

Patient Engagement Open Forum 2024

AGENDA

May 21-23, 2024 Baveno, Italy

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21 May, 13:00 - 21:00 (including dinner)

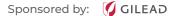
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12:00 - 13:30	Carlo 2	PEOF Virtual - 5th JPPaC PE Seminar "The Impact 'Medicine & Life' has on Pharma" by "Kan-i Net" Explore Japan's PE initiative named "Medicine and Life" by "Kan-i Net". Will feature the voices of people from project lead, patients, and pharma. Let's listen to people's voices and discuss together! Please note that the session will be held in Japanese and live-streamed as part of our broader PEOF Virtual events initiative. An Al live translation tool will be available on Zoom. Speakers and moderators: Kazuyoshi Hatanaka (JPPaC), Hideki Yamauchi (JPPaC), Akira Sato (JPPaC), Nobuyuki Suzuki (JPPaC) and more
13:30 - 14:30	Lobby/Winter Garden	Registration / Pre-event Coffee & Walking Lunch
14:30 - 15:15	Carlo 2	Plenary: the Power of a Village featuring speakers such as Anca Toma (EPF), Maria Dutarte (EUPATI), Oana Scarlatescu (EFPIA), Anke-Peggy Holtorf (HTAi), Clarissa Coolblall (ISPOR) and Sarunas Narbutas (Youth Cancer Europe)
15:30 - 17:00 Parallel Sessions	Planetario 3	Advocacy Roadmaps for Personalized Healthcare Are you committed to improving patient outcomes by ensuring patients have access to the right treatment at the right time? Are you looking for tools to drive system-level change, influence healthcare decision-makers, and advocate for better accessibility conditions in your country? Join us for a hands-on workshop where we will test two modules from a co-created advocacy roadmap. Share your experience and learnings from your access and advocacy work to help support precision medicine champions toward a future where personalized healthcare is accessible for all. Speakers and moderators: Runcie C.W. Chidebe (Project PINK BLUE - Health & Psychological Trust Centre), Nicole Sheahan (Global Colon Cancer Association), Bahija Gouimi (Association des Malades Atteints), Stuart Faulkner (University of Oxford), Ivica Belina (KUZ - Coalition of Association in Healthcare), Silvia Bornengo (The Synergist),
	Planetario 1	Patient Experience Data to Drive Decision Making Discover the transformative potential of Patient Experience Data (PED) in healthcare decision-making. This session will provide attendees with clear strategies for effectively leveraging PED in different healthcare decision-making scenarios. Expert speakers will draw from their experiences, covering PED's role in organizational strategy, regulatory and HTA submissions, and advocacy initiatives. Participants will engage in interactive group discussions to discover practical insights and actionable steps for integrating PED into the decision-making processes that matter most to you. Take advantage of this opportunity and learn how to harness the full potential of PED for informed healthcare! Speakers and moderators: Mark Skinner (Institute for Policy Advancement; ICER Board of Directors), Neil Bertelsen (HTAi/PFMD Board), Elisabeth Oehrlein (Applied Px), Eda Baykal-Caglar, (Michael J. Fox Foundation), Nobutaka Yagi (JPPaC)
	Planetario 2 (right)	Pioneering PE Publication Guidelines Have you ever considered publishing or presenting your PE initiatives in peer-reviewed journals or at

