RCE-ESMO-ESO Training Course for Rare Cancer Patient Advocates 2022

The 2022 Rare Cancer Patient Advocates' training course took place virtually from 8-10 February 2022. Over the course of three sessions, participants were informed about the latest relevant updates on the European policy agenda, as well as being able to network and exchange best practice examples from their local activities. Attendees also had the opportunity to participate in Patient Cafés focused on rare cancers in the new COVID-19 era and on how digitalisation can benefit rare cancer patients. Speakers from across the European rare cancer community participated in the training course, including rare cancer patient advocates, researchers, oncologists, and other relevant stakeholders.

Session 1: A crucial time for the European rare cancer policy landscape: Europe's Beating Cancer Plan and Cancer Mission

The first session of the training course focused on two key initiatives that demonstrate the European Commission's continued focus on cancer. Europe's Beating Cancer Plan, published in February 2021, is of crucial importance to the work of Rare Cancers Europe and the broader rare cancer community. In addition, the European Commission's Cancer Mission, operating under the Horizon Europe programme, has the objective of improving the lives of more than 3 million people by 2030 through prevention, cure and for those affected by cancer including their families, to live longer and better. Both initiatives present tremendous engagement opportunities for the European rare cancer community, and the session was aimed at equipping patient advocates with the knowledge to capitalise on this.

Prof**. Paolo Casali**, Rare Cancers Europe (RCE) and the European Society for Medical Oncology (ESMO), began the session by providing participants with a brief overview of RCE's main activities and achievements over the past two years. He gave an overview of RCE's structure, with it being a partnership of different stakeholders, including scientific entities and institutions, medical education providers, academia, patient groups and the pharmaceutical industry. Prof. Casali stated that RCE's partners are united in working towards RCE's strategic objectives, of:

- Improving the methodology of clinical studies and regulatory practices in rare cancers.
- Improving the organisation of healthcare in rare cancers.
- Improving access to rare cancer treatments and standard of care.
- Improving the education of healthcare professionals and information on rare cancers.

He stated that one of the main achievements of RCE in recent years was to make it clear that rare cancers are distinct from rare diseases, and that while there are commonalities between them there are also differences, which are important to note. A tangible RCE achievement in this regard was that when the European Joint Programme on rare diseases was launched, the European Commission also launched the EU Joint Action on Rare Cancers, with Prof. Casali stating that this would not have been possible without RCE's efforts. He also highlighted the publication of a set of 10 recommendations that resulted from the Joint Action on Rare Cancers and stressed that one of the core goals of RCE is to go ahead with these recommendations and to work on their EU-wide implementation over the next 10 years. In addition to the work on the EU Joint Action on Rare Cancers, Prof. Casali informed participants that RCE was involved in advocating on Europe's Beating Cancer Plan (EBCP) and said that RCE had launched a Call to Action on Rare Cancers in All Policies, linked to the EU's political agenda, which served to highlight the partnership's suggestions to address the unique set of challenges faced by the rare cancer community. In addition, Prof. Casali stressed the importance of networking in rare cancers, highlighting the importance of the 4 European Reference Networks linked to rare cancers, ERN EURACAN, ERN EuroBloodNet,

ERN GENTURIS and ERN PaedCan. He added that the rare cancer community could serve as a model for networking for common cancers. Prof. Casali concluded his remarks by looking ahead to RCE's forthcoming activities and the update of RCE's 2014 European consensus position paper on methodological recommendations for clinical studies in rare cancers, which will be one of RCE's main areas of activity in 2022 and 2023.

