EUROPEAN UNION

EHE EUROPE

Turning ultra-rarity into collaboration

A patient-led European initiative for epithelioid haemangioendothelioma (EHE)

Mariana Coutinho • EHE Europe

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Stronger Through Connection

BRUSSELS
29 SEPTEMBER – 01 OCTOBER

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Why EHE needs a different model

Ultra-rarity + unpredictable biology + unusual treatment decisions create a major evidence gap.



≈1 in 1M

ULTRA-RARE

At this scale, no single centre can generate enough evidence alone.

HIGHLY UNPREDICTABLE

Clinical behaviour can range from indolent disease to aggressive systemic involvement.

MULTI-ORGAN DISEASE

IT CAN OCCUR ANYWHERE IN THE BODY

A vascular sarcoma that can arise in liver, lung, bone, soft tissue and other sites.

Active surveillance ("watch and wait") can be the right treatment.

Chemotherapy is not a default and conventional sarcoma drugs often have limited activity.
No systemic agent is specifically approved for EHE.

→ The challenge is not only rarity. It is uncertainty.

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3,300+

GLOBAL COMMUNITY

The international EHE Facebook Group connects patients, caregivers and advocates worldwide.

PATIENT- DRIVEN RESEARCH

In 2020, a global HRQoL study recruited 115 EHE patients, from 20 countries, solely through the international EHE Facebook group.

>$15M

FUNDRAISING POWER

Community-reported global fundraising for EHE research over roughly the last decade.



The community is not waiting for research to happen.

Patients have raised funds, enabled recruitment, created organisations and connected researchers and healthcare professionals across borders.

Patients have already built momentum.

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Europe has a foundation and now we need to connect it

21 centres

EURACAN - EHE REGISTRY

A prospective European clinical registry designed to study EHE presentation, natural history, treatment patterns and outcomes. It aims to ultimately improve clinical knowledge and care for people living with this ultra rare cancer

10 countries

CROSS-BORDER REACH

Participating expert institutions span Europe and the UK.

>80 experts

EXPERT CONSENSUS

The 2020 global EHE consensus brought together multidisciplinary expertise and patient advocacy.

STARTER
STarting an Adult Rare Tumour European Registry

EHE Prospective Registry





ESMO Open
Volume 6, Issue 3, June 2021, 100170

Review

Epithelioid hemangioendothelioma, an ultra-rare cancer: a consensus paper from the community of experts

S. Stacchiotti [1], A.B. Miah [2], A.M. Frezza [1], C. Messiou [3], C. Morosi [4], A. Caraceni [5], C.R. Antonescu [6], J. Bajpai [7], E. Baldini [8], S. Bauer [9], R. Biagini [10], S. Bielack [11], J.Y. Blay [12], S. Bonvalot [13], I. Boukovinas [14], J.V.M.G. Bovee [15], K. Boye [16], T. Brodowicz [17], D. Callegaro [18], E. De Alava [19 20], M. Deoras-Sutliff [21], A. Dufresne [12], M. Eriksson [22], C. Errani [23], A. Fedenko [24], V. Ferraresi [25], A. Ferrari [26], C.D.M. Fletcher [27], X. Garcia del Muro [28], H. Gelderblom [29], R.A. Gladdy [30], F. Gouin [31], G. Grignani [32], J. Gutkovich [21 33], R. Haas [34 35], N. Hindi [36], P. Hohenberger [37], P. Huang [38], H. Joensuu [39], R.L. Jones [40], C. Jungels [41], B. Kasper [42], A. Kawai [43], A. Le Cesne [44], F. Le Grange [45], A. Leithner [46], H. Leonard [47], A. Lopez Pousa [48], J. Martin Broto [49], O. Merimsky [50], P. Merriam [51], R. Miceli [52], O. Mir [53], M. Molinari [54], M. Montemurro [55], G. Oldani [56], E. Palmerini [57], M.A. Pantaleo [58], S. Patel [59], S. Piperno-Neumann [60], C.P. Raut [61 62 63], V. Ravi [59], A.R.A. Razak [64], P. Reichardt [65], B.P. Rubin [66], P. Rutkowski [67], A.A. Safwat [68], C. Sangalli [69], G. Sapisochin [70], M. Sbaraglia [71], S. Scheipl [72], P. Schöffski [73], D. Strauss [74], S.J. Strauss [75], K. Sundby Hall [16], W.D. Tap [76], A. Trama [77], A. Tweddle [78], W.T.A. van der Graaf [79], M.A.J. Van De Sande [80], W. Van Houdt [81], G. van Oortmerssen [82], A.J. Wagner [51], M. Wartenberg [83], J. Wood [84], N. Zaffaroni [85], C. Zimmermann [86], P.G. Casali [1], A.P. Dei Tos [71], A. Gronchi [18]

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What EHE Europe is currently doing

1. We provide support, inform and connect EHE patients, as well as families and caregivers. We collect patient data and biosamples to advance research, advocate for greater EHE awareness and research funding, and ensure that patient perspective informs every EHE-related activity.

2. We aim to answer key questions about EHE biology, collect patient data and biosamples for research, screen existing drugs and compounds, and evaluate new treatment approaches.

3. We support grassroots engagement, build meaningful partnerships with researchers and funding institutions, invest in essential infrastructure such as EHE biobanks, and fund key initiatives including the EHE Observational Study and European EHE Prospective Registry.

4. We engage clinical teams, understand their challenges, connect them with patients through initiatives such as the annual EHE360 Conference, and promote best-practice protocols, including the ESMO EHE Consensus Paper.









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Our ask: help us expand cross-border collaboration in Europe

We need partners who can help us with:

MOBILISING THE PATIENT COMMUNITY

We are establishing a pan-European EHE Patient Network to ensure **engagement with all patients** regardless of their nationality or location.

DRIVING COLLABORATIVE RESEARCH

Encouraging expert centres to join our EHE research network and contribute to the development of key European infrastructure such as **EHE biobanks, studies and registries**.

COORDINATING MULTI-SOURCE FUNDRAISING

Engage with partners and funding groups in Europe to **help fund European research and infrastructure**, gather better data faster, leading to earlier breakthroughs and the development of new treatments.

COLLABORATING WITH CLINICAL EXPERTS

Continue to promote and increase awareness and clinical recognition of EHE among healthcare professionals across Europe and **encourage international collaboration more.**

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Connect with EHE Europe

https://linktr.ee/ehe_europe

If EHE is too rare for any of us to solve alone, collaboration is not optional - it is the only strategy.