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		medical/scientific conferences? Did you need support and guidance to help you develop a paper that describes your PE activity in a way that is suitable for peer-reviewed publication? By systematically documenting and disseminating robust PE practices and outputs, we can learn and build on efforts to deliver tangible progress in PE. In this working session, we will focus on building a framework for the 'How-to' guidance and invite contributors to join the efforts to elaborate step by step a practical resource that will become standard guidance for the development of robust PE publications. Speakers and moderators: Anne-Marie Hamoir (Twist Medical), Sheila Khawaja (Patient Engagement Expert)
	Carlo 2	Engaging Patients in AI Curious about the hype surrounding AI and its applications in healthcare? As AI technologies increasingly permeate the healthcare sector, understanding their impact on patient engagement is crucial. This session will explore how AI differs from traditional digital tools, address existing policy gaps, and enhance patient engagement across the healthcare continuum. Join us to explore the intersection of AI and PE, uncovering the promises, challenges, and opportunities that pave the way for the future of healthcare. Speakers and moderators: Kersten Sharrock (Sanofi), Sameer Pujari (WHO), Hannah-Marie Weller (DG CNECT), Mitchel Silva (EUPATI Fellow), and Derick Mitchel (IPPOSI)
	Planetario 2 (left)	Patients at the Heart of Early MedTech Development This session aims to let participants immerse themselves in different patient perspectives on Early Feasibility Studies for the development of medical devices. A role-play element will allow them to step into the shoes of patients and explore patient involvement in Early Feasibility Studies. Join us to gain an in-depth understanding of what Early Feasibility Studies are; to understand and explore the landscape for PE, and to exchange views with different stakeholders. Speakers and moderators: Yasemin Zeisl (EPF), Francesco Malandrini (SDA Bocconi), Claudia Louati (EPF), Valentina Strammiello (EPF), Phil Collis (HEU-EFS), Lucía Feito Allonca (HEU-EFS), Russell Wheeler (HEU-EFS)
17:00 - 18:00	Winter Garden	Networking Coffee Break
18:00 - 19:30	Carlo 2	Special Welcome Entertainment & Learning Learning about co-creation in a multi-stakeholder environment from a renowned string orchestra: How it works, what it takes, and the new levels of impact it allows when we apply collective action to system change. From the Annesci Quartet, with a brief introduction by Antoine Boivin (Canada Research Chair in Partnership with Patients and Communities)
19:30 - 21:00	Margherita Garden	Welcome Dinner - Pizza Party































22 May, 09:00 - 21:00 (including lunch & dinner)

07:00 - 09:00	Hotel Restaurant	Breakfast
09:00 - 10:00	Carlo 2	Plenary: Catalyzing the Patient Movement featuring Lara Bloom (The Ehlers-Danlos Society), Randall Rutta (National Health Council), Derick Mitchell (IPPOSI), Jennifer Austin (GlobalSkin), Amanda Bok (The Synergist), Nicholas Brooke (PFMD)
10:30 - 12:00 Parallel Sessions	Carlo 2	PE: Investors, Sustainability & Impact Are you passionate about building sustainable health systems that support better outcomes for people, economies, and society at large? Do you believe patient engagement (PE) can become a driving force in health system sustainability? This session will dive into a multi-dimensional approach for improved sustainability reporting and better investment decision-making through PE. Together with experts who have experience with life sciences sustainability reporting, healthcare impact investment, and their crossroads with PE, you will have the opportunity to co-create pathways towards elevating Patient Engagement (PE) to be a key denominator of what sustainability means. Don't miss out, join us and participate in putting the patient at the center for future-proof health systems! Speakers and moderators: Marc Ramis (Ship2BVentures), Samantha Knott (Roche), Heidi Muller (Galapagos), Nikul Bakshi (Parkinson's UK), Hayley Chapman (PFMD)
	Planetario 3	Revolutionizing Clinical Trials for DEI Are you ready to revolutionize clinical trials to reach diverse patient populations? Join us for a stimulating workshop where we'll delve into pivotal discussions and practical strategies. Building on the momentum of the PFMD Clinical Trials Distribution Network (CTDN) project, we'll focus on optimal engagement strategies with underserved and underrepresented (US/UR) populations. From exploring non-traditional entry points to digital solutions, we'll address the unique needs of US/UR communities. Don't miss this chance to shape the future of clinical trials with inclusivity and patient-centricity at its core. Let's drive meaningful change toward equitable healthcare together! Speakers and moderators: Alan Balch (Patient Advocate Foundation & National Patient Advocate Foundation), Derick Mitchell (IPPOSI), Yasemin Zeisl (EPF), Giorgio Barbareschi (EATG), Brian Goodman (PFMD), Silvia Bornengo (PFMD), Ylenia Paleari (Chiesi), Mitchell Silva (Esperity)
	Planetario 2 (left)	Transforming PE in Grant Funding Catalysts of Change in Health Research Funding! Join us as we unlock approaches for early engagement of patients in research and unveil innovative strategies by funding agencies. Discover how philanthropy pioneers new grant models to foster early engagement of patients in translational research. This interactive session involves more than just discussion; together, we will collaboratively develop recommendations to help funding agencies establish conditions for global early patient engagement. The inputs from this workshop will inform a publication to support research funders and other stakeholders in setting conditions for early patient engagement across the globe. Be part of the movement shaping tomorrow's research funding landscape! Speakers and moderators: Alexandre B Costa Alencar (Rising Tide Group), Kate Trenam (UCB), Stuart Faulkner (University of Oxford), Laura Garcia Bermejo (IRYCIS), David Velasco Gail (EATRIS, Health Institute Carlos III), Robert Joyce (EUPATI Fellow)
	Planetario 1	Equipping PE Champions in Industry & Academia Implementing a patient-driven culture and taking patient engagement to the next level in industry & academia requires shifts in organizational culture, leadership, and mindset, coupled with capacity building to expand the skillsets of individuals working in these sectors. These skills include communication and listening skills, knowledge about different therapeutic areas, the regulatory environment, and HTA process, awareness of the patient movement, as well as understanding of the structure and functioning



