Following Prof. Casali's welcome address, Ms. **Ariane Weinman**, the European Organisation for Rare Diseases (EURORDIS), provided an overview of Europe's Beating Cancer Plan (EBCP) and its implementation roadmap, along with an assessment of what they mean for the rare cancer community. She explained the timeline along which the EBCP was created, starting from the Rare Cancer Agenda 2030 published in September 2019, through to the launch of the EBCP in February 2021. Ms. Weinman praised the fact that the EBCP included a dedicated flagship initiative for paediatric cancer, while highlighting that rare adult cancers were hardly mentioned. This was in spite of the fact that rare adult cancers deserve particular attention due to their rarity and specificity. Ms. Weinman added that despite publications from EU projects such as RARECARE, RARECARENet and the EU Joint Action on Rare Cancers, no figures on rare cancers were included in the EBCP. Then, she added that rare cancers could benefit from actions in the EBCP in the field of research, early detection, access to care, innovative products and follow-up treatments. Ms. Weinman concluded her remarks by praising the work of the European Parliament's Special Committee on Beating Cancer (BECA) and their support for the recommendations that were been put forward in the Rare Cancer Agenda and in RCE's Call to Action on Rare Cancers in All Policies, launched in September 2021.

The next speaker, Ms. **Bettina Ryll**, a member of the first EU Cancer Mission Board, stated that although rare adult cancers are not directly mentioned in the EBCP, the plan and the continued focus on cancer policy at EU level will still benefit rare cancer patients. Given her experience on the Cancer Mission Board, she explained how the indicators of EU Missions have changed and now focus much more on the impact they are supposed to have. In the case of the Cancer Mission, this is the overall objective of saving 3 million lives by 2030. The Cancer Mission has a strong focus on unmet need, which, according to Ms. Ryll, provides an opportunity for rare cancers. In addition, she added that EU Missions are an exciting way for stakeholders to work together, with the potential to address the timely implementation of research findings, which is one area of concern for patients. She also highlighted the importance of early detection, which is an area of particular importance for rare cancers, due to the lack of feasibility of population-based screening, adding that the use of new technological solutions may be able to address this. Ms. Ryll concluded her remarks by stating that the rare cancer community has an advantage over other disease communities because of its experience in working together, particularly through multi-stakeholder partnerships such as RCE, while stressing that the opportunities in the Cancer Mission should be fully seized by the rare cancer community.

Following this focus on EU-level perspectives, four case studies were presented by speakers from Romania, Italy, the UK, and Sweden on the national experience of initiatives affecting rare cancer patients.

Romania*:* The first case study was presented by Ms. **Dorica Dan,** Romanian Rare Cancers Association, and focused on the Romanian National Plan for Cancer. The main objective of the national plan, launched in January 2022, is to have an integrated approach to cancer and achieve a well-established and standardised patient pathway between the various levels of care. Ms. Dan welcomed the inclusion of paediatric cancers in the national plan but regretted that they were not defined as "rare cancers", adding that rare cancers as such were not mentioned nor included in the plan. Furthermore, she stated that the national plan has special chapters for seven types of cancer: colorectal cancer, breast cancer, uterine/cervical cancer, pulmonary cancer, prostate cancer,

haematological cancer, and paediatric cancer. Ms. Dan explained that, within this context, rare cancer patient advocates in Romania have now prepared a proposal to include a specific chapter on rare adult cancers in the national plan.

Italy*:* The second case study was presented by Prof**. Francesco De Lorenzo,** Italian Federation of Cancer Patient Organisations, who gave more information on ongoing activities at national level in Italy. Prof. De Lorenzo explained that the objective of the federation is to bring patient organisations together to find out any new needs or requirement of rare cancer patients, and to bring this together into a unified position. He also highlighted that the federation collaborates very well with scientific societies and with the Italian national cancer organisation, which helps to give patient organisations a stronger voice in the debate. Prof. De Lorenzo concluded in giving more detail about the Italian experience of establishing a recognised Rare Cancer Network.

UK: Ms**. Jo Gumbs**, OcuMel, presented the third case study from her perspective as a patient advocate for a rare cancer in the UK. She pointed out one of the main issues around rare cancers, which is that historically they have been approached in the same way as more common cancers. More specifically, she explained that population-based screening, which works well for some of the more common cancers, is not fit-for-purpose for rare cancers. Nevertheless, she added her belief that early detection is key, and therefore urged rare patient advocates to listen out for novel practices at national level and try to have an input at the very beginning of those processes.

