WECAN Academy

The leading capacity-building event for cancer patient advocates

26th, 27th, 28th and 29th June
Rome, Italy

WECAN

The Workgroup of European Cancer Patient Advocacy Networks (WECAN) is a network of 24 dedicated umbrella cancer patient advocacy organizations operating across Europe.

WECAN represents cancer patients from all indications, uniting efforts at a pan-cancer level to drive meaningful improvements and advocate for change that benefits every patient.

Our thriving network, founded in 2015, is now a Foundation and it is preparing for its 10th year, marking a significant milestone in our mission to strengthen and expand our impact across Europe.

What is the WECAN Academy

There is no shortcut to knowledge. To be able to advocate for patients in all different areas of need – e.g. patient care, healthcare policy or research – more effectively and to grow a new generation of advocacy leaders, patient advocates need to continuously build their skills and expertise in those areas.

One of WECAN's key objectives is to increase the capacity and number of well-trained patient advocates and patient experts in order to further grow a community of activists across the community that can induce change in healthcare, and more specifically, in cancer.

That is why the WECAN Academy is a comprehensive **training program designed to empower patient advocates** of all levels -from novice to expert- by enhancing their understanding and skills across various areas of advocacy.

Training levels

Attendees have the opportunity to attend two tailored programs: WECAN SmartStart, designed for emerging advocates, and the WECAN Masterclass, created for more experienced advocates.

WECAN
Academy

Academy Workgroup

We sincerely thank the WECAN Academy workgroup members for providing their time to create and design this training event.

- **Alex Filicevas**, WECAN Chair, World Bladder Cancer Patient Coalition
- **Anita Kienesberger**, Childhood Cancer International
- **Bettina Ryll**, Melanoma Patients Network Europe
- **Gilliosa Spurrier-Bernard**, Melanoma Patients Network Europe
- **Denis Costello**, Chronic Myeloid Leukemia Advocates Network
- **Jan Geißler**, CML Advocates Network
- **Kathy Oliver**, International Brain Tumor Alliance
- **Michi Geißler**, Sarcoma Patient Advocacy Global Network
- **Debra Montague**, Lung Cancer Europe

WECAN Academy

Content: knowledge branches

The content is based on three pillars, which form the foundation of patient advocate knowledge:

- **Advocacy tools and skills** (e.g., financial sustainability of your organization)
- **Healthcare systems, policy, and access** (e.g., understanding inequalities, patients' rights mapping, or the basics of health economics and common challenges)
- **Research and data** (e.g., evidence-based advocacy and ensuring patientcentricity in clinical trials)

In general, half of the topics are fixed, while the other half evolves to meet the changing needs of the cancer patient advocacy community.

ADVOCACY TOOLS & SKILLS

- Accessing information
- Project management
- Presentation skills
- NGO governance
- Financial management
- Managing volunteers

HEALTHCARE SYSTEMS, POLICY & ACCESS

- Access to treatment & care
- Regulatory processes
- Healthcare system: EU vs country level
- Patients' rights