of their own organization and stakeholder group.

This session will initiate the co-creation around this framework of skills, commonly agreed quality criteria and set of learning outcomes for training on patient engagement for industry and academia.

Speakers and moderators: Victoria Siegrist (Roche), Helena Binder (EUPATI Fellow), Corina Ramers-Verhoeven (Industry Veteran), Emma Dorris (UCD)

Planetario 2 (right)

Navigating Ethical Waters: COI Training

While the concept of Patient Engagement is highly acknowledged and promoted, who can take part in the process is restricted via 'Conflict of Interest' policies. These policies vary between decision-makers, creating a range of potential barriers to patient participation in decision making. This session will offer reflections on scenarios and models of these policies. Participants from different stakeholder groups will be invited to identify practical solutions to navigate the various types of conflict-of-interest policies.

Speakers and moderators: Valentina Strammiello (EPF), Neil Bertelsen (HTAi Patient & Citizen Involvement in HTA Interest Group), Anke-Peggy Holtorf (Outcomes Strategies GmbH), Finn McCartney (EUPATI)

12:00 - 14:00

Hotel Restaurant **Break & Buffet Lunch**

Planetario 2

Empowering Advocates: Leaders of Change

Patient advocates, especially those with strong leadership potential and interest, starting from the early stages of their careers need nurturing, support, inspiration, and informal networks. It is important to equip future leaders in patient advocacy with the skills and knowledge necessary to advance the agenda of patients and effectively collaborate with various stakeholders, including industry, academia, regulators, health technology assessment bodies, healthcare professionals, and payers. There is an identified need for capacity building in the areas of advocacy and policy, scientific research, entrepreneurship, and general leadership skills. This session focuses on identifying the key skills required of patient leaders and gaps in currently existing training and support. The objective is to initiate the design of an innovative leadership training scheme for patient advocates that can be rolled out across different therapeutic areas and geographic regions.

Speakers and moderators: Maria Dutarte (EUPATI), Sarunas Narbutas (EUPATI Fellow, Youth Cancer Europe), Leanne West (iCAN), Victor Girbu (Youth Cancer Ambassador), Katie Rizvi (Youth Cancer **Europe**)

14:30 - 16:00 **Parallel Sessions**

Patient Involvement in Research Data Policies

In the realm of healthcare and medical research, the utilization of patient data is the basis for advancements. As we navigate the complexities of data access, sharing, and use, the session aims to spotlight the role of patients in shaping institutional and organizational policies. This focus will surround policies within health systems, payer organizations, review boards, and various patient and academic registries.

The primary objective of this session is to facilitate a dialogue between patients, researchers, and stakeholders, centering on the impact of institutional and organizational policies on contractual agreements for data use in research. By exploring these policies, participants will gain insights into the crucial intersections of ethics, societal considerations, and patient involvement.

