

MORE ON WECAN PATIENT TRAINING

A report by Izabella Pawlowska, Europa Uomo, Patient Officer

A hundred leading cancer patient advocates from 26 European countries, active across a wide spectrum of cancer types, spent four days from 6th till 9th July 2019 in Frankfurt, Germany, at the first training course to be developed and run by advocates themselves.

There were two training programmes: WECAN Smart Start and WECAN Masterclass. WECAN Smart Start: Starting and Building a National Non-Profit Patient Group focused on “beginners” in patient advocacy, and the WECAN Masterclass on Patient Advocacy for experienced patient advocacy leaders.

Smart Start is a three-day patient advocates’ educational course during which those who are relatively new to patient support and advocacy will have the opportunity to learn basic knowledge and tools which will provide the solid foundations for them to create and maintain a national not-for-profit advocacy/support organisation in their own country.

WECAN Smart Start concentrated on building a national non-profit patient group (strategic planning, legal aspects, governance, financial aspects, marketing) and from Cancer World: relationships and working within the system (clinical research, working with volunteers/physicians/industry/media, healthcare system processes). Moreover, it was about best practices and personal skills (patient meetings, making medical content understandable, presentation/moderation skills, online tools).

The Masterclass on Patient Advocacy was originally initiated by ESO (European School of Oncology) and took place three times between 2014 and 2018. It is now being taken forward by the patient community as the WECAN Masterclass in Cancer Patient Advocacy recommended by ESO.

The Masterclass is an important event for the cancer patient community, since there are limited opportunities available for highly experienced cancer patient advocacy leaders to enhance their understanding of key cancer policy issues and enhance their advocacy skills. Many issues and topics are similar across all cancer indication, so it is very important opportunity for advocacy leaders representing different cancer patient organisations active at a European or international level to meet, share and interact and enhance their skills and knowledge in advocacy.

WECAN Academy aimed to address common educational needs of the patient community. The WECAN Academy trains cancer patient advocates in three educational pillars: advocacy tools and skills, healthcare systems, policy and access, and research and data.

Advocacy tools and skills concentrated on topics like: how to develop good content and patient materials - print, online and video, financial management of non-profit patient organisations and evidence-based advocacy: use of 3rd party data to create advocacy impact. Good NGO governance and ensuring transparency and integrity, presentations skills: how not

to bore your audience to death, GDPR and data protection in patient advocacy and evidence-based advocacy for experts: new technologies to gather data and patient preference studies.

Healthcare systems, policy and access answered questions like: regulatory system, overview of access pathways - why is access to treatment, care and diagnostics an issue, how and why does access to treatment and care differ between EU Member States, and how to address it in advocacy and policy? Affordability and sustainability, difference between HTA and payer perspective, what is Europe's challenge? How to influence reimbursement decisions as a patient advocate? Moreover, it was also about healthcare ecosystem and stakeholder management, basics of health economics, pre-approval access: to clinical trials including cross-border, pre-approval, post-approval, and advocacy action and different perspectives on pricing and value of cancer medicines, including specific challenges related to combination therapies.

The last educational pillar was research and data and it was about basics of statistics, reading scientific papers and publications, how therapy development works, the development lifecycle, endpoints, trial design, patient engagement in research, hot topics in oncology: precision medicine, immuno-oncology, genomics, big data, real-world-data, patient-reported outcomes, and other patient-relevant measures and endpoints. Moreover, it contained information about basics of biobanks and registries – types, value, challenges, relevance for patient advocacy, how to improve patient relevance of clinical trials, and reviewing trial protocol and interpreting scientific data - identifying gaps, flaws and cheats.

A very interesting article about the WECAN training course is on this website and it is worth reading:

<https://cancerworld.net/news/cancer-patients-advocates-train-up-fellow-activists-across-europe/>



The representatives from Europa Uomo and organizers of WECAN Academy 2019.

From left to right: Ananda Plate, Izabella Pawlowska, Dag Utnes, Bernd Troche, Michaela Geissler and Thrainn Thorvaldsson.