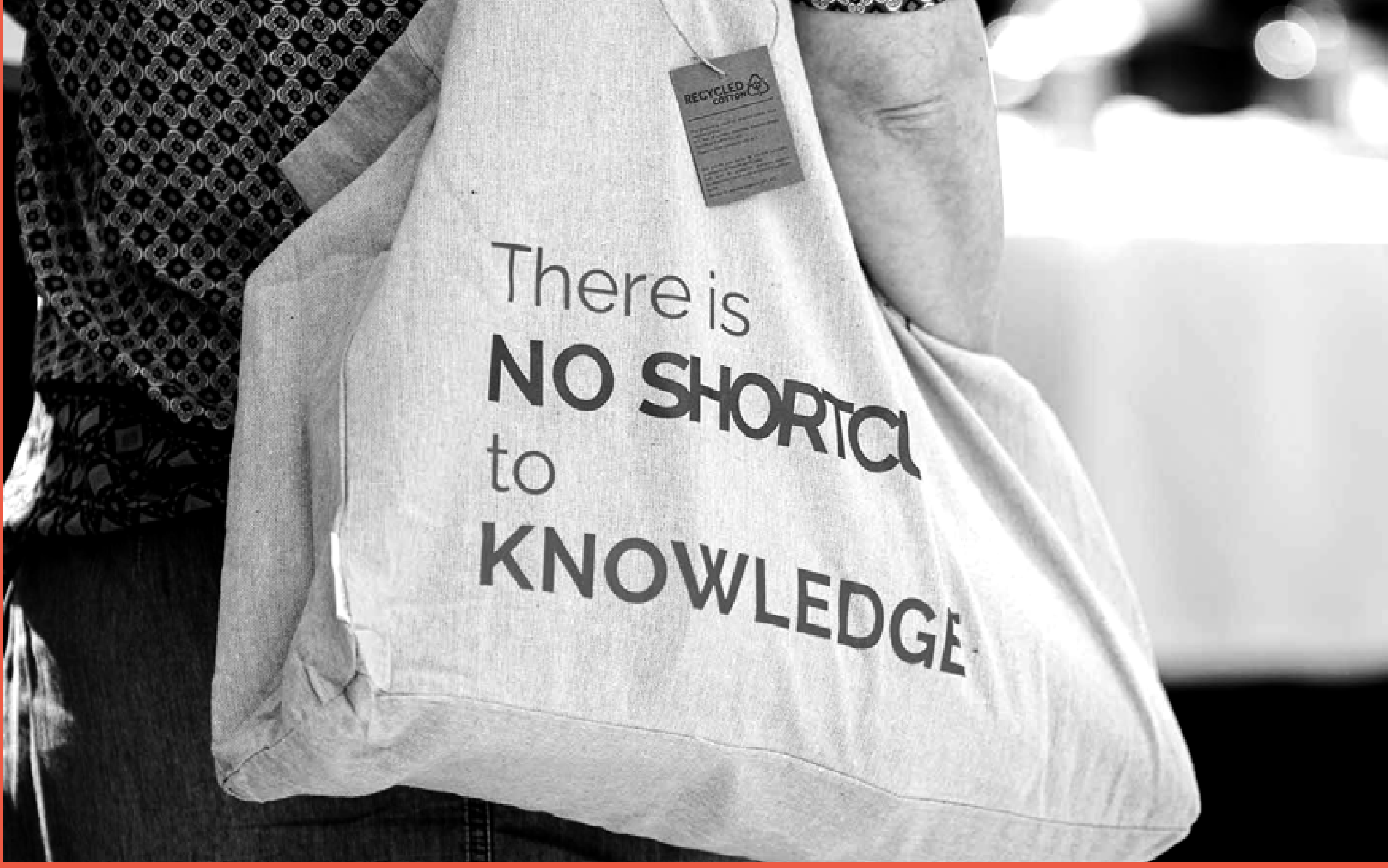
RESEARCH & DATA

- How research & development works
- PROs
- Reading scientific papers & interpreting data
- Evidence-based advocacy

Diversity, Equity and Inclusion (DEI) reflected in all above pillars.

WECAN Academy

Thursday, June 26th



SmartStart Day

● ADVOCACY TOOLS & SKILLS
● HEALTHCARE SYSTEMS, POLICY & ACCESS
● RESEARCH & DATA

08:15 - 09:00	**Registrations:** SmartStart, Faculty & Partners	
09:00 - 10:00	Welcome Ceremony & Ice Breaker I	Alex Filicevas Lidia Dyndor
10:00 - 11:00	**Health Economics Basics:** Concepts and Common Problems	João L. Carapinha
11:00 - 11:45	**Coffee Break**	
11:45 - 12:45	Drug development basics	Katerina Charapa Jan Geissler
12:45 - 13:45	**Inequalities Basics:** Mapping and Understanding Patients Rights	Erik Briers
13:45 - 14:45	**Lunch**	
14:45 - 15:45	**Heathcare Ecosystems & Stakeholder Management**	Jan Geissler
15:45 - 16:45	Ethical issues in patient advocacy	Kathy Oliver
16:45 -17:30	Connections & Conversations Beyond the Sessions (optional)	

WECAN Academy

Health Economics Basics: Concepts and Common Problems

joao@syenza.com

João Carapinha, Ph.D
Founder & Director at Syenza

What is it about

This session covers...

This session is designed to introduce the participant to the key components of economic evaluation in health care.

Why is it important

Why this session is necessary and where is the impact for the day-to-day work in patient advocacy.

Economic evaluation is one of the key components of the evidence base that underpins coverage and reimbursement decision making. It is essential that advocates understand what it is, its strengths and weaknesses, and why it is used at all, to be effective stakeholders in coverage and reimbursement decision making processes.

Key take-home message

A brief and to the point explanation of the sessions content and most important learnings.

This session will provide participants with answers to the following questions:

- What is an economic evaluation?
- What is cost effectiveness analysis?
- What is the Quality Adjusted Life Year and what are its strengths and weaknesses?
- What is the cost effectiveness threshold and why is it used to inform coverage and reimbursement decision making processes?
- How can equity considerations be incorporated into cost effectiveness analysis?

WECAN Academy

Drug development basics


katerina.charapa@eupati.eu


jan@lepaf.org

Katerina Charapa

Jan Geissler

What is it about

This session covers...

How does medicines development work – from Phase I to Phase IV
Why does patient involvement in clinical research make sense?
The roadmap on patient involvement in clinical research,
and meaningful input in clinical trials
Digging deeper and further trainings – EUPATI resources.

Why is it important

Why this session is necessary and where is the impact for the day-to-day work in patient advocacy.

Patient involvement in drug development is crucial for patient advocates as it empowers them to actively contribute to the development of new interventions that address patients' unmet needs and priorities.

