Abdulla Yaseen

عبدالله ياسين

Message to patients:

"Living with a medical condition can be tough, but our patients group is here to help. We've formed a strong community that understands and supports one another. Together, we can make a difference."

قد يكون التعايش مع حالة مرضية أمرًا صعبًا، لكن مجموعتنا هنا للمساعدة. بفضلكم قد شكنا مجتمعًا قويًا يفهم ويدعم بعضهم البعض. "معًا يمكننا إحداث فرق".

WHAT
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Рэспубліканскае грамадскае аб'яднанне «Дапамога пацыентам з спадчынным ангіаацёкам»



Patient leader:

Iryna Ausianik (President)

Ірына Аўсянік (старшыня)

Message to patients:

”I hope that one day every HAE patient will have access to effective HAE medicine, enabling them and their loved ones to live a life free from HAE attacks.”

”Я спадзяюся, што аднойчы кожны пацыент з спадчынным ангіаацёкам (САА) атрымае доступ да эфектыўных лекаў, што дазволіць ім і іх блізкім жыць жыццём без нападаў САА.”



WHAT
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HAE Belgium



Patient leader:
Vinciane Berckmans



WHAT
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HAE Austria



Hilfe zur Selbsthilfe



Patient leader:

Adelheid Huemer

Message to patients:

”HAE Austria aims to improve the quality of life for all HAE sufferers and their families. We are available for any questions related to HAE.”

”HAE-Austria hat sich zum Ziel gesetzt, die Lebensqualität aller HAE-Betroffenen und seiner Angehörigen zu verbessern. Wir stehen für Fragen aller Art im Zusammenhang mit HAE zur Verfügung.”

WHAT
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HAE Finland



Patient leader:

Tiina Kortesmäki

Message to patients:

"I hope that despite our challenging disease we can use the power of peer support and turn our disease to our strength."

"Toivoisin, että haastavasta sairaudesta huolimatta pystyisimme hyödyntämään vertaistuen voimaa ja saisimme käännettyä sairauden omaksi vahvuudeksemme."

WHAT
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HAE Croatia

Udruga oboljelih od hereditarnog angioedema HAE HRVATSKA



Patient leader:
Mihaela Šogorić



Message to patients:

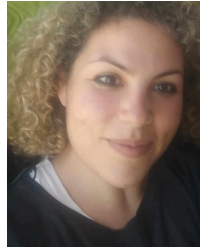
"YOU ARE NOT ALONE – we are stronger together!"

"NISTE SAMI- zajedno smo jači!"

WHAT
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HAE Cyprus



Patient leader:

Evangelia Englezakis
Ευαγγελία Εγγλεζάκη

Message to patients:

”Together we can make our HAE lives easier, more comfortable and bearable!”

”Μαζί μπορούμε να αντιμετωπίσουμε, να αποδεχτούμε τη ζωή μας με κληρονομικό αγγειοίδημα και να την κάνουμε ευκολότερη!”

WHAT
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HAE Greece

Όνομα συλλόγου-μέλους: Κληρονομικό Αγγειοίδημα Ελλάδας



Patient leader:

Asimina Krotsida

Ασημίνα Κροτσίδα



Message to patients:

”Valid and correct diagnosis for a better quality of life for patients with Hereditary angioedema.”

”Έγκυρη και σωστή διάγνωση για μία καλύτερη ποιότητα ζωής των ασθενών με Κληρονομικό αγγειοίδημα.”



WHAT
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HAE Czech Republic

Občanské sdružení na ochranu pacientů s hereditárním angioedémem



Patient leader:
Iveta Maselli



WHAT
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HAE Junior Czech Republic



Patient leader:
Camelia Isaic



Message to patients:

”Do you also want to raise a generation of HAEroes,
stronger than HAE?”

”Také si přejete vychovávat generaci
hrdinů silnějších než HAE?”



WHAT
MESSAGE
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HAE Estonia



Patient leader:
Oksana Jermolova

WHAT MESSAGE DO YOUR COUNTRIES WANT TO SHARE WITH THEIR HAE FAMILY?