Sweden: The fourth case study was set out by Ms. **Lise-Lott Eriksson**, Swedish Blood Cancer Association (SBCA), and focused on the access and reimbursement of drugs and therapies. She explained that, like many other countries, there is a problem with access to novel therapies in Sweden. Moreover, there are regional differences in access to treatments, which have a consequent impact on survival rates. Ms. Eriksson stated that in Sweden there is a lack of patient involvement in HTA processes, with only 1 patient advocate across the 2 HTA bodies in Sweden, with the role of representing not only rare cancers but also all other cancer areas and all other diseases. This is teamed with a situation where patient involvement is generally limited to dialogue meetings. To respond to this situation, Ms. Eriksson stated that SBCA undertook a project where they interviewed 25 patient organisations on their involvement in HTA. The results of this showed that all wanted to be involved early in the HTA process and highlighted that patient representatives should participate on the same terms as other actors, whereas patient advocates felt that their involvement was currently only a formality. Ms. Eriksson stated that SBCA is now advocating for expert patient advocates to be involved in their specific disease area, changeable in the HTA process depending on the disease area. She added that they also want to see the introduction of an option for a written submission from patient advocates, with the right to appeal an HTA decision if patient evidence is missing. Ms. Eriksson concluded her remarks by informing participants that the SBCA survey has gone in tandem with dialogue with politicians and other stakeholders in Sweden, as part of a broader advocacy campaign on getting patients further involved in HTA processes at national level.

During the first session, participants were:

- Informed that the topic of rare cancers is firmly on the EU's agenda, with a number of ongoing policy initiatives relevant for the rare cancer community. Participants were also introduced to Europe's Beating Cancer Plan and the EU's Mission on Cancer, with their importance for the rare cancer community being highlighted.
- Provided with an overview of RCE's activities in ensuring that the perspectives of its members, representing patient groups, education providers, research groups, scientific societies and healthcare providers, and the pharmaceutical industry, are fully reflected in EU policies. This included examples of RCE's work, including

the development of RCE's Call to Action on Rare Cancers in All Policies, as well as a look ahead to future activities.

- Given the opportunity to hear the perspectives of national level organisations active in rare cancer advocacy from stakeholders representing Romania, Italy, UK and Sweden. Ms. Dorica Dan, Romanian Rare Cancers Association, provided an insight on advocacy related to the inclusion of rare cancers in the Romanian National Plan for Cancer. Prof. Francesco De Lorenzo, Italian Federation of Cancer Patient Organisations, who gave more information on ongoing activities at national level in Italy and the Italian experience of establishing a recognised Rare Cancer Network. In addition, Ms. Jo Gumbs, OcuMel, presented her perspective as a patient advocate for a rare cancer in the UK and stressed the need for rare patient advocates to listen out for novel practices at national level and try to have an input at the very beginning of those processes. Finally, Ms. Lise-Lott Eriksson, Swedish Blood Cancer Association (SBCA), and provided a best practice example of advocacy at national level with an overview of the SBCA's project on patient involvement in HTA processes, the results of which showed the level of interest in patient involved early in the HTA process.

Session 2: Rare cancers in the new COVID-19 era

The second session of the training course featured three brainstorming sub-sessions, with participants taking each topic in turn and developing recommendations to ensure the European rare cancer community responds to the challenges posed by the pandemic. The first sub-session was centred on raising awareness on the importance of COVID-19 vaccination. The second sub-session looked at best practices around creating and maintaining digital patient communities during the COVID-19 pandemic, with the final sub-session seeing contributions from different stakeholders within the rare cancer community, who shared their experiences and best practice examples with participants.

Dr**. Wendy Yared**, Association of European Cancer Leagues (ECL), opened the patient café and introduced the three subtopics of the session. She reminded participants that the first sub-topic focused on raising awareness of the importance of vaccination against COVID-19. She then highlighted that the focus of the second sub-topic was on how the European Cancer Patient Coalition (ECPC) has worked to keep the focus of policymakers on cancer care during the pandemic. She added that in the final sub-session experts in healthcare, research and from the pharmaceutical industry would share their perspectives on rare cancers during and after the COVID-19 pandemic.