By engaging patients as partners in research, their unique perspectives, experiences, and preferences can be integrated into study design, implementation, and decision-making processes.

This active collaboration ensures that research aligns with patient needs, promotes patient-centered outcomes, and enhances the relevance and applicability of findings.

Key take-home message

A brief and to the point explanation of the sessions content and most important learnings.

Patient advocates play a pivotal role in advocating for patient-relevant clinical studies by contributing to the research questions that matter, the design of studies that deliver better and relevant health outcomes.

The type of input that the patient community can bring in the design, conduct and communication of studies is well described in the "roadmap on patient involvement in clinical R&D"

Patient advocates need to be informed about the drug development processes to act as research partners on equal eye level. EUPATI provides resources and training for patients and patient representatives

WECAN
Academy

Inequalities Basics: Mapping and Understanding Patients' Rights


erikbriers@telenet.be

Erik Briers

What is it about

This session covers...

This session will discuss inequalities between and inside countries, based on socio-economic parameters and inequalities between individuals based on differences in learning capacity and digital skills. These inequalities (and others) can be the cause of less quality of treatments and less years in good quality of life.

Inequalities can lead to changes in the treatment of one patient or lead to more important changes in the general healthcare system. Patient rights can be seen as a result of many discrepancies and inequalities. In the patients' rights are also provided basic reasons for patient advocacy.

Why is it important

Why this session is necessary and where is the impact for the day-to-day work in patient advocacy.

Acknowledging discrepancies and inequalities are important for patient advocates as they "should" lead to awareness and calls for action to take care of them. This will lead to better health care and especially to better health care for the underserved who need patient advocates to talk on their behalf to make sure that their rights are upheld.

Key take-home message

A brief and to the point explanation of the sessions content and most important learnings.

Stay alert for discrepancies and inequalities but be careful in the evaluation before going to war. The health care system is a delicate system and balance we should acknowledge and handle with care.

Heathcare Ecosystems & Stakeholder Management

jan@lepaf.org

Jan Geissler

What is it about

This session covers...

This session will:

- Introduce the healthcare ecosystem and its stakeholders as a complex adaptive system
- Reflect on the implications for us as patient advocates as one stakeholder group within the system
- Look at risks and opportunities when engaging with other stakeholder communities.

Why is it important

Why this session is necessary and where is the impact for the day-to-day work in patient advocacy.

Healthcare systems are complex adaptive systems composed of many different stakeholders, e.g. physicians, patients, insurances, policy makers, hospital administrations, the commercial sector with pharmaceuticals, diagnostics and devices, regulators, HTA etc. Every stakeholder group, including patients, has legitimate interests that at parts overlap with the interests of other stakeholder groups. Many problems faced by cancer patients are complex rather than complicated, both at the problem level but also at the organisational level where no single party fully owns the problem and solutions can only be found in collaboration and re-alignment. The pentahelix is often evoked when talking about multi-stakeholder collaborations, but the academia, public sector, commercial sector and civil society often rely on a neutral fifth party as enabling convenor and catalyst, a role that patient organisations can assume.

Understanding the underlying nature of the healthcare ecosystem and its behaviours allows to devise strategies that will work with instead of against the system, dramatically increasing chances for success.

Key take-home message

A brief and to the point explanation of the sessions content and most important learnings.

- Failure to understand the healthcare ecosystem in its complexity means that change measures are unlikely to succeed
- Awareness of overlapping and non-overlapping interests as well as of respective constraints and limitations is essential to formulate win/win/win solutions, the only way for a complex adaptive system to evolve
- Understanding stakeholder groups’ interests, concerns and constraints protects against co-option and being taken advantage of
- The ultimate purpose of healthcare is to serve patients; with this, patients have a unique convening power to facilitate cooperation, collaboration and progress between diverse stakeholder groups

Ethical issues in patient advocacy

kathy@theibta.org

Kathy Oliver

What is it about

This session covers...

This session covers common ethical challenges that arise within patient advocacy work and organizations. Using real-life, anonymized examples shared by participants, the session will explore dilemmas related to conflicts of interest, transparency, representation, partnerships with industry, confidentiality, and decision-making. Through interactive discussion, participants will reflect on how to navigate these situations responsibly and consistently with advocacy values.

Why is it important

Why this session is necessary and where is the impact for the day-to-day work in patient advocacy.

Why this session is necessary and where is the impact for the day-to-day work in patient advocacy: Ethical challenges are an unavoidable part of patient advocacy, whether working with stakeholders, representing diverse patient voices, or managing organizational resources. Recognizing and addressing these issues proactively is crucial to maintaining trust, legitimacy, and long-term impact. This session offers advocates a safe space to reflect, learn from real-world cases, and strengthen their ethical decision-making skills to better face complex situations in their daily work.

Key take-home message

A brief and to the point explanation of the sessions content and most important learnings.