HAE Egypt

معية الودمة الودائية الودائية بجمهورية مصر العربية



Patient leader:

Mohamed Osman

محمد عثمان

Message to patients:

"We understand that dealing with a medical condition can be challenging, but we want you to know that our patient group is here to offer support. We have built a close-knit community where we empathize with each other and provide mutual assistance. By joining forces, we have the power to create positive change."

نحن نتفهم أن التعامل مع أي حالة مرضية يكون أمرًا صعبًا، لكننا نريدكم أن تكونوا على يقين بأننا متواجدين على الدوام لتقديم الدعم. لقد قمنا ببناء مجتمع متماسك والذي من خلاله ندعم بعضنا البعض ونقدم دائما يد المساعدة المتبادلة. من خلال توحيد الجهود، لدينا القوة لإحداث تغيير إيجابي



WHAT
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HAE Georgia

მემკვიდრეული ანგიოედემა საქართველო



Patient leader:

Davit Ramazashvili

დავით რამაზაშვილი



Message to patients:

”From Awareness to Action: Together Against HAE”

”ცნობიერების ამაღლებიდან მოქმედებამდე: ერთად
მემკვიდრეული ანგიოედემის წინააღმდეგ”



WHAT
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HAE Italy



A.A.E.E. APS

Associazione volontaria per l'angioedema
ereditario ed altre forme rare di angioedema



Patient leader:

Pietro Mantovano

Message to patients:

"Knowledge is not rare!"

"La conscenza non è rara!"

WHAT
MESSAGE
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THEIR HAE
FAMILY?



HAE Libya



Patient leader:
Ahmed Ali Abodahair

Message to patients:

**"We must be strong in terms of the disease,
be patient, be united, and try as hard as
we can to get the medicine."**



WHAT
MESSAGE
DO YOUR
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HAE Morocco



Patient leader:
Imad EL AOUNI



Message to patients:

”There are still few of us in AMMAO! We must be more than that. To be more strong we need you to join us 😊”

”Nous sommes encore peu à AMMAO, on a besoin de plus de monde. On a besoin de vous. Rejoignez nous! 😊”

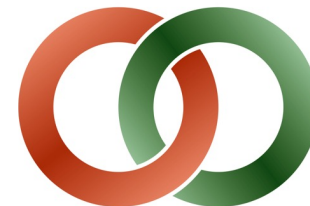
WHAT
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HAE Hungary



Patient leader:
István Nagy



Message to patients:

”Enjoy the present, fight for the future!”

“Élvezd a jelent, harcolj a jövőért!”

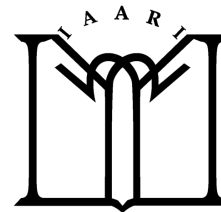


WHAT
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HAE Iran

مرکز تحقیقات ایمنولوژی، آسم و آلرژی (دانشگاه علوم پزشکی تهران)



Patient leader:

Dr.Zahra Pourpak

دکتر زهرا پورپاک

Message to patients:

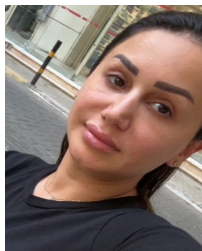
”Know that HAE cannot cripple love, it cannot shatter hope, and it cannot conquer the spirit.”

WHAT MESSAGE DO YOUR COUNTRIES WANT TO SHARE WITH THEIR HAE FAMILY?



HAE Iraq

جمعية الودمة الودائية الوراثةية بجمهورية العراق



Patient leader:

Sherin Merza

شيرين ميرزا

Message to patients:

”Please engage actively in our group activities in the coming months. Your participation is vital to making a difference in the lives of others facing similar challenges.”

يرجى المشاركة بنشاط في أنشطة مجموعتنا في الأشهر القادمة. مشاركتكم أمر حيوي لإحداث فرق في حياة الآخرين الذين يواجهون تحديات مماثلة

WHAT MESSAGE DO YOUR COUNTRIES WANT TO SHARE WITH THEIR HAE FAMILY?



HAE Jordan

جمعية الودمة الوعائية الوراثية المملكة الأردنية الهاشمية



Patient leader:

Bassam Mohammad Alelimat

بسام محمد عليمات

Message to patients:

”Together we are a force for change and empowerment.
Let us support and uplift one another as we navigate our
journeys towards better health and well-being.”