Mr**. Radu Ianovici,** European Cancer Patient Coalition (ECPC), opened his remarks by stressing how important it had been for the rare cancer community to remain connected during the pandemic. He also emphasised that patient associations have the role of transmiting what is happening at EU level to the national, regional, and local levels. He introduced the first speaker, Ms. **Kathy Oliver** from The International Brain Tumour Alliance (IBTA), who began by reminding participants of the importance of evidence-based advocacy, as it can shine a light on the inequalities in rare cancer care as well as influencing decision makers. To demonstrate this, she informed participants that in March 2020 the IBTA carried out a series of surveys on the effects of COVID-19 on the international brain tumour patient and caregiver community. One of the main findings from the surveys was that both patients and caregivers experienced stress and treatment delays due to COVID-19. The surveys also showed that they deemed physicians and brain tumour not-for-profit organisations as the most trusted sources of COVID-19 information, with Ms. Oliver highlighting that this was a good reminder of the importance of patient organisations. She concluded that the surveys had demonstrated there is some degree of understanding about COVID-19 and its affects on the brain tumour community, as well as the need to ensure that continuity and quality of care for rare

cancer patients is protected. In addition, the results highlight that careful consideration as to when virtual consultations and telemedicine solutions are the appropriate pathway.

Mr**. Radu Ianovici** (ECPC) gave participants an overview of the ECPC joint letter on COVID-19 and cancer as an example of a campaign to keep cancer care in focus during the pandemic. He explained that the aim of the letter, which was supported by 320 international, national and regional cancer organisations, called for policymakers to ensure that patients can access diagnosis and treatment safely, to identify the real impact of the pandemic on cancer services and design services to mitigate this, and to resource cancer services properly and safely for the long term. He went on to stress that every effort should be made to ensure that cancer services are not disrupted by any future austerity measures. Mr. Ianovici also added that ECPC runs the secretariat of the European Parliament's Challenge Cancer Intergroup and is working hard to ensure the impact of COVID-19 on cancer care is high on the parliamentary agenda. **Ms. Oliver** (IBTA), added more context to the advocacy work accompanied the launch of the letter, including outreach to Members of the European Parliament (MEPs) on the European Parliament's Special Committee on Beating Cancer (BECA) as well as contacting World Health Organization (WHO) representatives, health ministers and permanent representations from all EU countries. Ms. Oliver added that ECPC also took part in the first European cancer conference, organised by the French National Cancer Institute, where rare cancers were set as a priority of a proposed international intergovernmental cancer coordination mechanism, which will be developed in the near future. Ms. Oliver continued by stating that the EBCP has already been a success at EU level, but that it is essential to translate this success to national level. Therefore, she believes it is important that patient advocacy groups join forces to keep track of good measures that are being implemented at national level.

Prof. **Sergio Sandrucci**, European Society of Surgical Oncology (ESSO), presented the perspecitve of healthcare professionals. He focused on the challenges they faced during the pandemic and added that, in his opinion, restrictions in access to health systems was the main issue. He then denounced the fact that in Europe there were no concrete actions to overcome this problem, which led to a reduction in new cancer diagnosis. Prof. Sandrucci highlighted the impact of the pandemic on access to cancer treatment, and particularly disruption to cancer surgery. The impact of COVID-19 meant that some surgical theatres had to be used to create additional ICU capacity, with nearly 38% of global cancer surgeries having been cancelled during the 12-week peak of the pandemic. Prof. Sandrucci stated that this had an undoubted consequence on prognosis. He also set out the advantages and disadvantages of telemedicine and acknowledged that there are some advantages both to healthcare providers and patients from its use. However, Prof. Sandrucci concluded his remarks by stressing that the use of digital tools is often not suited to delivering bad news to patients as well as it being difficult for doctors to judge the condition of the patients they consult.