Ethical challenges are part of advocacy work, and being prepared to identify and address them is essential. Clear values, open dialogue, and a structured approach help navigate dilemmas while maintaining integrity and patient trust.care system is a delicate system and balance we should acknowledge and handle with care.

Friday, June 27th

SmartStart & MasterClass Day

● ADVOCACY TOOLS & SKILLS

● HEALTHCARE SYSTEMS, POLICY & ACCESS

● RESEARCH & DATA

08:15 - 09:00	**Registrations:** MasterClass	
09:00 - 10:00	Welcome Ceremony & Ice Breaker II	Alex Filicevas Lidia Dyndor
10:00 - 11:00	Evidence-Based Advocacy (Basic)	Rachel Giles
11:00 - 11:45	**Coffee Break**	
11:45 - 12:45	Reading and Interpreting Scientific Data Part I	Gilly Spurrier Bettina Ryll
12:45 - 13:45	Reading and Interpreting Scientific Data Part II	Gilly Spurrier Bettina Ryll
13:45 - 14:45	**Lunch**	
14:45 - 15:45	**EUPATI:** HTA 4 Patients I	Carolyn Ingram
15:45 - 16:45	Financial Sustainability of Your Organisation	Alex Filicevas
16:45 -17:30	Patient Advocacy speed professional "dating"	

WECAN Academy

Evidence-Based Advocacy
(Basic)


rachelhelengiles@gmail.com

Rachel Giles

What is it about

This session covers...

This session focuses on evidence-based advocacy which involves the utilization of research and data to support and promote practices, policies and recommendations that are grounded in evidence. Through this patient representatives and patient organizations influence decision-makers by presenting compelling and factual information.

Why is it important

Why this session is necessary and where is the impact for the day-to-day work in patient advocacy.

The patient community is uniquely positioned to advocate for patient needs, values and preferences. However, individual stories and opinions may lack the efficacy to persuade researchers, healthcare professionals or regulatory decision-makers. To ensure that healthcare truly aligns with the needs of the patients, patient advocates should generate and disseminate robust evidence.

Key take-home message

A brief and to the point explanation of the sessions content and most important learnings.

- Evidence is essential for progress, and it enables a variety of stakeholders to build upon existing knowledge and make informed decisions that drive innovation and improvement.
- Implementing evidence-based advocacy leads to better patient outcomes, more efficient use of resources and overall improvements in health.
- Healthcare systems are diverse and dynamic. This means that new evidence can reshape understanding, it aids in staying current with knowledge and allows us to remain open to new findings.

Reading and Interpreting Scientific Data:
Part I & II


bettina.ryll@mpneurope.org

Bettina Ryll


gilliosa.spurrier-bernard@mpneurope.org

Gilliosa Spurrier-Bernard

What is it about

This session covers...

Finding and interpreting the latest science and research, reviewing it for your community, and getting into the practice of reading scientific papers. Knowledge is not just power but also protection.

Why is it important

Why this session is necessary and where is the impact for the day-to-day work in patient advocacy.