معا لدينا القوة اللازمة للتغيير والتمكين. دعونا ندعم ونرتقي ببعضنا البعض أثناء رحلاتنا نحو
صحة ورفاهية أفضل.

WHAT MESSAGE DO YOUR COUNTRIES WANT TO SHARE WITH THEIR HAE FAMILY?



HAE Montenegro



Patient leader:
Marija Nikolić

Message to patients:

”Working collaboratively to raise awareness about Hereditary Angioedema (HAE) is crucial to improve the lives of both current and future patients.”

”Važno je da zajedno radimo na podizanju svijesti o HAE kako bi svakom sadašnjem i budućem pacijentu olakšali život.”

WHAT
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HAE N Macedonia



Patient leader:

Natasha Jovanovska Popovska
Наташа Јовановска Поповска

Message to patients:

"I swell but you cannot tell – I RUN LIKE HELL!"

"Отекувам, но не се повлекувам – ТРЧАМ!"



WHAT
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FAMILY?



HAE Romania



AEE Romania

Asociația Pacienților cu Angioedem Ereditar din România

Patient leader:

Ramona Petran

Message to patients:

**”Stay strong and fight for
your rights to modern therapy”**



WHAT
MESSAGE
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FAMILY?



HAE Denmark

HAE Scandinavia

A horizontal bar with segments of red, blue, yellow, and blue.
www.haescan.org



Patient leader:

Henrik Balle Boysen

Message to patients:

"HAE Scandinavia has become a reality to support patients and their families in Denmark, Norway, and Sweden in the best possible way. We also see that HAE Scandinavia plays an important role in building a strong network of doctors in Scandinavia who can utilize available treatments to the benefit of patients even more effectively."

"HAE Scandinavia er blevet en realitet for at støtte patienter og deres familier i Danmark, Norge og Sverige på bedst mulige måde. Vi ser også, at HAE Scandinavia har en vigtig rolle med at bygge et stærkt netværk af læger i Skandinavien, som på endnu bedre vis kan udnytte de tilgængelige behandlinger til patienternes fordel."



WHAT
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HAE Norway

HAE Scandinavia



www.haescan.org



Patient leader:

Trine Dahl-Johansen

Message to patients:

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HAE Sweden

HAE Scandinavia

A horizontal bar with segments of red, white, blue, red, yellow, and blue.
www.haescan.org



Patient leader:

Camilla Eriksson

Message to patients:

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HAE Israel



Patient leader:
Avi Buskila



WHAT
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FAMILY?



HAE Kazakhstan



Patient leader:

Yekaterina Tatarenko

Message to patients:

"We could achieve – so you can do it too"



HAO Казахстан
пациентская организация

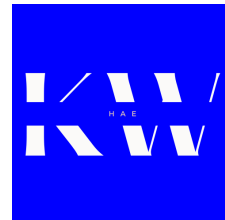


WHAT MESSAGE DO YOUR COUNTRIES WANT TO SHARE WITH THEIR HAE FAMILY?



HAE Kuwait

جمعية الؤمة الوءائية بءولة الكوءت



Patient leader:

Mubarak Al Ajami

مبارك العجمي

Message to patients:

"Your help and support are the foundation of our work. Together, we can face the challenges of living with chronic diseases, please be certain that we are not alone in this journey thanks to the continuous support of HAEi as well as the Kuwaiti Ministry of Health, doctors and all Kuwaiti medical institutions."

مساءءءكم وءعمكم هي أساس عملنا. معاً، يمكننا مواءهة آءءيات الءعايش مع الأمراض المزمنة، ىرءى العلم وكذلك وزارة الصءة الكوءتية HAEi بأننا لسنا وءءنا فى هءه الرءلة بفضل الءعم المسءمر من قبل منءمة والساءة الأطباء وءمىع المؤسساء الءبىة الكوءتية



WHAT
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HAE Latvia



Patient leader:
Prof. Natalja Kurjane

WHAT
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FAMILY?



HAE Lebanon



Patient leader:
Nour El Chami

L^{HAE}B

Message to patients:

"I am working on creating an organization concerning HAE, in order to help providing medicine to patients in Lebanon with good price, and to communicate better with each of us."

