



DOING MORE THAN A SCRATCH

Using new technologies to help people with
psoriatic disease

Report from the Panel discussion held
at the Committee of Regions

Brussels
25 May 2023





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Introduction

The European Federation of Psoriasis Movements - EUROPSO organized a panel discussion titled "Doing More than a Scratch: Using New Technologies to Help People with Psoriatic Disease." This event was hosted by the European Committee of Regions on Thursday, May 25, 2023, at the European Committee of the Regions building. The discussion featured insights from various experts on challenges in the patient journey, the current state of psoriatic disease treatment in Europe, and the importance of further research in this field.

EUROPSO is a growing coalition of patient organizations dedicated to psoriatic disease in Europe. It currently represents 22 organizations from 20 European countries, all sharing the common goal of advancing psoriatic disease diagnostics, treatment, and research within the European political and public spheres. EUROPSO, established in November 1988, operates as an umbrella organization in Europe and has forged strong connections with global psoriasis movements, including the International Federation of Psoriasis Associations (IFPA), the National Psoriasis Foundation (NPF) in the United States, and the Nordic Psoriasis Alliance (NORDPSO).

As a prominent advocate for psoriasis patient associations in Europe, EUROPSO envisions a future where every psoriatic patient receives proper diagnosis and optimal treatment. We believe this event marks the beginning of numerous pan-European initiatives aimed at benefiting psoriasis patients across the continent.

While significant progress has been made in treating psoriatic disease, with the European Commission approving 38 drugs for Psoriasis since 1999, this success reinforces the value of ongoing research in this therapeutic area. Research efforts continue to be vital for providing more treatment options to psoriatic patients throughout Europe.

Executive Summary

The European Federation of Psoriasis Movements (EUROPSO) hosted a panel discussion titled "Doing More than a Scratch: Using New Technologies to Help People with Psoriatic Disease" at the European Committee of Regions on May 25, 2023. This event brought together experts and stakeholders to address key challenges in psoriatic disease treatment, the current state of treatment in Europe, and the importance of ongoing research.

The event highlighted significant progress in psoriatic disease treatment, with the European Commission approving 38 drugs since 1999. However, it underscored the importance of continued research in this field to provide more treatment options. Key speakers, including Mr. Ivan Žagar, Mr. Jan Koren, Ms. Sultana Koukopoulou, and Mr. David Trigós-Herraez, emphasized the significance of digital health and the need for collaboration among various stakeholders to drive positive change in psoriatic disease care across Europe. They discussed the EUROPSERVATORY Project, which collects data to assess clinical trial trends and revealed concerning shifts in research projects to Eastern European countries.

The panel discussion concluded by emphasizing the ongoing need for research, collaboration, and patient advocacy in psoriatic disease. Stakeholders agreed on the importance of equal treatment access, advancing research, and involving patients in decision-making.

Recommendations include promoting collaboration and knowledge sharing among stakeholders, ensuring equal access to treatment, and continuing scientific research in psoriatic disease to improve patient care.

Looking ahead, EUROPSO plans a high-profile event in November 2023 to chart the future for psoriatic patients in Europe.



Report

Mr. Ivan Žagar, President of the National Delegation of Slovenia in the Committee of Regions, opened the event by expressing gratitude to all participants. He emphasized that "Digital health is not only a priority for the future but also a current reality, especially after the pandemic. Our actions here extend our national-level efforts, as we have supported Slovenian psoriasis organizations over the years. It is crucial to facilitate meaningful dialogues among different stakeholders, including healthcare authorities, medical professionals, pharmaceutical industry representatives, and, most importantly, patients."

Mr. Jan Koren, President of EUROPSO, echoed this sentiment, noting that this event marked EUROPSO's first pan-European gathering despite the organization being 35 years old. He stressed the importance of uniting various voices, including commercial, patient, and professional perspectives, to eliminate noise in the system and drive positive change in psoriatic disease care across Europe. He highlighted the omission of psoriatic disease from the EU's Healthier Together Initiative, designed to address noncommunicable diseases, emphasizing the need to raise awareness regarding timely diagnosis and treatment.

The main topic of the day centered on "Using New Technologies to Help People with Psoriatic Disease." This theme was presented by Ms. Soultana Koukopoulou, a EUROPSO Board Member from Greece, and Mr. David Trigos-Herraez, EUROPSO Vice-President from Spain. Ms. Koukopoulou emphasized the overarching goal of promoting clinical research, improving treatment access, and reducing the stigma associated with psoriatic disease. She explained that clinical research was essential due to the limited response to current treatments and the decreasing efficacy of existing treatments over time. New therapeutic options, scientific advancements, and improved quality of life for patients are key benefits of clinical research. She outlined a four-step cycle for driving change, starting from clinical trial development, evaluating innovation, enhancing clinical practice, and ultimately ensuring better access to treatments.

Ms. Koukopoulou highlighted EUROPSERVATORY Project, a digital tool developed as part of EUROPSO's flagship project. EUROPSERVATORY aims to collect data from 20 European countries to assess the situation regarding clinical trials and psoriatic disease. The software, developed to simplify information retrieval, revealed concerning trends,

such as a lack of new research entering the pipeline and a shift of clinical research projects to Eastern European countries. The software also provides additional trial information, including sponsors and molecules under investigation.