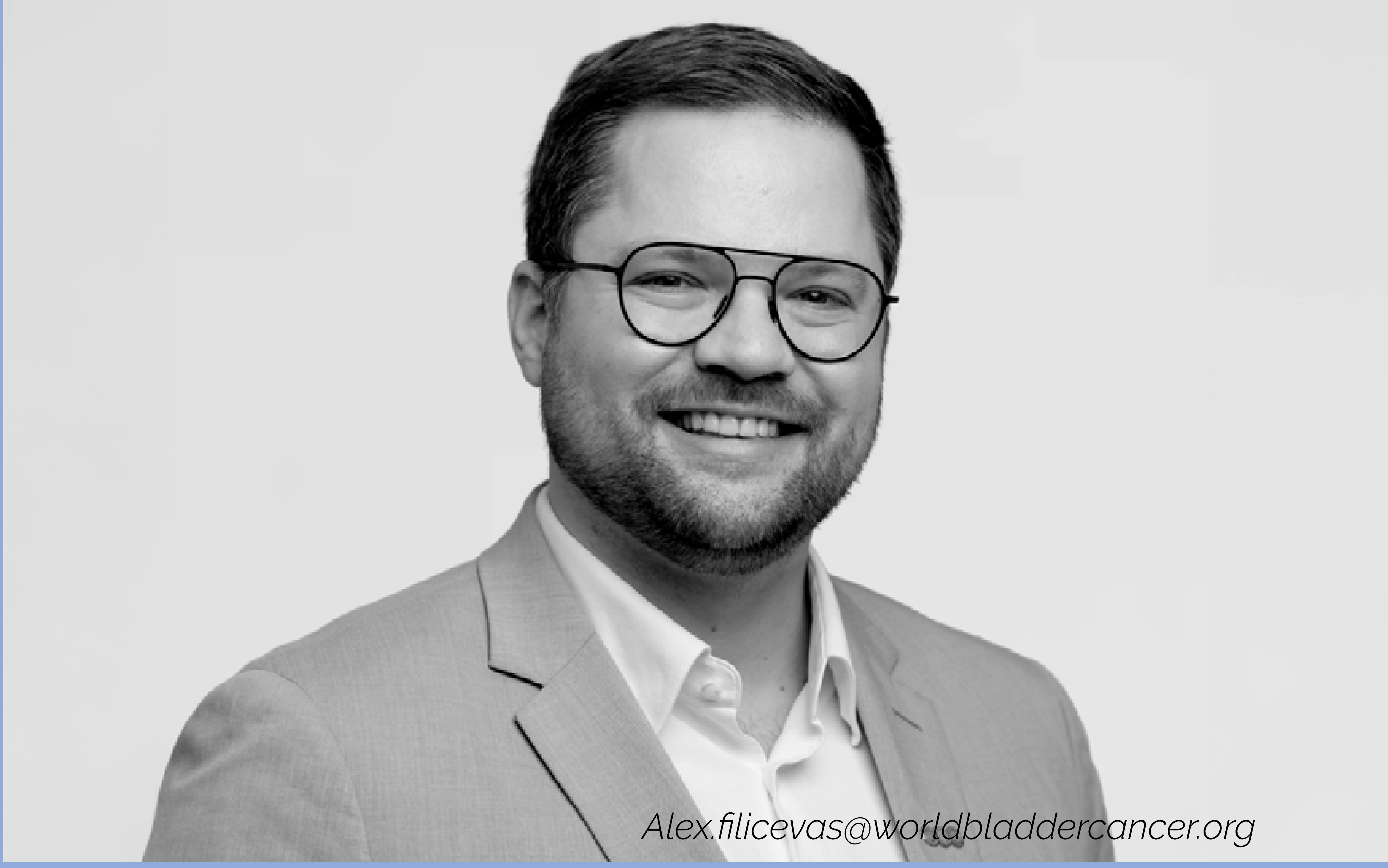
Being up to date on the latest research in your cancer and knowing about upcoming treatments and development is vital for the patient community both to make sure patients are receiving optimum treatment and management and for effective advocacy. As Patient Advocates, this falls to us to know what information is useful, how to read and critique the published research and then to disseminate this effectively to your community.

Key take-home message

A brief and to the point explanation of the sessions content and most important learnings.

The session is in two parts – Part 1 is an Introduction to where to find good, safe scientific information, what it looks like, how to avoid the pitfalls into pseudoscience and how to disseminate back to your community. Part 2 is a workshop to practice these skills on real Scientific Publications from across Cancer Indications, to start the process of Reading Scientific papers and extracting the pertinent information. It is just Practice. At the end you will do an elevator pitch for your Research Paper.

Financial Sustainability of Your Organization



Alex.filicevas@worldbladdercancer.org

Alex Filicevas

What is it about

This session covers...

Maintaining the Financial sustainability of your patient organization:

- Fundraising for patient organizations: Basic principles
- Identification and solicitation of funding
- Types of funding
- The importance of transparency

Why is it important

Why this session is necessary and where is the impact for the day-to-day work in patient advocacy.

Financial sustainability is critical to fuel our work. Without funding, and security in that funding and sound financial planning, the work organizations do to support patients, educate, and advocate for better access and treatment, as well as the thousands of other things in between, would not be possible. In order to have a strong advocacy community, we need strong patient organizations and comprehensive financial management is key to achieving that.

Key take-home message

A brief and to the point explanation of the sessions content and most important learnings.

This session will provide an introduction to fundraising, types of funding, budget planning, and key principles on working well with industry.

WECAN Academy

Saturday, June 28th

SmartStart & MasterClass Day

● ADVOCACY TOOLS & SKILLS

● HEALTHCARE SYSTEMS, POLICY & ACCESS

● RESEARCH & DATA

09:00 - 10:00	**EUPATI:** HTA 4 Patients II	Carolyn Ingram
10:00 - 11:00	How do we ensure Patient-Centricity in Clinical Trials	Rachel Giles Bettina Ryll
11:00 - 11:45	**Coffee Break**	
11:45 - 13:00	**EU Cancer Policy in Action:** What the Beating Cancer Plan and Cancer Mission Mean for Patient Advocates	Norbert Couespel Bettina Ryll Anita Kienesberger
13:00 - 13:45	**NGO Governance:** Managing a Crisis	Ananda Plate
13:45 - 14:45	**Lunch**	
14:45 - 15:45	Pharmaceutical Policy (Advanced)	Stefan Weber
15:45 - 16:45	**AI for Patient Advocacy:** From Science to Influence	Javier Ferrando
16:45 -17:30	Connections & Conversations Beyond the Sessions (optional)	

WECAN Academy

How do we ensurePatient-Centricity in Clinical Trials

bettina.ryll@mpneurope.org

Bettina Ryll

rachelhelengiles@gmail.com

Rachel Giles

What is it about

This session covers...