من أجل المساعدة في توفير الدواء اللازم للمرضى في HAE، أعمل على إنشاء منظمة معنية بـ
لبنان بسعر جيد، وكذلك لكي يتم

التواصل فيما بيننا بشكل أفضل.

WHAT
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HAE Portugal



Patient leader:
Inês Pessoa



Message to patients:

**"It is possible to live with
hereditary angioedema without attacks."**

**"É possível viver com
angioedema hereditário e sem crises."**



WHAT MESSAGE DO YOUR COUNTRIES WANT TO SHARE WITH THEIR HAE FAMILY?



HAE Spain



Patient leader:

Sara L. Smith Foltz

Message to patients:

”For 25 years, AEDAF, in collaboration with medical professionals and the industry, has been focused on informing, bringing together and advocating for HAE patients in Spain in their struggle to improve their time to diagnosis and the treatment of this rare disease. Much progress has been made, especially in the last 10 years, but there is still a long way to go ...”

”AEDAF lleva 25 años trabajando, en colaboración con los profesionales médicos y la industria, para informar, reunir y apoyar a los pacientes de AEH en España en su lucha para mejorar el tiempo de diagnóstico y el tratamiento de esta enfermedad rara. Se han conseguido grandes avances, sobre todo en los últimos 10 años, para queda mucho camino por recorrer ...”

WHAT MESSAGE DO YOUR COUNTRIES WANT TO SHARE WITH THEIR HAE FAMILY?



HAE Tunisia

جمعية الونمة الوراثية بدولة الكويت



Patient leader:

Arbia Barhoun

عربية برهون

Message to patients:

"We all know how much suffering we go through because we have no medicine for a disease that threatens our life and comfort. We should be optimistic that we are on the right track. We must shake hands and work together towards a goal, which is to provide ourselves and our children with medicine and to enjoy a good life without fear or pain like all other human beings."

نعم جميعًا مدى المعاناة التي نمر بها لأنه ليس لدينا دواء لمرض يهدد حياتنا وراحتنا. يجب أن نكون متفائلين بأننا نسير على الطريق الصحيح. يجب أن نتصافح ونعمل معًا من أجل هدف ، وهو تزويد أنفسنا وأطفالنا بالدواء والتمتع بحياة طيبة دون خوف أو ألم مثل جميع البشر الآخرين.



WHAT
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HAE UK



Patient leaders:

Angela Metcalfe and **Rachel Annals**

Message to patients:

”Be your own HAE advocate. Maintain an honest relationship with your HAE medical team. Ensure you have an adequate supply of HAE medication. Keep in touch with your HAE patient organisation.”



WHAT
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FAMILY?



HAE Lithuania



Patient leader:

Rytis Pareščius

Message to patients:

“Please do not afraid what you don’t know, your knowledge could save your life in the future.”

“Nebijokite, jei kažko nežinote, jūsų žinios gali išgelbėti jums gyvybę ateityje.”



WHAT
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FAMILY?



HAE the Netherlands

Vereniging voor Angio-oedeem



Patient leader:

Maria (Marijk) Beekman-Kortekaas



Message to patients:

"Stronger Together!"

"Samen staan we sterk!"

WHAT
MESSAGE
DO YOUR
COUNTRIES
WANT TO
SHARE WITH
THEIR HAE
FAMILY?



HAE Oman

سلطنة عمان



Patient leader:

Maryam Mohamed Al Balushi

مريم محمد البلوشي

Message to patients:

"As a patient representative, I would like to share that HAE awareness is developing in Oman, I am doing everything I can to achieve the best in identifying people who are suffering from HAE without realizing it. I hope to help all patients around Oman."

بصفتي ممثلاً للمرضى ، أود أن أشير إلى أن يتطور في عمان ، وأنا أفعل كل ما في وسعي لتحقيق الأفضل في تحديد الأشخاص الذين يعانون من الؤذمة الوعائية الوراثية دون أن أدرك ذلك. أمل أن أساعد جميع المرضى في جميع أنحاء عمان.

WHAT MESSAGE DO YOUR COUNTRIES WANT TO SHARE WITH THEIR HAE FAMILY?