Speakers and moderators: Gözde Susuzlu (EPF), Lotte Groth Jensen (IDERHA/DEFACTUM), Diego Villalón (IDERHA PAB member)

Planetario 3

Carlo 2

Moving the PE needle in MedTech

Building upon the 2023 virtual PEOF session "Building the bridge from Pharma to Medtech with Patient Engagement," this in-person session will focus on unraveling the Patient Engagement (PE) landscape within the Medtech sector. The collaborative session aims to co-create a "system map" of the current PE landscape, identifying the various key stakeholders, current challenges, opportunities, trends, available resources, case studies, initiatives, and building recommendations for the future of PE in Medtech. Our goal is to equip participants with valuable insights into the evolving PE landscape in Medtech. We will explore the key components of the current landscape and identify specific actions needed to accelerate

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its evolution. Join us in contributing to the acceleration of PE in Medtech! Together, we will chart a strategic path forward for the future of PE in Medtech. Speakers and moderators: Sandra Sa (Roche Diagnostics), Holger Bartos (Boehringer Ingelheim International GmbH), Chandana Fitzgerald (HealthXL), Mandy Sandkuhler (Mended Hearts), Wil Woan (Heart Valve Voice), Brian Goodman (PFMD) Planetario 1 Patient-Partnered Care: Engagement Initiatives with HCPs As the healthcare landscape steers towards patient-partnered care, our role as fellow architects of this change has never been more vital. During this session, we will embark on a journey to reimagine healthcare delivery, where every voice, from patients to providers, contributes to informed decision-making. We'll hear from thought leaders sharing their innovative approaches and describing how each stakeholder, from patients to HCPs to industry, plays a role in patient-partnered care. During the co-creation activity, we'll collectively identify shared visions for the future of patient-partnered care delivery and collaborate to outline actionable steps we can all take toward that future. Speakers and moderators: Dr. Antoine Boivin (Canada Research Chair in Partnership with Patients and Communities), Dr. Nneka Nwokolo (ViiV Healthcare, Chelsea & Westminster Hospital), Marc van Grieken (EUPATI Fellow), Lara Bloom (The Ehlers-Danlos Society) Winter **Networking Coffee Break** 16:00 - 16:30 Garden Planetario 2 PEPs is a place to discuss PE in practice to develop and further the commitment of industry professionals to PE. The goal is to provide a stakeholder-specific community and trusted environment for industry professionals working in Patient Engagement to look at the environment for upcoming trends, opportunities, and risks, in addition to sharing best practices and common challenges. Speakers and moderators: Bronwyn Lewis (Boehringer Ingelheim) Stakeholder group: industry Planetario 1 <u>Advancing PE Across the Healthcare Ecosystem</u> Join a dynamic forum where healthcare leaders from research, institutions, consultancy, and beyond converge to discuss patient engagement's pivotal role in shaping tomorrow's healthcare landscape. Dive into collaborative dialogue to address diverse PE priorities and foster mutual learning to forge the future of patient engagement together. Speakers and moderators: Lode Dewulf (Independent expert), Nicole Wicki (PFMD) and others 16:30 - 17:30 (Stakeholders Stakeholder group: everyone but patients and industry Specific Carlo 2 **Catalyzing the Patient Movement** Sessions) What would it take for the patient movement to be able to 'close shop'? - to become redundant? - in the kind of way that could be embraced and celebrated? Although the answer to this guestion is 'it's likely we'll never stop' we can also dare to imagine what a 'best' future could look like. One collective answer is to become part of the solution. This session sense-checks and further explores what it could take to catalyze the patient movement into a next, more impactful, more sustainable, and healthier level for all those concerned: advocate, patient, provider, payer, policy-maker, and society-at-large. Building on the 'Patient Movement Catalyst' work that started at PEOF 18 months ago and continues to grow, participants will engage and exchange on concrete, hands-on, collective solution-, strategy- and alignment-building. Speakers and moderators: Lara Bloom (The Ehlers-Danlos Society), Randall Rutta (National Health Council), Derick Mitchell (IPPOSI), Jennifer Austin (GlobalSkin), Amanda Bok (The Synergist), Nicholas **Brooke (The Synergist, PFMD)** Stakeholder group: patients Winter **Break** 17:30 - 18:00 Garden





































18:00 - 19:00 **Made with Patients Awards Ceremony** Carlo 2 19:00 - 19:30 Royal Garden Made with Patients Celebration cocktail Hotel **Dinner** 19:30 - 21:00 Restaurant





