How can we as patient advocates ensure that clinical trials benefit the patients who participate in the trial as well as those outside the trial?

Why is it important

Why this session is necessary and where is the impact for the day-to-day work in patient advocacy.

There is currently a lot of talk about ‘patient-centricity’ in clinical trials. However, what makes a trial truly patient-centric? And what can we as patient advocates do to ensure that clinical trials are good for our communities?

Key take-home message

A brief and to the point explanation of the sessions content and most important learnings.

- Patient-centricity in clinical trials is more than having consulted patients in the trial design process.
- The interests of clinical trial participants come first, before other parties’ interests.
- patient advocates can directly and indirectly affect the design of clinical trials.

WECAN Academy

EU Cancer Policy in Action: What the Beating Cancer Plan and Cancer Mission is & update

Bettina Ryll

bettina.ryll@mpneurope.org

Anita Kienesberger

a.kienesberger@ccieurope.eu

Norbert Couespel

norbert.couespel@europeancancer.org

What is it about

This session covers...

This session covers the core aspects of the EU's Beating Cancer Plan and the EU Cancer Mission from a policy implementation perspective. It explains how these initiatives function, their strategic pillars, and their implications for national cancer policies. Additionally, it introduces projects such as ECHoS and the National Cancer Mission Hubs and explores the role of patient advocates in these contexts.

Why is it important

Why this session is necessary and where is the impact for the day-to-day work in patient advocacy.

Understanding EU cancer policy is essential for patient advocates who wish to engage effectively at both national and European levels. This session empowers advocates by showing them how to influence and benefit from policy frameworks, funding programs, and collaborative platforms. It equips them with the knowledge to shape strategies, contribute to their implementation, and leverage resources like EU4Health or the European Health Data Space to support their organizations' goals.

Key take-home message

A brief and to the point explanation of the sessions content and most important learnings.

A clear grasp of the EU's Beating Cancer Plan and Cancer Mission enables patient advocates to identify impactful opportunities for engagement, funding, and collaboration, enhancing their role in shaping cancer policy and care at both national and European levels.

WECAN Academy

Pharmaceutical Policy
(Advanced)


stefan.weber@astrazeneca.com

Stefan Weber

What is it about

This session covers...

This session considers the challenges that health systems face in providing access to the many new health technologies that are coming to market. It will provide participants with a conceptual model for thinking about what a fair price might look like, explore the roles of risk and uncertainty in price determination, as well as the dynamic effects of prices on investment in future innovation.

We will look at the complex balance between the goal to enable timely access, meet local affordability and willingness to pay while maintaining global equity in funding R&D, and meeting investor expectations.

Why is it important

Why this session is necessary and where is the impact for the day-to-day work in patient advocacy.

Media coverage of access to specific drugs often present the issue as one of whether an identified individual's life is not worth price that the company charges for the product. These cases occur when the drug pricing system has failed. A sustainable and fair drug pricing system cannot be founded on individual stories and cannot operate on the front (web)page of newpapers. The processes and considerations that drive drug prices are multi-factorial and complex. Advocates must understand this to be effective partners of both the private and public sector actors in drug price determination processes.

We will investigate the value of cancer medicines but at the same time will portray a critical view of "value-based-pricing" by highlighting systemic issues and internal/external constraints limiting such practice.

Key take-home message

A brief and to the point explanation of the sessions content and most important learnings.

This session will provide participants with answers to the following questions:

- Is it ethical or efficient that prices and access vary between countries and health systems?
- How can we think about a fair price for drugs?
- What is the relationship between current drug prices and future innovation?
- Can health care payers use this relationship more effectively?

WECAN Academy

Session learning objectives:

Clear, specific, and measurable statements that describe what participants are expected to know, understand, or be able to do by the end of a session or training module.

- Understand complex pricing systems
- Critically evaluate “value-based pricing”
- Navigate ethical dilemmas in pricing and access
- Interpret the impact of pricing on future innovation
- Engage effectively with stakeholders
- Apply knowledge to real-world advocacy

AI for Patient Advocacy: From Science to Influence


info@javierferrando.com

Javier Ferrando

What is it about

This session covers...

This one-hour session introduces Artificial Intelligence (AI) with a special focus on large-language-model (LLM) tools such as ChatGPT, Claude and Copilot as a practical ally for Patient Advocates (PAs). After a plain-language overview of how today's AI works, we will explore hands-on examples that show how it can:

- speed-read and summarise scientific literature;
- translate complex findings into patient-friendly language;
- draft evidence-based policy briefs or position statements;
- monitor regulatory or legislative changes;
- amplify campaigns through data-driven messaging and social-media content.

Throughout the session we will use real advocacy scenarios and freely available tools so participants leave knowing exactly where to click next.