Dr. **Sandrine Marreaud,** European Organisation for Research and Treatment of Cancer (EORTC), presented the perspective of the research community and discussed the conduct of clinical research during the COVID-19 pandemic. Dr. Marreaud mentioned some of the challenges that were faced during this period, including an increased operational burden for conducting studies, increased study duration and cost and decreased patient enrolment. Dr. Marreaud also stated that the sanitary measures implemented during the pandemic led to deviations from protocol requirements and procedures, which affected data integrity. Dr. Marreaud also talked about adaptations in the way researchers had to interact with patients, because of these restrictions and precautions. Subsequently, she highlighted that alongside these difficulties there were some positive elements that should be taken into consideration in the future. She then explained that there is a need for discussions on how to adapt existing processes to facilitate the continuation of research during future pandemics, which must not be discounted.

Dr. Marreaud also stated her belief that telemedicine will offer an opportunity for patients that might be reluctant to embark in a clinical trial, such as those who do not currently live close to the trial location.

During the last sub-session Ms. **Federica Castiglione**, Novartis (RCE partner), provided participants with an overview of industry activities on rare cancers during the pandemic. She stated that Novartis had conducted outreach to patients and patient organisations to develop a deeper understanding of the challenges they faced. For patients, these challenges included difficulties in accessing healthcare and treatment, whereas patient organisations had to contend with the diversion of funds from existing project to those dedicated to COVID-19. Ms. Castiglione added that Novartis had been involved in efforts through the European Federation of Pharmaceutical Industries and Associations (EFPIA) to ensure access to and supply of medicines during the COVID-19 pandemic. These efforts included enhancing virtual services, as the pandemic accelerated the digital transformation, including the development and implementation of personalised engagement models. In addition, EFPIA worked on protecting the integrity of clinical trials and supporting patient organisations. Ms. Castiglione concluded her remarks by providing an overview of policy proposals developed by EFPIA to minimise medicine supply shortages from lessons learnt during COVID-19. Ms. Castiglione stated that these include improving the understanding and transparency of patient needs at Member State level for appropriate planning and forecasting, as well as ensuring the availability of critical medicines at EU level, in line with patients' needs.

During the second session, participants were:

- Informed on the importance of evidence-based advocacy, as it can shine a light on the inequalities in rare cancer care as well as influencing decision makers. To demonstrate this, Ms. Kathy Oliver from the IBTA presented a series of surveys on the effects of COVID-19 on the international brain tumour patient and caregiver community, which demonstrated there is some degree of understanding about COVID-19 and its affects on the brain tumour community, as well as the need to ensure that continuity and quality of care for rare cancer patients is protected.
- Shown the importance of multi-stakeholder advocacy, through the example of the ECPC joint letter on COVID-19 and cancer as an example of a campaign to keep cancer care in focus during the pandemic. The letter was supported by 320 international, national and regional cancer organisations, and called for policymakers to ensure that patients can access diagnosis and treatment safely, to identify the real impact of the pandemic on cancer services and design services to mitigate this, and to resource cancer services properly and safely for the long term.
- Introduced to the impact of COVID-19 on access to cancer treatment, and particularly disruption to cancer surgery, which had an undoubted consequence on prognosis. Prof. Sergio Sandrucci, European Society of Surgical Oncology (ESSO) also acknowledged that there are some advantages from telemedicine for both to healthcare providers and patients from its use and stressed that the use of digital tools is often not suited to delivering bad news to patients as well as it being difficult for doctors to judge the condition of the patients they consult.
- Presented with the perspectives of the research community on the conduct of clinical research during the COVID-19 pandemic. Dr. Sandrine Marreaud**,** European Organisation for Research and Treatment of Cancer (EORTC), mentioned some of the challenges that were faced during this period, including an increased operational burden for conducting studies, increased study duration and cost and decreased patient enrolment. Dr. Marreaud stated her belief that telemedicine will offer an opportunity for patients that might be reluctant to embark in a clinical trial, such as those who do not currently live close to the trial location. Providing the industry perspective, Ms. Federica Castiglione, Novartis (RCE partner), provided

examples of patient engagement conducted outreach to patients and patient organisations to develop a deeper understanding of the challenges they faced. For patients, these challenges included difficulties in accessing healthcare and treatment, whereas patient organisations had to contend with the diversion of funds from existing project to those dedicated to COVID-19.