23 May, 09:00 - 14:30 (including lunch)

Hotel **Breakfast** 07:00 - 09:00 Restaurant Planetario 3 Linking PE with Experience Data: Strategy Roadmap Dive into a groundbreaking exploration of how Patient Engagement and Patient Experience Data intersect to reshape healthcare. This session is an exciting journey towards weaving together the voices of patients directly into the fabric of healthcare data, setting the stage for a new era of patient-centered care. Join us as we unravel the powerful synergy between active patient involvement and the generation of meaningful PED. You'll be at the heart of crafting and refining the PE & PED Roadmap through dynamic case studies and hands-on group activities. Our collective mission? To perfectly align our efforts with the noble goal of enhancing patient care and elevating quality across the board. Speakers and moderators: Andrew Knill (Sinus UK), Bronwyn Lewis (Boehringer Ingelheim), Allison FitzGerald (GlobalSkin), Jennifer Bright (ICHOM), Victoria Livingstone (Gilead Sciences) Planetario 1 **Fireside Chat: Advocacy in Action** Is there a 'career development plan' for patient advocates? How can patient advocates continue to grow stronger in knowledge and capacity throughout their lives? This session is built as an informal conversation around these themes, highlighting some practical and personal examples of sources of support and tools for patient advocates in their learning journey. Questions addressed by both to the panelists and the audience are: where to find support and tools, how to implement learnings in your work with the patient community, how to train and support others, how to seek further learning and make time for it, how to balance between being an individual patient expert/advocate and a representative of a patient organization or community etc. The expected outcomes of the conversation are to capture some best practices and resources to be shared with the PEOF community Speakers and moderators: Rebecca Mwebe (EUPATI Fellow), Estelle Jobson (EUPATI Fellow) 09:00 - 10:30 Planetario 2 **Catalyzing the Patient Movement Parallel** (left) What would it take for the patient movement to be able to 'close shop'? - to become redundant? - in the **Sessions** kind of way that could be embraced and celebrated? Although the answer to this question is 'it's likely we'll never stop' we can also dare to imagine what a 'best' future could look like. One collective answer is to become part of the solution. This session sense-checks and further explores what it could take to catalyze the patient movement into a next, more impactful, more sustainable, and healthier level for all those concerned: advocate, patient, provider, payer, policy-maker, and society-at-large. Building on the 'Patient Movement Catalyst' work that started at PEOF 18 months ago and continues to grow, participants will engage and exchange on concrete, hands-on, collective solution-, strategy- and alignment-building. Speakers and moderators: Lara Bloom (The Ehlers-Danlos Society), Randall Rutta (National Health Council), Derick Mitchell (IPPOSI), Jennifer Austin (GlobalSkin), Amanda Bok (The Synergist) Carlo 2 Women-Centered Care and R&D Women's health is an underserved area for innovation. While stakeholders are beginning to address innovation gaps in women's health, no coordinated agenda across sectors with a global focus exists to align their efforts across healthcare and R&D. Join us for an interactive session focusing on the implementation of equitable PE in healthcare and R&D, starting with women and including mothers as a case example. An international multi-stakeholder panel of experts will share best practice examples where patient-centric approaches have been effectively implemented to make clinical trials and care practices more representative based on sex and gender in order to extract replicable best practices for better patient outcomes.

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A hands-on workshop will draw from the experiences of a multi-stakeholder audience to explore what we collectively want advocacy to achieve, and the role that different stakeholders can play in advancing





		advocacy towards these change asks. The inputs from this workshop will inform the publication of a joint call to action/policy to activate a collaborative multi-stakeholder partnership to collectively address these challenges. Speakers and moderators: Eleanor Nwadinobi (Medical Women's International Association, MWIA), Maike Scharp (Bill & Melinda Gates, Innovation Equity Forum), Jamie White (Innovation Equity Forum, NIH), Nneka Nwokolo (ViiV Healthcare, Chelsea & Westminster Hospital), Julieta Kavetuna (National Assembly of Namibia), Susan McClure (PMC, Genome Creative), Mariam Jashi (Global Sepsis Alliance, MWIA, UNITE Parliamentarians Network)
	Planetario 2 (right)	PE in Central and Eastern Europe The aim of this session is to facilitate the exchange of best practices and case studies between the CEE region and other regions in Europe and beyond, focused on financial sustainability, added value of POs and patient involvement in health policymaking; and to highlight the innovation in patient involvement and engagement coming out of the CEE region and the synergies that can be found with other regions in Europe and beyond Speakers and moderators: Oana Scarlatescu (EFPIA), Sarunas Narbutas (Youth Cancer Europe), Gregor Cuzak (Executive Director, Zveza Pacientov, Slovenia), Neringa Ciakine (POLA)
10:30 - 11:00	Winter Garden	Coffee Break
11:00 - 12:30	Carlo 2	Plenary: Driving Change Plenary & Closing including Dr. Nneka Nwokolo (ViiV Healthcare, Chelsea & Westminster Hospital), Estelle Jobson (EUPATI Fellow), Ritu Jain (Debra International), Jennifer Bright (ICHOM), Randall Rutta (National Health Council) and many more!
12:30 - 13:30	Hotel Restaurant	Goodbye Lunch & Departure





