HAE Poland



**PIĘKNIE
PUCHNĘ**
Polskie Stowarzyszenie
Pomocy Chorym
z Obrzkiem Naczynioruchowym



Patient leader:
Michał Rutkowski

Message to patients:

”No matter what the circumstances are, never give up!
We have achieved so much together, and only the sky is
the limit.”

”Bez względu na okoliczności, nigdy się nie poddawaj!
Osiągnęliśmy razem tak wiele, więc nie ma granic, których
nie pokonamy.”

WHAT
MESSAGE
DO YOUR
COUNTRIES
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FAMILY?



HAE Kenya



Patient leader:
Patricia Karani

Message to patients:

**”Do not fear a diagnosis of HAE.
There are knowledgeable doctors in the country
who can help you realize a normal life with HAE.”**



WHAT MESSAGE DO YOUR COUNTRIES WANT TO SHARE WITH THEIR HAE FAMILY?



HAE Germany



Patient leader:

Lucia Schauf



Message to patients:

"We have an open ear for everyone and are happy to assist with anything related to HAE. We can't perform miracles, but we help make them come true."

"Wir haben für jeden ein offene Ohr und helfen gerne weiter, bei allem was mit HAE zusammen hängt. Wunder können wir keine verbringen, aber wir helfen dabei, sie vielleicht wahr werden zulassen."



WHAT
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HAE Switzerland



Patient leader:
Helene Saam

Wir halten zusammen.



www.hae-vereinigung.ch

Schweizer Vereinigung für Betroffene,
Familienangehörige, Freunde und Ärzte

Message to patients:

”The Swiss HAE Association produced a film titled 'HAE – Simply Explained!' which explains the rare disease Hereditary Angioedema (HAE) in a simple manner for individuals affected by HAE and those interested in HAE. It explains in non-medical language what triggers the disease, how the processes in the body work, and what can be done about it.”

”Die Schweizer HAE-Vereinigung produzierte einen Film mit dem Titel 'HAE – einfach erklärt!', welcher die seltene Krankheit Hereditäres Angioödem (HAE) für HAE betroffene und HAE interessierte Personen auf einfache Weise erklärt. Es wird in nicht medizinischer Sprache erklärt, was die Krankheit auslöst, wie die Abläufe im Körper funktionieren und was dagegen gemacht werden kann.”

WHAT
MESSAGE
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HAE Qatar

HAE قطر



Patient leader:

Ameera Elawad

أميرة العوض

Message to patients:

”Our HAE is not something which burdens us by making us different. It makes us unique and strong. I hope one day everyone in Qatar will be able to treat their HAE without any problems.”

مرضنا ليس شيئاً يثقل كاهلنا وبجعلنا مختلفين بل يجعلنا فريدين وقويين. أمل أن يتمكن كل مريض دون أي مشاكل HAE بقطر يوماً ما من إيجاد علاج



WHAT
MESSAGE
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FAMILY?



HAE Russia

Общество пациентов с Наследственным
Ангионевротическим Отеком



Patient leader:

Elena Bezbozhnaya

Message to patients:

"With the development of gene therapy in the near future, great prospects are opening up, and with them very real hopes! Everyone is important, everyone matters, we are all one big HAE family! Take care of yourself and your loved ones, be happy!"

"С развитием генной терапии в недалеком будущем открываются большие перспективы, а вместе с ними и вполне реальные надежды! Каждый важен, каждый имеет значение, все мы – одна большая семья HAO! Берегите себя и своих близких, будьте счастливы!"

Thank you!



WHAT MESSAGE DO YOUR COUNTRIES WANT TO SHARE WITH THEIR HAE FAMILY?



Patient leader:

Ahmad Aleliwi

Message to patients:

”Even HAE is a rare disease, but it is well known now. Do not give up. Please remember. At the beginning, the medications were only IV, then SC and now they work on oral medications, hopefully it will be available in all the whole world.”

هو مرض نادر لكنه الان أصبح معروفا تماما. فلا تيأس ابدا. HAE على الرغم من مرض

وتذكر أنه في البداية كانت طريقة إعطاء الدواء عن طريق الحقن الوريدي فقط ثم أصبحت تحت الجلد والان يتم العمل على تطوير ادوية يسهل تناولها عن طريق الفم. نأمل ان تتوفر في جميع انحاء العالم.