Session 3: Cancer care: ensuring that digitalisation benefits rare cancer patients

The final session in the training course addressed the key developments in digital technologies due to COVID-19 as well as the continuing development of digital technologies in health. The session focused on how digitalisation has impacted the way in which patients receive treatment, the effect on diagnosis, as well as patient-physician communication. The session was structured to allow the participants to be fully aware of the changes and opportunities offered by the increased digitalisation of the health field.

Prof. **Fedro Peccatori,** European School of Oncology (ESO), opened the session by highlighting that digitalisation has made communication between doctors and patients much easier. He stated that digitalisation in healthcare has many facets, from the use of electronic patient charts allowing easy data retrieval to automatic double checks for medical prescription, as well as easy exchange of information amongst professionals. Prof. Peccatori added that COVID-19 had required the oncology community to make full use of the available technologies, accelerating the digital evolution.

Mr. **Markus Watenberg,** Sarcoma Patients EuroNet, introduced the general trends and future challenges on digitalisation and rare cancers for patients. Mr. Wartenberg set out a number of these trends, such as the increasing burden of cancer on health systems while prevention and early detection are still poorly used. In addition, Mr. Watenburg stressed the need for faster and better access to affordable therapies and the dramatic differences between healthcare systems in Europe. He also outlined the poor level of patient involvement in policies and research as well as the lagging of digital infrastructure and investment. Furthermore, Mr. Wartenberg stressed that digitalisation will be key to solve these challenges and that it will continue to shape our societies in the next years, along with other trends such as globalisation and climate change. Moreover, as investment in digitalisation has increased in recent years, healthcare has become an area of opportunity, meaning it is now a key topic where all stakeholders need to work closely together. Mr Wartenberg concluded the opening of the session adding that digitalisation is changing healthcare systems and the role of patients, involving them more and more, and that it brings support, care, research and other solutions to our homes. Given this, digitalisation will also bring solutions and improvements to the rare cancer community as well.

Prof**. Giancarlo Pruneri**, University of Milan, provided a comprehensive overview of digital pathology before the pandemic and how, during this period, it was seen as a tool for research and education only. He drew up a list of digital pathology advantages and disadvantages, while emphasising the fact that the advantages outway the disadvantages. These are the possibility to have, amongst others, a digitalised archive and virtual repository, electronic clinical records and records for genomic analysis. On telepathology for rare tumours, Prof. Pruenri also stated that digital pathology is the best instrument to obtain a second opinion as networking also appears as a solution for rare tumours and biomarkers. He concluded his remarks by adding that the COVID-19 pandemic has indicated the need to evolve on digital pathology to improve diagnosis, treatment and prognosis.

Prof**. Jean-Yves Blay**, ERN EURACAN, Rare Adult Solid Cancers, began his remarks by highlighting the speed of change in this area, and that he was providing his perspective as the director of a hospital and the responsible person for a network. He highlighted that the COVID-19 pandemic showed that it is possible to make the best use of digitalisation and teleconsultation for patient care, saying that the tools for teleconsultation had long been available but not fully used. Blay added that the major increase of its use during the pandemic has changed the landscape of how the EU thinks, with learnings on the importance of clinical physical examination of patients and proof that it is feasible at international level. The same goes for clinical trials, as it used to be impossible to do remote consultation for patients taking part of a trial and now it is feasible. On the management of patients with rare cancers, he specifically refered to the NetSARC network (which includes 26 French reference centres on sarcoma) and how this connection is a good solution to limit the inequalities of care across different regions. Connecting all centres and having electronic patient records connected to the registry enables doctors to measure what is happening in real life. Blay then added that, alongside digital pathology being a major change in the way in which rare cancer care is delivered, there is an additional aspect that must not be overlooked and must be given further though, which is the need for investment to cope with storage requirements for additional data.