Ongoing Activities:



EUPATI Lounge (Winter Garden)



Synapse Area (Winter Garden)



Made with Patients Awards Ceremony (Margherita Garden)

Sit and chat with the EUPATI team and learn how we provide patient engagement through education. Explore the EUPATI Open Classroom & Toolbox with demo sessions. Get to know EUPATIConnect, the National Platforms & our patient engagement training with us!

Visit the Synapse Area to chat with the team, get support, and upgrade your presence online. Mini-workshops and demo sessions will also give an in-depth look at how you can make the most out of specific Synapse features and tools, including the Metrics Selector, the latest Group feature & more. Come engage with the team for live co-creation and exchange of feedback

This year, we will celebrate inspiring patient engagement champions and initiatives during an award ceremony and cocktail hour on Day 2 of PEOF. Building on some of last year's PEOF co-creation activities, the awards will shine a light on those advancing PE in the health ecosystem. The Award winners will be called on stage to receive their awards & give their speeches. A celebratory cocktail hour will follow after the Awards ceremony.



EPF Booth: European Election Campaign 2024 #Vote4Patients (Winter garden)



Help Desk (Lobby - Next to Carlo 2)



Gravitate Health Booth (Winter garden)



Ongoing Activities (Winter Garden)

Support the EPF Election Campaign and endorse our manifesto.

Background

The European Parliament elections will take place between 6 and 9 June 2024. This is a key moment for European democracy: MEPs take decisions that affect the daily lives of everyone, including important healthcare issues that have a direct impact on patient organizations and patients' lives.

Objective

The European Patients' Forum strives to work towards a truly participatory, democratic, and impactful involvement of patient organizations. Our mission is to advance the interests of patients and patients' communities by strengthening their

Find us daily at the PEOF Info Desk to get information about Agenda & Ongoing Activities, On-site contacts & support, and COVID safety updates

Support the European project Gravitate-Health in providing a patient-centric personalized digital medication management solution - test it here & now

Background

It is becoming increasingly complex for patients to manage their medication regime, including understanding potential drug interactions and side effects coupled with people's lifestyles and other health conditions. The Gravitate-Health project aims to provide a digital, personalized solution that empowers people impacted by diseases and under

- Inspiration into action- Share top ideas and suggestions that you wish to see implemented by PEOF 2025.
- Voice your opinion Vote for the session topic that has the most potential to be turned into a scientific publication.
- Make gratitude go-round -Extend your heartfelt appreciation for your fellow attendees with our appreciation cards and let the good vibes wash over the event.
- Women's Health Opportunity Map Join the movement in women-centered care! Discover an art installation of the Women's Health Innovation Opportunity Map and add your ideas for implementation & collaboration!
- Professional portraits- Need to refresh your LinkedIn / Synapse profile picture? Say no more, as

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collective impact across Europe through effective advocacy, education, empowerment, and partnership.

This booth will present EPF's 2024 elections campaign, centered around our Patient Organisations' manifesto. The manifesto outlines our vision of European patient advocacy for the years to come.

active treatment regimens to effectively and easily manage their medications digitally for improved drug adherence and ultimately, improved health outcomes.

Objective

PEOF participants are invited to get hands-on and test the heart of the Gravitate-Health project the G-lens -, a digital health solution for personalized medication management. Seeking feedback from potential end users (e.g. patients, caregivers, HCPs), Gravitate-Health representatives hope to learn about unmet needs from the patient community and improvement opportunities around user utility of the solution. Your participation and feedback will catalyze delivery of future G-lens developments.

- you will be able to do that at PEOF with a professional photographer.
- Photobooth- Bring your energy into focus at the interactive photo booth with a vibrant backdrop, fun props & more to click that perfect group picture and share it on social media (with #PEOF, of course!).

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