WHAT
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HAE Slovakia

Občianske združenie imunodeficietných pacientov HAE



Patient leader:

Michaela Semková



Message to patients:

"You are not alone. We all stand together and support each other."

"Nie ste sami. Všetci stojíme pri sebe a navzájom sa podporujeme."

WHAT MESSAGE DO YOUR COUNTRIES WANT TO SHARE WITH THEIR HAE FAMILY?



HAE Serbia



Patient leader:

Jovana Cvetković Lazić

Message to patients:

”Stay strong, keep striving, and always keep sight of our incredible progress. Our collective efforts are transforming the landscape of HAE, and each step forward brings us closer to a brighter tomorrow. Believe in the power of resilience, embrace hope, and let us continue to rewrite the narrative of HAE, one triumph at a time.”



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HAE Slovenia

Društvo bolnikov HAE



Patient leader:
Teja Iskra Cigljar



Message to patients:
"Together we can do more"

"Skupaj zmoremo več"

WHAT MESSAGE DO YOUR COUNTRIES WANT TO SHARE WITH THEIR HAE FAMILY?



HAE Turkey

Herediter Anjiyoödem Hastaları Dayanışma
ve Yardımlaşma Derneği



Patient leader:

Gökben Yurdakul and Ersan Sevinç

Message to patients:

”Remember that we are a big family aiming to raise awareness about Hereditary Angioedema and achieve permanent and profound changes together. You are not alone. We are here for you.”

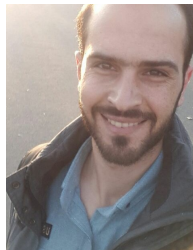
”Herediter Anjiyoödem hastalığıyla ilgili toplumda bilinç oluşturmak ve kalıcı, köklü değişimlere birlikte ulaşmak için büyük bir aile olduğumuzu asla unutmayın. Yalnız değilsiniz. Biz buradayız.”

WHAT
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HAE Syria

الوذمة العرقية الوراثية في سوريا



Patient leader:

Muhammad Al Mashaan

محمد المشعان

Message to patients:

”Now by HAEi we are stronger than before. I hope we can achieve conquering on this disease together.”

نحن الآن أقوى بوجود منظمة الوذمة العرقية الوراثية و نأمل بتحقيق الانتصار على المرض
بوجودنا إلى جانب بعضنا البعض



WHAT
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HAE Ukraine

УКРАЇНЬСКА АСОЦІАЦІЯ ПАЦІЄНТІВ НА СПАДКОВИЙ АНГІОНЕВРОТИЧНИЙ НАБРЯК



Patient leader:

Natalia Formaniuk

Наталя Форманюк



Message to patients:

”Join our team to deepen your knowledge of Hereditary Angioedema and participate in development of the organization together!”

”Приєднуйтеся до нашої команди, щоб поглибити свої знання про Спадковий ангіоневротичний набряк та прийняти участь в розвитку організації разом!”

WHAT MESSAGE DO YOUR COUNTRIES WANT TO SHARE WITH THEIR HAE FAMILY?



HAE UAE

جمعية الودمة الوعائية الوراثية بدولة الإمارات العربية المتحدة



Patient leader:

Shradha Singhania

شرادا سينغانيا

Message to patients:

”Be strong and have faith in medical science. We have come a long way from no medication to multiple on-demand medicines available in UAE. Trust your doctors, and together we can do it!”

كونوا أقوياء وكونوا مؤمنين بالعلوم الطبية. لقد قطعنا شوطاً طويلاً بداية من عدم وجود أي دواء إلى تواجد العديد من الأدوية المتوفرة عند الطلب في الإمارات العربية المتحدة. ثقوا بأطبائكم، ويمكننا القيام بذلك معاً!



WHAT
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HAE South Africa



Patient leader:
Janice Strydom



HAE
SOUTH AFRICA

Message to patients:

“Our patients are an essential part of creating a strong support organisation; the voice of our community, advocating for developments in care and educating the public as well as sharing experiences with other patients and their families. We have made much progress with regards to raising awareness and access to modern treatment options over the past few years, and although we still have unmet needs and some challenges ahead, there is good reason for hope and optimism.”



HAEi
REGIONAL
CONFERENCE
EMEA
MUNICH
1-3 SEP 2023

TAKE ACTION