



From patient empowerment in pulmonary hypertension “to” PROMs, from the side of the patient

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WSPH Updates
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Definition of patient empowerment

"A process through which people gain greater control over
decisions and actions affecting their health" (WHO)

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MY TALK

- How patient empowerment started
- Empowerment at PH community level - examples
- Empowerment at individual PH patient level
- Use of PROMs as patient empowerment tools
- Concluding remarks



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HOW PATIENT EMPOWERMENT STARTED

- 80s-90s: **General trend** initiated when patients started to have a collective voice (HIV/AIDS; breast cancer movements)
- 1990s: **First PH patient associations** (1991 US, 1996 FR & DE).
- 2000: Patient empowerment process accelerated by the **rise of internet** (access to information & knowledge exchange opportunities).
- Since 2000: Gradual **inclusion of patient input** in the work of key stakeholders.
- The **introduction of PROMs** represents an important milestone in validating the patient experience.
- Patient empowerment **codified by Charters**: European Patients' Forum 2016, PAH Patient Charter 2021.



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EMPOWERMENT AT PH COMMUNITY LEVEL

- On a **collective level** the PH patient community has gained recognition and (*some*) power (today 90 associations, 5 continents and three umbrella organisations)
- National and global **awareness and advocacy** activities
- Involved in/collaborates with:
 - Health authorities' (national, EU)
 - Scientific community (ESC, ERS, ELF, ESOT, WSPH, ERN Lung, PVRI...)
 - Regulatory agencies (EMA, FDA) & HTA bodies
 - Industry (patient advisory bodies, expert panels...)
- However, **major disparities** continue to exist in access to expert centres, diagnosis, treatments, surgery, and other forms of support - **much remains to be done.**



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EXAMPLES OF PH COMMUNITY EMPOWERMENT



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GLOBAL AWARENESS AND ADVOCACY

- **World Pulmonary Hypertension Day - May 5**
 - Founded in 2012 by the Spanish PH association ANHP
 - Involvement of 80 associations on average every year
 - Coordinated by PHA Europe with common theme & branding
 - Aim: raise awareness, advocate for patient rights.
 - Involvement of patients, HCPs, health authorities, industry
- **Rare Disease Day:** last day of February every year
- **European Organ Donation Day:** October
- **CTEPH Awareness Month:** November

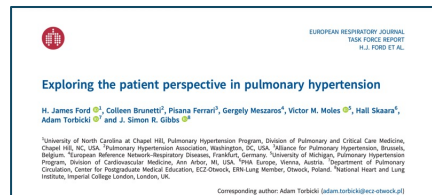


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WORLD SYMPOSIUM ON PH




- Patients started to be involved in the WSPH in 2018 when a Task Force on “Patient perspectives” was created.
- The 2024 Task Force was composed of 4 patients/patient advocates (Gergely Meszaros, Colleen Brunetti, Pisana Ferrari and Hall Skaara) and 4 HCPs (Simon Gibbs, Adam Torbicki, Jimmy Ford and Victor Moles)
- This collaboration led to the development of a paper which was presented at the plenary session.
- This paper is part of the published proceedings of the work of the 15 Task Forces.



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EUROPEAN SOCIETY OF CARDIOLOGY



JOURNAL ARTICLE | GUIDELINES
2022 ESC/ERS Guidelines for the diagnosis and treatment of pulmonary hypertension: Developed by the task force for the diagnosis and treatment of pulmonary hypertension of the European Society of Cardiology (ESC) and the European Respiratory Society (ERS). Endorsed by the International Society for Heart and Lung Transplantation (ISHLT) and the European Reference Network on rare respiratory diseases (ERN-LUNG).

Marc Humbert, Gabor Kovacs, Marius M Hoeper, Roberto Badagliacca, Rolf M F Berger, Margarita Brida, Jørn Carlsen, Andrew J S Coats, Pilar Escobedo-Subias, Pisana Ferrari, Diogenes S Ferreira, Hussein Ardeschir Ghofrani, George Giannakoulas, David O Kiley, Eckhard Mayer, Gergely Meszaros, Blin Nagavci, Karen M Olsson, Joanna Pepke-Zaba, Jennifer K Quint, Göran Rådegran, Gerald Simonneau, Olivier Sitbon, Thomy Tonia, Mark Toshner, Jean Luc Vachiery, Anton Vonk Noordegraaf, Marion Delcroix, Stephan Rosenkranz, ESC/ERS Scientific Document Group

- Patient participation in the work of the ESC started in 2018 with creation of the ESC Patient Forum
- This provided opportunity to participate in the ESC/ERS PH clinical guidelines (2020-2022)
- First time ever that patient advocates are co-authors (Gergely Meszaros and Pisana Ferrari)
- Opportunity to speak at ESC Congresses (e.g. London 2024 on clinical trials, see photo)
- Co-authorship of articles (e.g. ESC PH Quality Indicators).
- Participation in different committees.



