

EU-NetwOArk Patient Council founded!

Is it possible to form a strong European osteoarthritis patient representative body under the umbrella of the EU-NetwOArk? This fundamental question was discussed at the first OA Summit Ötztal from June 13 to 16, 2024 in Umhausen. With success!

Over 500 million people worldwide are affected by osteoarthritis. According to the [Global Burden of Disease Report](#), this figure could double by 2050.

A cure is not (yet) in sight. From a European perspective, the [COST Action CA21110 NetwOArk](#) is an open network that aims to bring together all key OA stakeholders, including patients and patient advocacy groups, scientists, doctors, pharmaceutical companies, small and medium-sized enterprises, medical device manufacturers and policy makers.

Launched in October 2022, **The European Network on OsteoArthritis** now brings together over 200 clinicians, researchers, patients and patient organizations from seventeen countries. Together, all stakeholders are working towards the goal of establishing the European Society for Osteoarthritis (EUSOA).

The participants of the **1st OA Summit Ötztal** from June 13 to 16, 2024 in Umhausen in the Tyrolean Ötztal have come a big step closer to this overarching goal.

Organized by [Arthrose Forum Austria](#) and the [Vivea Gesundheitshotel Umhausen in Ötztal](#), patient representatives from

- Germany
- Switzerland
- Portugal
- Netherlands
- Austria

Together with members of the **NetwOArk Leadership Team**, we discussed basic questions that are relevant for the establishment of a **Patient Council (PC)**:

- How to shape the role of OA patients and patient advocates at European level under the NetwOArk umbrella?
- How can "one voice" be created for interaction with politics, healthcare and regulatory authorities in order to have a European lobby?
- How can the differently organized and resourced OA patient organizations work together across countries?
- How can the visibility of the Patients' Council be ensured and how can an optimal flow of information between the individual patient organizations and the EUSOA be founded function?

- How can language barriers be overcome? Especially for patients/organizations from countries where English is not the common language?
- How can a budget be secured and the financial burden for individual patients who do not belong to organizations with an available budget be managed? This applies in particular to countries where there is no formal OA patient organization(s).

The **intensive exchange** during the OA Summit Ötztal ultimately led to an extremely positive result. The foundation stone for the **NetwOArk Patient Council** was successfully laid!

The **founding group** of the NetwOArk **Patient Council** consists of the following people - in alphabetical order:

Corné Baatenburg de Jong, NetwOArk Leadership Team, ReumaNederland, Netherlands

Barbara Egger-Spiess, patient representative, Arthrose Forum Austria, Austria

Peter Herrchen, patient representative, ArthroseKompetenzNetzwerk TEPFIT e.V., Germany

Christoph Ladel, NetwOArk Working Group4 Lead, Germany

Andrea Nicole Nüesch, patient, Switzerland

Sylvia Nürnberger, NetwOArk Leadership Team, Austria

Mike Rupp, patient, host Vivea Gesundheitshotel Umhausen in the Ötztal valley, Austria

Elsa Silva, patient representative, Núcleo de Osteoartrose - Liga Portuguesa Contra as Doenças Reumáticas, Portugal

As a **guiding principle** for the establishment and further development of the Patient Council under the umbrella of COST Action CA21110 NetwOArk, the founding group emphasizes an "open culture".

Only in this way can a European alliance and the participation of patients in the European Society of Osteoarthritis (EUSOA) succeed.

Anyone who wants to is therefore **cordially invited** to participate in the international **Patient Council**. OA patient organizations - regardless of whether they are "lone fighters" or established leagues - from **all European countries** as well as **Turkey** and **Israel** should be addressed.

Another key issue that the founding group has addressed is the **status** of the Patient Council. The founding group has positioned itself clearly in this respect:

The Patient Council is a superordinate or **supplement** to the existing structure of **COST Action 20111 - NetwOArk** (Core Group, Management Committee and Working Groups).

NetwOArk Team Leader **Sylvia Nürnberger** sums it up: "In COST Action 21110 - EU NetwOArk, there are four Working Groups with different tasks. The Patient Council can be seen as a kind of additional working group, but with overarching tasks."

This means, for example, that the Patient Council supports the four existing working groups with **advice and recommendations**. Sylvia Nürnberger describes the constellation of the Patient Council around the existing working groups in NetwOArk metaphorically as a form of "citizen service".

The founding group is convinced that the Patient Council as an interface will definitely have advantages for all sides. Collaboration and exchange between clinicians, researchers and patient organizations can now take place at **eye level**. The Patient Council will have a strong voice in the EUSOA and patients will be implemented as **partners**.

Please spread the word: Patient organizations, patients and patient representatives who are interested in participating in the **EUSOA Patient Council** should contact Management Committee Member and Working Group IV Leader, **Chris Ladel**.

A separate e-mail address has been set up for unbureaucratic contact and expression of interest in participating in the Patient Council: patient.council@netwoark.eu .

In addition, www.netwoark.eu/patient-council has already set up a separate area on the NetwOArk website for the Patient Council.

At www.netwoark.eu, interested patient representatives can also find information on the objectives of

- The European NetwOArk on OsteoArthritis
- European Society of Osteoarthritis (EUSOA)
- the organizational structure of NetwOArk
- and the member area

Finally, a brief review of the 1st OA Summit Ötztal, where the participants were able to get to know the concept of the **Osteoarthritis Health Vacation** - a unique initiative in Austria by the Vivea Health Hotel Umhausen in Ötztal together with Arthrose Forum Austria.

The highlight of the three-day 1st OA Summit Ötztal - apart from the very successful exchange - was the trip to **Sölden** and ascent with the Gaislachkogel cable car to the summit of the Gaislachkogel at over 3,000 meters, a visit to the James Bond 007 Elements Adventure World and a stop at the ice Q restaurant.

A big thank you to host **Mike Rupp** for the invitation to the Vivea Gesundheitshotel Umhausen in Ötztal and Summit organizer **Barbara Egger-Spiess!**