Why is it important

Why this session is necessary and where is the impact for the day-to-day work in patient advocacy.

AI has leapt from buzzword to daily workhorse: in a January 2025 poll of healthcare leaders, AI tools overtook EHR usability as the top technology priority for the year. Meanwhile, regulators and professional bodies are actively shaping rules on transparency, bias and patient safety.

- For patient advocacy this means:
- Faster evidence digestion: quicker, data-anchored responses to policy consultations.
- Clearer patient communications: improved health literacy and engagement.
- Stronger policy influence: timely, well-referenced briefs that resonate with lawmakers.
- More equitable advocacy: AI can surface under-represented voices and analyse disparities, helping PAs argue from a health-equity angle.

Missing this wave risks slower reactions, heavier workloads and less persuasive advocacy.

WECAN Academy

Key take-home message

A brief and to the point explanation of the sessions content and most important learnings.

“AI will not replace PAs, but PAs who harness AI will out-inform, out-communicate and out-influence those who don’t.”

By the end of the session, you will know the when, where and how of using trustworthy AI tools to turn data into action, while staying alert to ethics, privacy and bias.

Learning goals

- Define core AI/LLM concepts (training data, prompting, hallucinations, privacy safeguards).
- Identify five high-impact AI use cases in scientific review, plain-language translation, policy drafting, trend monitoring and campaign design.
- Execute at least two live workflows (e.g., summarising a paper and generating a policy brief outline) on your own device.
- Assess benefits vs. risks of AI adoption, including bias mitigation and data-protection checkpoints.
- Plan your next steps by mapping one advocacy process where AI could save time or deepen impact within the next month.

Sunday, June 29th

MasterClass Day

● ADVOCACY TOOLS & SKILLS
● HEALTHCARE SYSTEMS, POLICY & ACCESS
● RESEARCH & DATA

09:00 - 10:00	Patient Reported Outcomes and Other Patient-Relevant Measures and Endpoints.	Erik Briers
10:00 - 11:00	Evidence-Based Advocacy (Advanced)	Denis Costello
11:00 - 11:45	**Coffee Break**	
11:45 - 12:45	**Inequalities Advanced:** Tackling and Addressing Inequalities. Equity, Diversity, Inclusion (DEI)	Michael Rynne
12:45 - 13:45	Not being the Victim of Hidden Agendas	Academy Programme: committee members
13:45 - 14:45	**Lunch**	
14:45 - 15:45	Closing Ceremony	
15:45 -16:45	Connections & Conversations Beyond the Sessions (Optional)	

WECAN Academy

Patient Reported Outcomes and Other Patient-Relevant Measures and Endpoints

erikbriers@telenet.be

Erik Briers

What is it about

This session covers...

The session will focus on patient-reported outcomes (PROs), other patient-relevant measures, and endpoints, all discussed from the perspective of patient advocates. Participants will gain an in-depth understanding of various PRO types and measurement methodologies. We will address the challenges of PRO administration in both research and clinical settings and explore how to analyze and report PRO results to meaningfully influence future patient care.

Why is it important

Why this session is necessary and where is the impact for the day-to-day work in patient advocacy.

This session explores the integration of patient-relevant measures in patient advocacy, emphasizing their role in enriching our understanding of disease impact and treatment effectiveness from the patient's viewpoint. PROs and other patient-relevant measures are essential in capturing information on patient experiences, functional abilities, and quality of life, providing a necessary complement to clinical outcomes. However, measurement of PROs in clinical trials and clinical practice is still an emerging field. Challenges include the lack of meaningful PRO instruments or their inadequate utilization, hindering their accurate assessment. Incorporating PROs as endpoints in clinical trials supports regulatory decision-making, influences treatment choices, and aids in the development of guidelines, thereby enhancing day-to-day patient advocacy efforts.

Key take-home message

A brief and to the point explanation of the sessions content and most important learnings.

Participants will gain insights into:

- The differences between PROs, measurements of PROs and patient-reported experiences (PROMS, PREMS)
- The difference between quality of life and health related quality of life
- The proper measurement of PROs by exploring various types of PRO tools, including generic, symptom-specific and disease-specific measures
- Cutting-edge methods for collecting PRO data, such as electronic PROs (ePROs)
- Applications of PROs in clinical trials and clinical practice
- Involvement of patient advocates in selecting meaningful PROs, analyzing and disseminating clinical trial results, demonstrating their critical role

WECAN
Academy

Evidence-Based Advocacy
(Advanced)

denis@cmladvocates.net

Denis Costello

What is it about

This session covers...

This session focuses on evidence-based advocacy which involves the utilization of research and data to support and promote practices, policies and recommendations that are grounded in evidence. During this session we will go through how to set-up an evidence generation project and how to use patient data for advocacy.

Why is it important

Why this session is necessary and where is the impact for the day-to-day work in patient advocacy.