Prof**. Virginia Ferraresi**, Istituto Regina Elena (IFO), provided participants with an overview of the experience of her institute during the COVID-19 pandemic, which was identified as the referral centre for non-COVID-19 oncological disease for the Lazio region, in Italy. She stated that the reorganisation of clinical activities and the implementation of communication tools with oncological patients became a priority during this period, with the pandemic having seen an increase in the use of digital tools and digitalised interactions. Prof. Ferraresi informed participants that telemedicine is acknowledged in Italian legislation and that in this context it was strongly recommended during the pandemic as a recognised communication tool, with the purpose of protecting privacy. On future challenges related to the use of digital health solutions, she highlighted the difficulty of virtual referral of patients with rare tumours to reference centres with specific expertise, as well as teleconsultation and telecollaboration activities between external specialists or other attending physicians who follow the patient and “expert” specialists to remotely share the optimal therapeutic strategy.

Dr**. Helena Ullgren,** European Oncology Nursing Society (EONS), provided an overview of the nursing aspects of the transformation of cancer care in the COVID-19 pandemic. She provided participants with examples of the adoption of digital health, as well as lessons learnt. As a general overview Dr. Ullgren reported that patients are generally positive on the adoption of digital health in Sweden, with video consultations being seen as an excellent option. However, she said that further roll-out was partly limited due to the lack of a harmonised system for digital health. She spoke in agreement with earlier points on the fact that the pandemic had greatly accelerated the use of digital health solutions, with Sweden having implemented a digital care plan with patients as co-creators.

During the third session, participants were:

- Informed that digitalisation in healthcare has many facets, according to Prof. Fedro Peccatori**,** European School of Oncology (ESO). There is also an increasing burden of cancer on health systems while prevention and early detection are still poorly used, according to Mr. Markus Watenberg**,** Sarcoma Patients EuroNet, who introduced the general trends and future challenges on digitalisation and rare cancers for patients. Mr. Wartenberg stressed that digitalisation will be key to solve these challenges, adding that digitalisation is changing healthcare systems and the role of patients, involving them more and more, and that it brings support, care, research and other solutions to our homes.

- Provided with a a comprehensive overview of digital pathology before the pandemic by Prof. Giancarlo Pruneri, University of Milan. Digital pathology is the best instrument to obtain a second opinion as networking also appears as a solution for rare tumours and biomarkers, with the COVID-19 pandemic having indicated the need to evolve on digital pathology to improve diagnosis, treatment and prognosis.
- Introduced to the speed of change in this area by Prof. Jean-Yves Blay, ERN EURACAN, Rare Adult Solid Cancers. The COVID-19 pandemic showed that it is possible to make the best use of digitalisation and teleconsultation for patient care and the major increase of its use during the pandemic has changed the landscape of how the EU thinks. Following this change, there is now the need for investment to cope with storage requirements for additional data. Participants were also given a real-world example of the reorganisation of clinical activities during COVID-19 by Prof. Virginia Ferraresi, Istituto Regina Elena (IFO). The implementation of communication tools with oncological patients became a priority during this period, with the pandemic having seen an increase in the use of digital tools and digitalised interactions.
- Also given the opportunity to hear the nursing aspects of the transformation of cancer care in the COVID-19 pandemic, thanks to Dr. Helena Ullgren, European Oncology Nursing Society (EONS). In the national context, patients are generally positive on the adoption of digital health in Sweden, with video consultations being seen as an excellent option. However, further roll-out is partly limited due to the lack of a harmonised system for digital health.

The RCE-ESMO-ESO Training Course for Rare Cancer Patient Advocates 2022 recordings and presentations are available on RCE's website, at the page available here.