Mr. Trigos-Herraez introduced EUROPSO's EUROPSEVATORY Project, explaining its three phases: investigating the current state of clinical trials in Europe, gaining insights into the lives of psoriatic patients, and making successful projects of EUROPSO members publicly available. The first phase, focused on R&D and clinical trials, highlighted the need for new treatments and the potential scarcity of options in the future.

Ms. Frida Dunger Johnsson, Executive Director of IFPA (the International Federation of Psoriasis Associations), emphasized the importance of advocacy in shaping policies. IFPA represents 63 member organizations from 56 countries, collectively advocating for the rights of 60 million people affected by psoriasis. She mentioned significant achievements, including the World Health Organization's Resolution on psoriasis in 2014 and the WHO Global Report on Psoriasis in 2016, which serve as advocacy tools at both international and national levels.

IFPA's annual IFPA Forum brings together stakeholders from the psoriatic disease community to address unmet needs, develop action plans, engage policymakers, and share patient perspectives. Ms. Johnsson stressed the need to advocate for access to care, not just availability, highlighting the importance of universal health coverage.

Dr. Laura Savage, a Consultant Medical Dermatologist (Leeds Teaching Hospitals NHS Trust) and Honorary Senior Lecturer (Faculty of Medicine and Health, University of Leeds), discussed therapeutic advancements over the past two decades. While progress has been made in improving patient outcomes and satisfaction with treatments, challenges remain, including patients who do not respond to biologics and the need for research into psoriatic arthritis.

Dr. Savage also addressed the growing biosimilars market and the potential impact on the pharmaceutical industry's motivation to innovate. She emphasized the importance of long-term effectiveness, patient-centered approaches, and the need for more patients to participate in clinical studies.

Conclusion

The panel discussion highlighted the ongoing need for research and collaboration in the field of psoriatic disease. While significant progress has been made, challenges such as limited treatment options, the shifting landscape of clinical research, and the importance of patient-centered care remain.

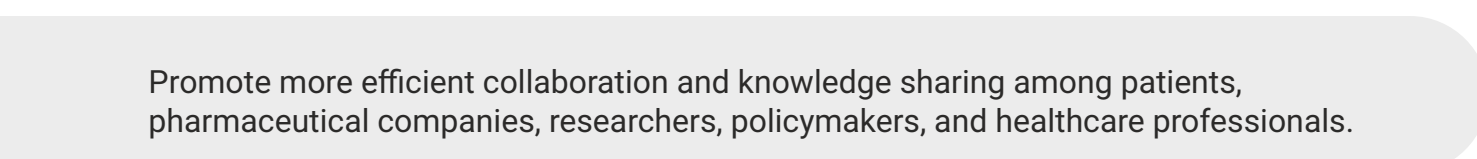
There is a consensus among stakeholders that efforts must be united to ensure equal access to treatment, advance research, and address unmet needs, both medical and social. Advocacy for universal health coverage and specialist care is crucial, as is the involvement of patients in decision-making processes.

As we move forward, patient organizations seek to quantify the potential cost savings of investing in screening, prevention, and early intervention for comorbidities associated with psoriatic disease. Evaluating calls to action from existing documents, such as the Global Report on Psoriasis, and fostering multi-stakeholder collaboration are priorities.

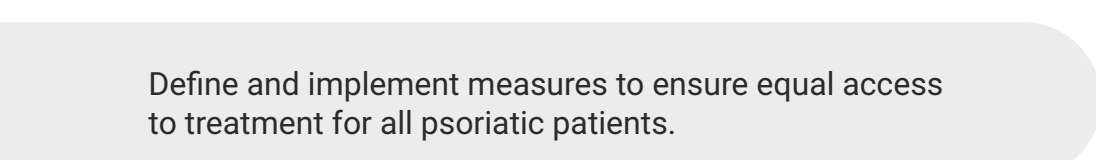
As a follow-up to this discussion, EUROPSO plans to organize a high-profile event in the EU Parliament in November 2023, bringing together all relevant stakeholders to chart a course for the future of psoriatic patients across Europe.



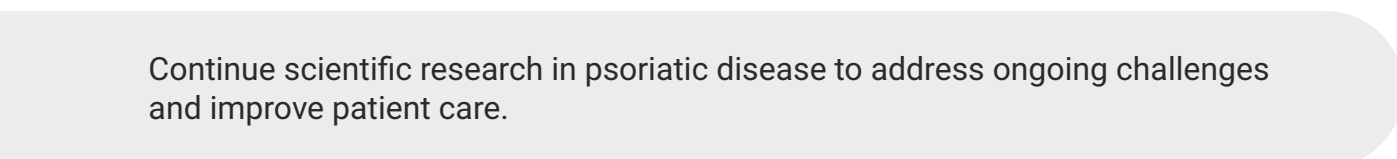
Recommendations



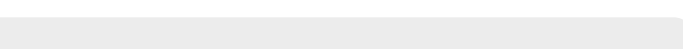
Promote more efficient collaboration and knowledge sharing among patients, pharmaceutical companies, researchers, policymakers, and healthcare professionals.



Define and implement measures to ensure equal access to treatment for all psoriatic patients.



Continue scientific research in psoriatic disease to address ongoing challenges and improve patient care.





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