The patient community is uniquely positioned to advocate for patient needs, values and preferences. However, individual stories and opinions may lack the efficacy to persuade researchers, healthcare professionals or regulatory decision-makers. To ensure that healthcare truly aligns with the needs of the patients, patient advocates should generate and disseminate robust evidence. We know that evidence-based advocacy is increasing with more and more organizations generating and publishing evidence however, the process is often not well targeted, planned or strategic.

Key take-home message

A brief and to the point explanation of the sessions content and most important learnings.

- Evidence is essential for progress, and it enables a variety of stakeholders to build upon existing knowledge and make informed decisions that drive innovation and improvement.
- Evidence-based advocacy integrates research, data and expert analysis into decisions that aim to enhance effectiveness and credibility of advocacy efforts.
- As advocates we should implement evidence generation with a clear and common purpose. The focus of an evidence-based advocacy project should be on the impact you want to have and that will guide the evidence needed to be generated.
- Emerging trends and innovations in evidence-based advocacy, such as big data analytics, digital advocacy tools and different means of engagement are essential for staying informed and updating strategies.

WECAN Academy

Inequalities Advanced: Tackling and Addressing Inequalities (DEI)

michaelrynnecll@gmail.com

Michael Rynne

What is it about

This session covers...

This session covers the foundational principles and practical applications of Equity, Diversity, and Inclusion (EDI) in cancer care. It explores how systemic inequalities and unconscious bias affect access to and quality of care, particularly for marginalized populations such as LGBTQ+ individuals, ethnic minorities, people with disabilities, and socioeconomically disadvantaged groups. It also examines the roles patient advocates can play in addressing these inequalities and fostering inclusive environments within their communities and organizations.

Why is it important

Why this session is necessary and where is the impact for the day-to-day work in patient advocacy.

This session is necessary because health inequalities have a direct impact on cancer outcomes. Many patients delay or avoid seeking care due to fear of discrimination, and healthcare systems often lack the policies, knowledge, and resources to provide inclusive care. For patient advocates, understanding EDI is crucial to effectively support all individuals in their communities, influence healthcare systems, and promote policy changes that lead to more equitable care. The session empowers advocates to be intentional in their inclusion efforts and to become visible champions of underrepresented voices.

Key take-home message

A brief and to the point explanation of the sessions content and most important learnings.

Equity in cancer care requires more than good intentions it demands awareness, action, and systemic change. Patient advocates have a vital role in recognizing bias, understanding privilege, and using their influence to ensure that everyone, regardless of background or identity, has access to respectful, appropriate, and effective care. Inclusion starts within our organizations and spreads outward through intentional, educated, and courageous action.

WECAN Academy

Learning goals

Participants will:

- Understand the concepts of equity, diversity, inclusion, privilege, and bias in the context of cancer care.
- Identify how systemic inequality manifests in healthcare settings and affects patient experiences and outcomes.
- Learn practical strategies to foster inclusive practices within their organisations and advocacy work.
- Reflect on their own position of privilege or marginalisation and how it influences their role.
- Develop skills for courageous conversations and actions to challenge exclusion and amplify marginalised voices.
- Explore the responsibilities and limits of patient advocates in promoting inclusion without needing to be “experts”.

OurNetwork

ALAN

Childhood Cancer International EUROPE

CLLAN CLL ADVOCATES NETWORK

CML ADVOCATES NETWORK

DIGESTIVE CANCERS EUROPE

EUROPA DONNA The European Breast Cancer Coalition

EUROPA UOMO The Voice of Men with Prostate Cancer in Europe

EURORDIS RARE DISEASES EUROPE

IBTA INTERNATIONAL BRAIN TUMOUR ALLIANCE

IKCC International Kidney Cancer Coalition

THE MDS ALLIANCE ALLIANCE • ALLIANZ • ALIANZA

mpn an

MPE Myeloma Patients Europe

MPNE

INCA International Neuroendocrine Cancer Alliance

LuCE Lung Cancer Europe

LYMPHOMA COALITION

PANCREATIC CANCER EUROPE

Sarcoma Patient Advocacy Global Network

THYROID CANCER ALLIANCE

World Bladder Cancer Patient COALITION

YOUTH CANCER EUROPE

World CUP Alliance

HECADE HEREDITARY CANCER ADVOCATES EUROPE

Building trust, collaboration, and alignment to strengthen cancer patient advocacy across Europe.

WECAN Academy

Sponsors of the Academy

abbvie
AMGEN
AstraZeneca
Boehringer Ingelheim
Daiichi-Sankyo
Incyte
IPSEN Innovation for patient care
Jazz Pharmaceuticals
MERCK
MSD
sanofi
SERVIER
Pfizer
Roche

We thank our sponsors for standing with the cancer patient advocacy community and helping make WECAN Academy a reality.

WECAN Academy

WECAN
Academy

There is no shortcut to knowledge

wecanadvocate.eu