EUROPEAN RESPIRATORY SOCIETY



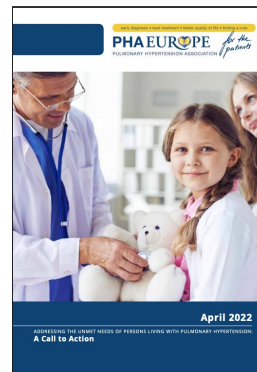


- Patients began their collaboration with the ERS in 2023 with creation of the European Lung Foundation (ELF) PH Patient Advisory Group.
- ERS provided support for organisation of PH Question Time webinar (2023) and other activities initiated by the PH PAG
- Gives opportunity to speak at ERS Congresses (e.g. 2024 session on WSPH)
- And participation in ERS Task Forces (e.g. PH at altitude, 2025)



PH POLICY PAPERS

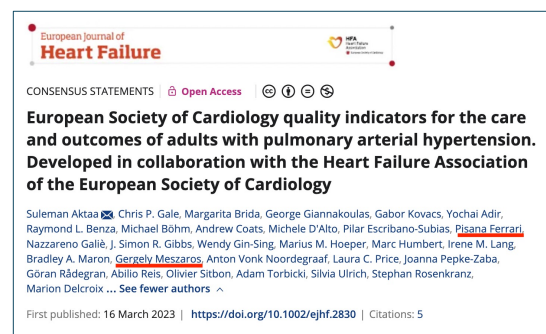
- Three PHA Europe policy papers have been presented at European Parliament public events.
- Fruit of the work of a Roundtable of international PH experts
- First Call to Action on Unmet needs in 2012.
- 2nd Call to Action on improving access to organ transplant in the EU in 2015.
- Updated Call to Action on Unmet needs of PH patients in April 2022
- Hosted by a MEP, featured a very prestigious panel of international PH experts as speakers
- 5 key domains for action (see photo)



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ESC QUALITY INDICATORS FOR PH

- Team of 30 experts included professionals with diverse backgrounds and two patient advocates.
- This diversity underscores the necessity for a comprehensive 360° view of PH care.
- A very important initiative which can:
- Facilitate the identification of areas requiring improvement.
- Motivate and enable healthcare professionals (HCPs) to develop enhancement plans.
- Support international comparisons, collaborations, and registries.
- Published 2023.



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EMPOWERMENT AT INDIVIDUAL PH PATIENT LEVEL

On an **individual level** there are still **many challenges** for true empowerment:

- Health literacy in general & in understanding PH
- Access to technology
- Cultural and religious beliefs
- Paternalistic view of medicine (patient AND HCP!)
- Language barriers
- Resistance to knowledge (as a coping mechanism)

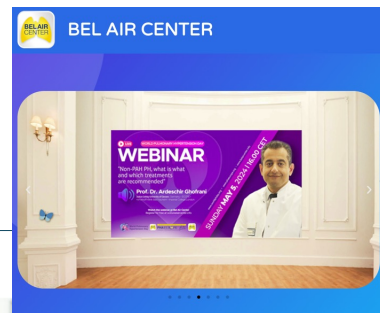
Patient associations play a key role in addressing these issues via:

- Informational materials, education and training
- Support for projects and campaigns
- Provision of computers and other digital devices
- Opportunities for exchanges with other patients and with HCPS
- Helplines, mentoring/buddy programs
- Multilingual resources



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KEY ROLE OF PATIENT EDUCATION PLATFORMS



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USE OF PROMS AS PATIENT EMPOWERMENT TOOLS

- PROMs are not normally thought of as patient empowerment tools, but they are!
- They **give patients a direct voice** in their care.
- They validate that **patient experiences matter**.
- **The empowerment effect:** PROMs encourage patients to focus on their own experiences, feelings, and preferences
- **Body awareness:** PROMs encourage active self-monitoring and paying close attention to symptoms, side effects, & warning signs.
- **Communication:** PROMs give patients tools to communicate with doctors
- **Game changer:** PROMs correlate with treatment outcomes.



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CONCLUDING REMARKS

- We have witnessed a major transformation: patients are no longer passive recipients of care, but **partners** in their health journey.
- Grassroot patient movements laid the ground; **internet** accelerated the process.
- **Patient associations** have played and continue to play a key role.
- They have a **strong collective voice**, but challenges remain.
- **QoL revolution:** PROMs have validated the patient experience and can contribute to patient empowerment but are still **underused** and **present challenges** in their application.
- Is their value truly understood, by patients and HCP alike?
- Suggestion: PROMs training course for patients and HCP
- ... Empowerment is a **work in progress**, not a completed task. Onward!



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Thank you for your kind attention